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Exploring women's experiences of breast or trunk lymphoedema following breast cancer treatment

Janet Ann Ulman

A thesis submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy

December 2021

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Award	Doctor of Philosophy
Date of Submission	December 2021
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Abstract

Although cancer survivorship is frequently couched in celebratory or defiant language, many women who have breast cancer must live with treatment side effects such as lymphoedema. Estimates of breast lymphoedema are as high as 90.4%¹, yet there remains scant research and patient information about either breast or trunk lymphoedema (BTL); and women's experiences remain absent in the academic literature.

The aim of the study was to explore women's experiences of developing and living with BTL. The study was underpinned by The Silences Framework² which was developed to facilitate research into marginalised topics. Fourteen women aged between 41 and 83 took part in individual, unstructured interviews; most participants had lymphoedema in their treated breast. Ten women took up the invitation to use images in their interview. Data analysis drew upon the Voice-Centred Relational Method and its analytical tool the Listening Guide³.

It emerged that women were unprepared for the development of BTL; symptoms were unfamiliar and distressing to many women. Frequently women's concerns were ignored or dismissed by healthcare professionals (HCPs), resulting in lengthy delays in obtaining a diagnosis and appropriate treatment. For some participants, the practical and emotional impact of BTL was profound.

The study recommendations address women's disempowerment and marginalisation resulting from a lack of patient information about the risk of BTL and poor awareness among HCPs. They include providing patients with information about BTL in a consistent, personalised, and repeated manner; educating HCPs about BTL symptoms, management, and impact upon patients; harnessing women's expertise within patient resources; and developing methods to promote BTL's early detection and management.

¹ Verbelen, H., Gebruers, N., Beyers, T., De Monie, A. C., & Tjalma, W. (2014). Breast edema in breast cancer patients following breast-conserving surgery and radiotherapy: a systematic review. *Breast cancer research and treatment*, 147(3), 463-471.

² Serrant-Green, L. (2011). The sound of 'silence': a framework for researching sensitive issues or marginalised perspectives in health. *Journal of research in nursing*, 16(4), 347-360.

³ Gilligan, C., & Eddy, J. (2017). Listening as a path to psychological discovery: an introduction to the Listening Guide. *Perspectives on medical education*, 6(2), 76-81.

Acknowledgements

My thanks go to my wonderful supervisory team – Professor Heidi Probst, Professor Laura Serrant and Associate Professor Margaret Dunham. Their support, advice, wisdom, and encouragement have sustained me and enthused me. I also thank Dr Claire Craig for her guidance on using visual methods in research, and Bea Turpin, Research Support Librarian, for her assistance. I am very grateful to Sheffield Hallam University for the Vice-Chancellor scholarship which funded this study.

My heartfelt thanks go to the women who shared their stories with me, and to lymphoedema specialists Lynda and Lisa who shine with a passion to improve patients' experiences. I also thank *Breast Cancer Now* for their interest and support in ensuring that the findings from this study will be heard.

I thank my Dad, for his unwavering support; and Angela and Jayne, for their belief in me. Finally, I thank my husband for his unending patience and care.

I write this in memory of Deb Harrop - I am deeply grateful for her keen interest in my research and her expert advice on the systematic literature review.

Finally, this thesis is dedicated to my Mum - I know that she would have been proud.

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Glossary of terms and abbreviations

AJCC - American Joint Commission on Cancer

ALND – axillary lymph node dissection

BCRL - breast cancer-related lymphoedema

BCS – breast-conserving surgery

BCT – breast-conserving therapy

Biomarker – a sign of the degree or presence of a disease

BL – breast lymphoedema

BMI – body mass index

BRCA - BReast CAncer gene

BrEQ – Breast Edema Questionnaire

BTL – breast and/or trunk lymphoedema

CES-D - Center for Epidemiological Studies Depression Scale

CoP – community of practice

CI – confidence interval

CTCAE - Common Terminology Criteria for Adverse Events

Cutaneous – referring to the skin

DCIS - ductal carcinoma in situ

EORTC - European Organisation for Research and Treatment of Cancer

Gray – a unit of radiation dose; normally abbreviated to Gy

HBO₂ – hyperbaric oxygen; a form of treatment for radiation late side-effects

HCP – healthcare professional

HFUS – high-frequency ultrasound

HR - hazard ratio

KT – kinesiology tape/taping; a treatment for lymphoedema which lifts the skin away from the underlying tissues to promote the flow of lymph fluid

LCIS - lobular carcinoma in situ

LG – The Listening Guide

LSIDS - Lymphedema Symptom Intensity and Distress Survey

LVA – lymphaticovenous anastomosis. A surgical treatment for lymphoedema in which lymphatic vessels are re-routed into the venous circulation

Lymphoedema – a chronic condition causing swelling due to the build-up of lymph fluid in bodily tissue caused by damage or disruption to the lymph system

Manual lymphatic drainage (MLD) – a form of massage to promote lymph drainage, moving lymph fluid away from swollen areas

MDT – Multidisciplinary team

MRI – magnetic resonance imaging

ONS - Office for National Statistics

OR – odds ratio

PALB2 -partner and localizer of BRCA2

Parenchyma – refers to breast tissue which is functional, i.e. glandular or fibrous

PMRT - post-mastectomy radiotherapy

PROM – patient-reported outcome measure

QoL – quality of life

RCOPE – an instrument to measure religious coping

RCT – randomised controlled trial

RR – relative risk

RT - radiotherapy

SHLOC scale - Spiritual Health Locus of Control scale

SLNB – sentinel lymph node biopsy

SWLS - Satisfaction With Life Scale

TDC - tissue dielectric constant

Trunk – an anatomical term describing areas of the upper body including the breast, chest, back and armpit.

TSF – The Silences Framework – a theoretical framework underpinned by criticalist thought

US - ultrasound

VAS – visual analogue scale

VCRM – voice centred relational method: a form of data analysis.

Chapter 1

Introduction

Record numbers beating breast cancer in the UK

More than 130,000 UK breast cancer deaths have been avoided in the last 30 years⁴, according to new Cancer Research UK analysis to mark breast cancer awareness month.

Breast cancer deaths in the UK hit a record high in 1989, when around 15,600 women lost their lives to the disease – but thanks to research developing new tests and better treatments, the death rate for women has since fallen by 44%.

Press Release 4 October 2019, Cancer Research UK

Cancer survivorship is frequently couched in celebratory or defiant language, such as *Cancer Research UK's* use of 'beating' breast cancer in the extract above. While news of a reduction in the death rate is undoubtedly welcome, the reality for many women who have breast cancer is that they must deal with the consequences of treatment side effects. This is reflected in cancer now being perceived as a chronic condition (World Health Assembly 2017). Women's difficulties are further compounded if those side effects are poorly understood, not consistently monitored and frequently unrecognised amongst healthcare professionals (HCPs). The result is the creation of an environment which provides limited opportunity for women's experiences to be heard. This thesis aims to redress this by seeking to listen to and understand those experiences as they relate to breast or trunk lymphoedema (BTL) as a side effect of treatment for breast cancer. For the purposes of this thesis, the term 'trunk' includes the chest, armpit, back and shoulder (Lymphoedema Support Network 2019).

⁴ Calculated by Cancer Research UK's Cancer Intelligence Team as the difference between observed mortality and number of deaths expected each year if the mortality rate had remained at its 1989 level until 2017, based on the method set out in Siegel R, Ward E, Brawley O, Jemal A. Cancer statistics, 2011: the impact of eliminating socioeconomic and racial disparities on premature cancer deaths CA: A *Cancer Journal for Clinicians* 61(4) pp 212-36

Chapter outline

The importance of some medical understanding about breast cancer for a fuller appreciation of the research topic is acknowledged, and for this reason the reader is signposted to Appendix 1 for further detail. Medical context for the research topic includes information about the epidemiology and natural history of breast cancer, its diagnosis and breast cancer staging, details of the breast cancer pathway for England and Wales, types of treatment, and treatment side effects. This chapter provides breast cancer statistics before explaining that lymphoedema is recognised as a potential consequence of breast-conserving surgery, mastectomy, and radiotherapy for breast cancer; and that for women undergoing such treatment there is a risk of developing lymphoedema in the breast or trunk as well as in the arm. Current knowledge and understanding of BTL is discussed, including methods of assessment, incidence, risk factors and treatment options.

Although the perspective of women with arm lymphoedema has been relatively well documented in the literature (Fu 2008; Fu and Rosedale 2009; Johansson et al. 2003; Karlsson et al. 2015; McGrath 2013; Radina et al. 2008), I suggest that the same cannot be said for the experiences of women who have BTL. That is, the voice of these women appears to be absent in the literature. In this chapter I argue, therefore, that since the focus of research on 'breast cancer-related lymphoedema' is upon lymphoedema of the *arm*, there is an apparent gap in knowledge about women's experiences of breast or trunk lymphoedema. Hence women's experiences remain unheard or may even be silenced. I discuss the importance of understanding those experiences, adopting the position that women's experiences constitute a legitimate form of knowledge, thereby offering a rationale for the study. I set out the study aims and research question; and explain the relevance of The Silences Framework (TSF) as a theoretical approach to facilitate an exploration of the apparent silences around women's experiences. The chapter ends with a summary of the current and subsequent chapters in this thesis.

Overview

Breast cancer statistics

Breast cancer is the most common cancer in women and is a global issue, with over 2.2 million women in 2020 diagnosed with the disease worldwide (World Health Organization International Agency for Research on Cancer (IARC) 2020a). According to figures released by the Office for National Statistics (ONS), 45,790 women in England were diagnosed with breast cancer in 2017 (ONS 2019). The incidence rate rose between 2008 and 2017 from 165.5 to 166.7 cases per 100 000 population and is rising: 3.19 million cases are estimated to be diagnosed worldwide by 2040 (IARC 2020b). Meanwhile in recent decades survival rates have markedly improved, with age-standardised net survival rising from 53% in 1971-1972 to 87% in 2010-2011 (Cancer Research UK 2014). By 2040, population survival from breast cancer is anticipated to reach 1.7 million (Bartlett et al. 2013). In England 75.9% of women who were diagnosed with breast cancer between 2013 and 2017 are predicted to survive ten years or more (Cancer Research UK n.d.).

Some men do develop breast cancer; however, the incidence rate is low, with men constituting less than one per cent of cases of breast cancer (Cancer Research UK 2021). Evidence for a link between breast lymphoedema and increased breast size (Barnett et al. 2011) also indicates that women are more likely to experience this condition after treatment for breast cancer. It is therefore necessary in the first instance to study women to understand the impact of breast (as well as trunk) lymphoedema upon individuals who are most likely to experience this condition.

Development of lymphoedema after treatment for breast cancer

Both surgery and radiotherapy can cause disruption or damage to the lymph nodes in the axilla (Adriaenssens, Verbelen et al. 2012; Degnim et al. 2012; Young-Afat et al. 2019). This puts women at risk of developing lymphoedema, a chronic condition

involving the accumulation of protein-rich lymph fluid in the tissues which results in swelling. As the arm, breast and trunk share lymphatic drainage routes at the axilla, they are all at risk of developing lymphoedema. Nevertheless, there is a strong bias in academic journals towards the investigation and reporting of arm lymphoedema, leading to a substantial body of research that supports understanding about the factors influencing lymphoedema in the arm. This is reflected in a recent systematic review determining the incidence of arm lymphoedema which identified 72 articles (DiSipio 2013). It is also common in journal articles to see the breast and trunk included in a definition of the umbrella term *breast cancer-related lymphoedema* (BCRL) but for the subsequent focus to be entirely on the arm (see a review of risk determinants and aspects of management by Nassif et al. 2020, for example). Radina et al. (2015) used the term to refer to lymphoedema of the arm, hand, or upper chest; however, in most of the literature the term BCRL is synonymous with lymphoedema of the arm. Women's experiences of arm lymphoedema have also been extensively explored (Fu 2008; Fu and Rosedale 2009; Fu and Kang 2013; Hare 2000; Jeffs et al. 2016; Karlsson et al. 2015; Radina et al. 2008, 2014, 2015).

In contrast, lymphoedema in the breast or trunk has received relatively little research attention even though it was recognised as a side effect of cancer treatment two decades ago (Carl and Hartmann 1998; Lamb et al. 1999). Hence, understanding of the factors that increase the risk of developing BTL is more limited - impacting upon healthcare practitioners' ability to inform and prepare women for this as a potential side effect of treatment. Furthermore, there is minimal evidence about women's experiences of living with BTL. This will be demonstrated in Chapter 4 which details a review of the available literature.

Moffatt et al (2019) have noted that the lymphatic system plays a part in all types of oedema, irrespective of the underlying mechanism; it is the inability of the lymphatics to drain fluid which accumulates for *any* physiological reason which causes swelling to occur. Hence, the term 'chronic oedema' has been proposed as a term which encompasses chronic swelling with complex physiological causes as well as 'conventional' lymphoedema (Moffatt et al 2019). Despite this, the terms 'oedema' and 'lymphoedema' remain undefined or are used interchangeably by many authors

within the existing literature about BTL. Consequently, the development of the evidence base for BTL appears hindered by a lack of an accepted definition for this condition, although an attempt to reach an expert consensus for the term breast lymphoedema was reported in an unpublished master's thesis (Smith 2013). A systematic review investigating the incidence of and risk factors for breast lymphoedema following breast-conserving surgery (BCS) and radiotherapy (RT) (Verbelen et al. 2014) provided one distinction offering the potential to differentiate the two terms. The review indicated that 'oedema' can be used to refer to the first weeks after treatment, at which time oedema may be considered a normal response to trauma (ie tissue damage) as opposed to a longer-term response resulting from lymphatic insufficiency. It is the latter which is the focus of this study; hence the term 'lymphoedema' will be used. However, some authors do use the term 'oedema' for swelling which would appear in fact to be lymphoedema; in such cases, oedema which is present two months or more after treatment will be considered as lymphoedema. This distinction is also important for clinical practice as management options are different (Mortimer and Levick 2004). For instance, it may be that during RT, HCPs observe swelling in a patient's breast which is an anticipated oedematous response to the treatment; but it is also possible that patients present with breast lymphoedema which has already developed following surgery. HCPs may not be alert to this distinction, which is important to their understanding and recognition of breast changes both during and after treatment.

Throughout this thesis, whenever a particular anatomical region relating to the study topic (i.e., either the breast, trunk, or chest wall) is specifically under discussion it will be identified; otherwise for ease of reading the term BTL will be used as shorthand to capture the breast and trunk (which includes the chest wall).

Breast or trunk lymphoedema (BTL)

This section presents current knowledge and understanding in relation to breast lymphoedema, with specific reference to trunk lymphoedema where relevant.

The presentation of breast lymphoedema has been described by several authors in terms of signs and symptoms at clinical presentation (Boughey et al. 2014; Clarke et al. 1982; Degnim et al. 2012) including skin oedema, erythema, peau d'orange, breast heaviness and swelling. Pezner et al. (1985) included skin pore hyperpigmentation as a potential sign of breast lymphoedema. Other authors have proposed that the findings of skin thickening, increased parenchymal density (ie. the density of the functional breast tissue) and interstitial fluid using ultrasound (US) techniques is evidence of breast lymphoedema, at times at a sub-clinical level (Adriaenssens, Belsack et al. 2012; Rönkä et al. 2004; Wratten et al. 2000; Wratten et al. 2002; Wratten et al. 2007).

Meanwhile, Hisano et al.'s (2021) observational study raises questions about what symptoms actually constitute signs of lymphoedema. In their small study (n = 13), sources of swelling of the trunk were determined using three techniques: MRI to establish fluid content; clinical assessment (observation and palpation); and subjective symptoms as reported by participants. The results suggested that neither clinician assessment nor patient report correlated with objective fluid content. Nevertheless, the small sample size and the choice of patient-reported symptoms - which appear to be broadly related to the arm rather than the trunk - indicate the need to treat these findings with caution. It does however highlight the potential for ambiguity in reports of lymphoedema. The next section discusses a range of techniques for the assessment of breast lymphoedema and demonstrates the lack of any widely accepted measure.

Assessment of BTL

Several studies have used clinical observation and patient reports to rate the presence or degree of BTL according to its severity (Clarke et al. 1982; Kelemen et al. 2012; Knobf and Sun 2005; McCormick et al. 1989; Olivotto et al. 1996), or simply whether breast lymphoedema is present (Goffman et al. 2004). Meanwhile in Tan and Wilson's (2019) case study the treating physiotherapist employed circumferential measurements at three defined points at and below the axilla to determine changes in overall breast and trunk size over time.

A range of objective measures have been proposed to identify breast lymphoedema. Adriaenssens, Belsack et al. (2012) suggested that objective measurements can be obtained using US techniques. The authors distinguished between cutaneous breast lymphoedema which was measured with high-frequency ultrasound (HFUS) to determine an increase in skin thickness over 2 mm; and parenchymal breast lymphoedema identified using US elastography. However, there is no evidence that the measures were tested for sensitivity and specificity. Others have measured cutaneous lymphoedema by determining skin thickness and fluid collections using HFUS (Wratten et al. 2007) and US (Rönkä et al. 2004), sometimes in conjunction with clinical examination. Meanwhile Moseley and Piller (2008) reported that bioimpedance spectroscopy and tonometry techniques - measuring fluid volume and tissue fibrosis respectively - were able to indicate the presence of breast oedema (as post-operative swelling) and breast lymphoedema. Although the researchers reported low covariance measurements in this pilot study and therefore provide some evidence of reliability (1.29% - 3.25% for tonometry; 0.2%-0.86% for bio-impedance), it is not an indicator of the accuracy of the techniques to measure fluid volume and tissue fibrosis and so arguably has limited usefulness.

The validity of an instrument known as the MoistureMeterD Compact⁵ to measure breast lymphoedema was developed by Greenhowe et al. (2017) with 100 women who underwent unilateral mastectomy and free flap breast reconstruction. Using repeated testing with this instrument, which was previously validated for measuring arm lymphoedema, the authors argued that the validity of the instrument was strengthened by the consistency of the results from the unoperated breast. Similarly, in a first step towards a robust method of assessing for trunk lymphoedema, Mayrovitz and Weingrad (2018) also used the MoistureMeterD⁵ to measure the tissue dielectric constant (TDC) to establish reference values for specific anatomical sites. By providing a measurement of tissue water, TDC values have the potential to provide a method for the early detection of trunk lymphoedema. This concurs with the findings of other studies (Koehler and Mayrovitz 2020; Mazor et al. 2019). Koehler and Mayrovitz's (2020) prospective longitudinal study demonstrated that from the time of the first TDC assessment at two weeks post-surgery, TDC values remained high for those women

⁵ Delfin Technologies Ltd, Finland

who developed trunk lymphoedema (as determined by clinical assessment at 78 weeks). Meanwhile, Mazor et al. (2019) found higher TDC measures for the lateral thorax on the operated side in participants (n=112) who did not have BCRL as well as those who did (n=78), suggestive of early clinical signs of lymphoedema. A potential technique for the early detection of lymphoedema in the breast specifically is evidenced in a recent small pilot study (10 participants with breast lymphoedema, 10 control participants) showing that indocyanine green lymphography could identify changes which preceded clinical evidence of breast lymphoedema (Heydon-White et al. 2020). This technique is minimally invasive, involving injections into the skin and subcutaneous fat.

While there remains no accepted, standardised assessment method for breast lymphoedema, patients with the condition have been involved in the development of a tool to aid diagnosis (Verbelen et al. 2020). The section of this tool which addresses patient-reported symptoms of breast symptoms has been found to be valid and reliable (Verbelen et al. 2020). Known as the Breast Edema Questionnaire (BrEQ), the Dutch version is currently available for use in clinical practice or research.

Incidence of BTL

To understand the relevance of breast lymphoedema to the breast cancer survivorship experience, it is also important to attempt to understand how common breast lymphoedema is among patients following breast cancer treatment. A wide range of estimates for the incidence of lymphoedema in the breast has been reported. In a systematic review of 28 studies reporting on breast lymphoedema following BCS and RT, Verbelen et al. (2014) noted incidence rates of between 0% and 90.4%. Although most of the studies appraised were not randomised controlled trials, it is reasonable to assume that the variation in incidence rates reported is not solely due to bias in the execution or reporting of the studies. Rather, it seems likely that the absence of an accepted definition of breast lymphoedema, the lack of a validated measurement tool, different surgical and radiotherapy regimes, and differences in follow-up intervals after treatment are at least partly responsible. The authors of a more recent systematic review of breast lymphoedema used similar reasoning (Abouelazayem et al. 2020).

Additionally, the use of a range of terminology which may or may not reflect BTL increases the difficulty of estimating incidence. For instance, in their examination of variables associated with health-related quality of life after surgery for breast cancer, Taira et al. (2011) reported indicators such as 'tightness, tenderness or discomfort' in the breast for patients who had BCS; 'tightness and/or tenderness' in the chest wall for those who had mastectomy; and 'swelling (chest wall, breast, and/or axilla)'.

Risk factors for BTL

The risk factors for BTL remain unclear. This section will discuss the findings of studies which have investigated BTL - usually specifically lymphoedema of the breast - as an outcome of breast-conserving surgery (BCS) and radiotherapy, as well as determining the influence of patient characteristics such as body mass index (BMI); systemic therapies such as chemotherapy; and tumour characteristics.

The correlation of breast shape and size with breast lymphoedema has been investigated in several studies (Adriaenssens, Verbelen et al. 2012; Barnett et al. 2011; Boughey et al. 2014; Goffman et al. 2004; Hille-Betz et al. 2016; Pezner et al. 1985). In some instances, bra cup size has been used as a measure of breast size although this is arguably an inaccurate indicator. A small study (n=131) found no significant correlation between breast lymphoedema and a pre-operative bra cup size of C or above (Adriaenssens, Verbelen et al. 2012). However, Boughey et al. (2014) found a non-significant association between breast lymphoedema and bra cup size at the level of multivariate analysis. Meanwhile, in their retrospective analysis Hille-Betz et al. (2016) (n=159) observed a correlation between large and ptotic breasts and breast lymphoedema (multivariate analysis, $p = 0.016$); and Pezner et al. (1985) reported an association between bra cup size and the development of breast lymphoedema ($p < 0.03$: bra cup sizes A or B compared to C, D, or DD), (n = 45; 47 breasts for the analysis). Similarly, in a small pilot study (n = 20) Adriaenssens, Belsack et al. (2012) found a significant correlation ($p = 0.01$; relative risk not reported) between breast size and breast lymphoedema risk. However, the authors do not define 'bigger' cup size, so that the percentage of women falling into this category may be 85% (cup size B or above); 40% (cup size C or above); or 5% (cup size D or above). This, combined with the

absence of a risk ratio and the small and non-random sample, leads to a lack of confidence in the results of this study. More convincing evidence of the correlation of breast lymphoedema and breast size (described as breast volume) is provided by the results of the randomised controlled trial (RCT) reported by Barnett et al. (2011). In this study (n=1014) an odds ratio (OR) of 3.65 was identified (95% confidence interval [CI] 2.54 -5.24, $p < 0.0005$, where the OR signifies the increase in risk per one litre increase in breast size). This large trial also concluded that older women were significantly more likely to have developed breast lymphoedema (multivariate analysis after end points dichotomised: OR 1.44, CI 1.18-1.76, $p < 0.0005$ where OR signifies the increase in risk per 10-year age increase).

A weak but significant positive correlation between BMI and the extent of breast lymphoedema after BCS and RT was demonstrated by Adriaenssens, Verbelen et al. (2012) ($p = 0.046$, $r = 0.171$). The findings of a pilot study (n = 20) by Adriaenssens, Belsack et al. in the same year (2012) contradicted this, concluding from a multivariate regression analysis that a high BMI was not a risk factor for breast lymphoedema (no details reported); however, a lack of a significant correlation in this study may be the result of the small sample size. Stronger evidence of an association between BMI and breast lymphoedema risk was demonstrated in Boughey et al.'s (2014) cohort study. Of the 98 women who had axillary surgery, BMI was found to be statistically significantly correlated with the development of breast lymphoedema (OR 1.81, 95% CI 1.19 – 2.95, $p = 0.004$). Similarly, Goffman et al.'s (2004) cohort study demonstrated in a multivariate analysis that BMI was a statistically significant risk factor for breast lymphoedema ($p = 0.0038$).

Treatment risk factors

An association between the extent of axillary surgery and the development of breast lymphoedema has been reported by some researchers (Clarke et al. 1982; Rönkä et al. 2004). In a study of 74 women by Clarke et al. (1982), 41% of the sample developed breast lymphoedema; on further analysis, 79% of women who underwent axillary dissection went on to develop breast lymphoedema as opposed to only 6% of those

who had no axillary surgery (Table 1). As this study was conducted many years ago, subsequent advances in surgical techniques make any comparisons with more recent research unfeasible. Nevertheless, the findings demonstrate that earlier surgical techniques appear to have contributed to poorer outcomes for patients and played an important part in the development of breast lymphoedema. More recently, Degnim et al. (2012) reported an incidence of breast lymphoedema of 31% amongst a sample of 124 women, although when this figure is adjusted to retain only those women who had breast cancer (i.e., excluding those women in the sample who had a benign tumour) the rate becomes 41% which is identical to the findings in the study by Clarke et al. (1982). However, the authors did not find an association between the extent of axillary surgery and the development of breast lymphoedema. This is reflected in Boughey et al.'s (2014) study of risk factors (discussed earlier) where it was determined that axillary surgery of any type was the strongest predictor of breast lymphoedema (OR 134; 95% CI 18 to > 1000, $p < 0.0001$). The small sample sizes employed in these studies – particularly the small numbers of women in subgroups by type of surgery - together with the lack of accepted criteria for breast lymphoedema – are likely to contribute to this conflicting evidence. Meanwhile the findings of the study by Rönkä et al. (2004) demonstrated a significantly higher incidence of breast lymphoedema in women who underwent more extensive axillary surgery. Using US, the authors determined that those women who underwent axillary lymph node dissection (ALND) developed significantly thicker skin ($p = 0.004 - 0.0001$ across the breast segments), subcutaneous oedema ($p = 0.001$) and fluid collection ($p = 0.0001$) than those who underwent sentinel lymph node biopsy (SLNB) in the operated breast. Although this study was larger ($n = 160$) than the studies above, the authors do acknowledge that there were several potential influences including radiotherapy (RT) variables, systemic therapy, participant age and BMI. Despite this, a more recent retrospective study ($n = 159$) reported by Hille-Betz et al. (2016) also demonstrated a higher risk of breast lymphoedema with more axillary clearance (OR 10.59, $p = 0.004$, 95% CI 2.1 - 53.36).

Table 1: Incidence rate of breast lymphoedema according to extent of axillary surgery (within-group rates)

Author	Dates relevant to data collection	Extent of axillary surgery:		
*ALND = axillary lymph node dissection **SLNB = sentinel lymph node biopsy		Dissection/ALND* incidence	Sampling/SLNB** incidence	None
Clarke et al. 1982 (n = 76) Overall incidence = 41% p < 0.0001, increased incidence for ALND group	Patients underwent RT between May 1973 & March 1980; median follow-up = 23 months (range: 12 months to 7.5 years) across multiple visits	79% (26/33)	25% (3/12)	6% (2/31)
Rönkä et al. 2004 (n = 160) Overall incidence = 34% (by clinical examination, CE) p < 0.05, node +ve & SLNB group US = measurement of subcutaneous oedema by ultrasonography	Patients underwent surgery between April 2000 and December 2001; median follow-up = 12.6 months (range: 11.3 to 18.8) months after surgery (one visit, preceded by mammography and ultrasound of the breast)	48% (22/46) – CE (tumour +ve nodes) 35% (20/57) – CE (tumour -ve nodes) 70% - US	23% (13/57) - CE 28% - US	N/A

Author	Dates relevant to data collection	Extent of axillary surgery:		
*ALND = axillary lymph node dissection **SLNB = sentinel lymph node biopsy		Dissection/ALND* incidence	Sampling/SLNB** incidence	None
Degnim et al. 2012 (n = 92) Overall incidence = 41% No significant difference	Recruitment took place between September 2006 & February 2009; median length of follow-up = 11 months (range: 3-14 months) up to 12 months post-surgery, in one or more visits at 3 months or later	45% (5/11)	49% (33/67)	0% (0/14)

Table 1 (continued): Incidence rate of breast lymphoedema according to extent of axillary surgery (within-group rates)

Other contributory factors may include complications of surgical treatment. For instance, in Fu et al.'s (2011) cross-sectional study with 130 women, 27% were reported to have developed a post-operative seroma which required needle aspiration; breast lymphoedema rates were significantly different to those without a seroma (OR 10.64, $p < 0.001$).

There is some evidence for an association of breast lymphoedema with RT. A retrospective data analysis calculated that the risk of developing breast lymphoedema increased by 23% per 100 cm³ increase in breast volume receiving RT (Kelemen et al. 2012). The reasons for this could be related to the larger amount of irradiated breast tissue, or as a response to greater dose inhomogeneity in women with larger breasts.

However, in a retrospective analysis of records for 279 patients (a subset of the UK FAST hypofractionation randomised trial) (Goldsmith et al. 2011), larger breasts were an independent risk factor for changes in breast size and shape after whole breast RT using 3D dosimetry ($p = 0.006$ for trend) which could not be explained by dose inhomogeneity alone.

Lundstedt et al. (2010) examined the long-term effects of RT using a questionnaire developed with women who had been treated for breast cancer with 365 recurrence-free women who had participated in a randomised trial (BCS either with or without RT after surgery) 10-17 years earlier. Amongst the symptoms reported there was no statistically significant difference in the incidence of breast lymphoedema between the group of women who had received RT and the group who had not. It is unclear how breast lymphoedema was described to respondents, however, so that breast pain may have been a symptom of breast lymphoedema. Reports of breast pain during the preceding six months were statistically higher in the group which had received RT in relation to occasional breast pain ($p = 0.0008$); breast pain at least once per week ($p = 0.0003$); breast pain upon breast pressure (0.0005); and breast pain upon touching the breast ($p = 0.0309$).

Fekrmandi et al.'s (2020) retrospective study ($n = 296$) reported a rate of 45.9% for breast swelling occurring three months or more after RT (at which stage it is presumed to be breast lymphoedema), with trends reported for specific RT techniques.

Moreover, a recent RT trial comparing shorter fractionation schedules of 26 Gy or 27 Gy in five fractions with the standard 15-fraction schedule of 40 Gy (the FAST-Forward trial) identified a small but statistically significant increase in the incidence of breast lymphoedema with the shorter, 27 Gy schedule (incidence of 3.4%, compared to 1.5% incidence with the standard fractionation schedule of 40 Gy; $p < 0.0001$) (Brunt et al. 2020). The incidence of breast lymphoedema was also higher with the shorter schedule of 26 Gy (2.4%) compared to the standard schedule, but not significantly.

Analysis of follow-up assessments occurred longitudinally over five years after treatment; Brunt et al. (2021) subsequently reported no significant difference between treatment groups in the incidence of moderate or marked breast lymphoedema at five years post-treatment (0.7%, 1.8% and 1.7% for treatment with 40 Gy, 27 Gy and 26 Gy

respectively). It is worth noting that the data did not capture patient assessment of breast lymphoedema but was clinician-reported, using a single subjective measure (a four-point Likert scale: none, a little, quite a bit or very much). Moreover, only moderate and marked breast lymphoedema was recorded in the incidence data (i.e., quite a bit or very much) potentially minimising breast lymphoedema incidence.

Degnim et al. (2012) offered a hypothesis for why some women may develop breast lymphoedema after surgery while in others it may not develop until after RT. The researchers suggested that the impaired lymphatic system may still be able to function after surgery; however, the additional disruption caused by RT “crosses the threshold to overload, yielding clinical edema” (p.6).

Other risk factors

Tumour size has also been highlighted as a possible risk factor for breast lymphoedema, with larger tumours being reported as associated with its development (tumour size 1.9 +/- 1.4 cm in cases of breast lymphoedema versus 1.4 +/- 0.7 cm where breast lymphoedema was absent, $p < 0.05$) (Kelemen et al. 2012). The location of the tumour in the upper outer quadrant was found to be a significant variable for breast lymphoedema in both univariate ($p = 0.0042$) and multivariate ($p = 0.0035$) regression analyses as well as in a chi square analysis ($p = 0.0043$) in a retrospective data review ($n = 240$) (Goffman et al. 2004). Conversely, in their prospective study ($n = 131$) Adriaenssens, Verbelen et al. (2012) did not find any significant differences in breast lymphoedema in relation to tumour location.

Other risk factors which have been investigated include air travel and using hot showers, baths, or saunas. Analysis of data in a recent systematic review determined that for patients who have been treated for breast cancer, air travel was not associated with lymphoedema (Co et al. 2018). Interestingly, while this is reflected in patient information produced by *Breast Cancer Now*'s website, details on the web pages for *Cancer Research UK* advocate wearing a compression garment; this is also reflected by the advice on the Macmillan website. Meanwhile, there is conflicting advice about the use of saunas or hot showers and baths: while *Breast Cancer Now*

report that this is not a risk factor, *Cancer Research UK* recommends avoiding this activity (see Appendix 3 for details of links to the webpages referred to in this section).

Treatment for BTL

It is important to note that BTL is a chronic condition which can be managed but not cured. While most effective treatments appear to be in their infancy, hyperbaric oxygen (HBO₂) therapy was used successfully in a case study reported over twenty years ago (Carl and Hartmann 1998). Likewise, a preliminary study demonstrated the effectiveness of HBO₂ therapy in reducing breast lymphoedema (treatment n = 32 versus control n = 12, p < 0.001) (Carl et al. 2001). Teguh et al. (2016) also reported a significant reduction in breast swelling (lymphoedema) (p < 0.05) using HBO₂ in a pre-post intervention study involving 57 women. Carl et al. (2001) reported no toxicities from the use of HBO₂; while Teguh et al. (2016) documented some mild side effects, i.e., reversible myopia and reversible fatigue (8 out of 57 participants for each side effect). However, as noted by Teguh et al. (2016), there are no prospectively randomised trials to determine the effectiveness of this therapy and so the results should be treated with caution. Currently, breast lymphoedema is excluded from the conditions accepted for HBO₂ therapy reported at the tenth European consensus conference on hyperbaric medicine (Mathieu et al. 2017); and there are only seven designated providers of this therapy across England, restricting its availability.

A form of treatment which is more widely used for breast lymphoedema is manual lymphatic drainage (MLD). This is a form of gentle massage which encourages the flow of lymph away from areas where the lymph system architecture is compromised towards functioning lymph areas, thereby alleviating swelling. There is some evidence from small-scale studies for the effectiveness of MLD in treating breast lymphoedema, such as in Goffman et al.'s (2004) cohort study in which 21 of 23 patients who had breast lymphoedema were successfully treated. Similarly, Linnitt and Young's (2007) case study reported on the success of MLD in treating chronic breast swelling.

Treatments may be recommended in combination: in Degnim et al.'s (2012) study, more than half of those participants who had breast lymphoedema were recommended some form of compression treatment combined with MLD. There is

some limited evidence for compression therapy as a treatment for breast and trunk lymphoedema. A small prospective longitudinal pilot study (n = 25) conducted by Gregorowitsch et al. (2019) offers some modest evidence – using clinician and patient - reported outcomes - for the effectiveness of a made-to-measure compression vest in reducing breast or chest wall pain and swelling over at least six months. Pneumatic compression devices have also been used with some success for both trunk and arm lymphoedema (Hammond and Mayrovitz 2010; Ridner et al. 2010) although the participant numbers are small (n=5 and n= 12 respectively) and so the findings are tentative. Meanwhile, Johansson et al.'s (2019) pilot study (intervention, n= 28; control, n= 28) found no effect of a compression sports bra over a normal bra in reducing objective and subjective symptoms of breast oedema (diagnosed at three months post-RT). In this instance, the authors speculated whether the cause of the oedema was in fact delayed acute radiation-induced oedema which was unrelated to any disruption to the lymphatic system. Meanwhile, compression has also been employed in lymphoedema prevention. The use of an individualised compression garment from one to seven months post-surgery (mastectomy and ALND) has been shown to reduce the development of trunk lymphoedema (n=19) compared to women in a control group (n = 18) who received no such intervention (Hansdorfer-Korzon et al. 2016).

Finally, surgical techniques present a promising method to treat breast lymphoedema, such as supermicrosurgical lymphaticovenous anastomosis (LVA) which has been shown in some recent case studies to be very effective (Giacalone and Yamamoto 2017; Scaglioni et al. 2021).

The patient experience of BTL

A message posted in September 2020 on a patient forum hosted by *Breast Cancer Now* comments on how the patient “had to really push for” MLD for her breast and arm lymphoedema. Describing a lack of regular follow up and review and limited local resources, her request to be referred for specialist help was also declined. She describes her difficulty in finding a suitable bra because of her significant breast

swelling which was very visible to her; and she had found a compression bra unsupportive and of no use.

So far, BTL has been described in this chapter using the accepted forms of knowledge which dominate: that is, medical, technical and statistical. But gaining an understanding of women's experiences from their personal perspective - and within the broader political, social, and cultural context of breast cancer - illuminates an important form of evidence. In terms of medical care and aftercare, it presents opportunities to inform practice, enabling women to have the optimum quality of life during and after treatment. Adopting this perspective also seeks to position women's testimonies as a form of accepted and legitimate knowledge. Speaking of women's stories about living with treatment side effects, Nielson affirmed that they "not only serve a critical utility in illuminating the cancer experience, they also have the potential to create new forms of knowledge" (Nielson 2019, p.7).

In recent decades, breast cancer's perception as a hidden and shameful entity has altered because of the activism which took place in the 1970's and 1980's (Sile 2020). Illness experiences which had been surrounded by "silence and shame" (Sile 2020, p. 3) began to be presented publicly through words and images. Notable examples include the photographer and activist Jo Spence in the posthumous publication *Cultural Sniping: The Art of Transgression* which includes powerful images evoking her experiences of breast cancer (Spence 1995). More recently, they include Emilia Nielson's (2019) examination of what she terms "disruptive breast cancer narratives" which sit in opposition to the 'pink ribbon' culture which emphasises celebration, positivity, and survivorship. Nielson (2019) commented that within this culture, women "are expected to endure whatever cancer brings in its wake ... silently, stoically, and privately" (p. 8).

Hence the celebratory attitude towards survivorship promoted by the 'pink ribbon' culture obscures the fact that many individuals are living diminished lives because of treatment side effects (Balmer 2015a; Porroche-Escudero 2014). Moreover, the sentiments of this culture have an ability to silence and devalue those whose experiences do not conform to them. Nielson (2019) highlighted the difference between being 'muzzled' - and hence unable to express oneself - and 'not being

listened to'. While she acknowledges that there is a distinction in relation to the strict definition of the terms, in fact the difference is complex and the distinctions less clear in a cultural context where women are supposed to keep in check any feelings of frustration, anger, disappointment and pain. It means that narratives which do not fit the dominant expression of survivorship remain marginalised. This culture has emerged despite formal recognition of the survivorship needs of individuals with the creation of the National Cancer Survivorship Initiative (Richards et al. 2011) and the Living with and Beyond Cancer programme (Department of Health, Macmillan Cancer Support and NHS Improvement 2013). Indeed, it is known that for some women with early-stage breast cancer, undergoing diagnosis and treatment can have adverse psychological effects including anxiety and depression during radiotherapy (Kawase et al. 2012) and symptoms of post-traumatic stress disorder in the year following a breast cancer diagnosis (Voigt et al. 2017).

Porroche-Escudero (2014) has written about the negative impact of silencing women's concerns, including the physical, emotional, and financial implications. These important counter-narratives to the normative discourse include accounts of women living with the challenges of treatment side effects or where survival is not the outcome. I argue that documenting women's experiences creates a counter-narrative to what constitutes currently accepted knowledge about BTL. This serves to widen our perspective and understanding; for instance, these accounts have the potential to display the heterogeneity among individuals' experiences, defying the cultural stereotypes which are presented for public consumption.

Researchers who seek to understand women's personal experiences must also negotiate the tensions inherent in bringing their own representations of these private accounts into public, academic contexts. Edwards and Ribbens (1998) warned that "... the voices of particular groups, or particular forms of knowledge, may be drowned out, systematically silenced or misunderstood as research and researchers engage with dominant academic and public concerns and discourses" (p. 2). Such risks of further silencing women and the range of potential causes of these silences will be explored in further detail in Chapter 5 in discussing the theoretical framework which was chosen for this study: that is, The Silences Framework (Serrant-Green 2011). In this and

subsequent chapters I also use the first person frequently to reflect the central importance of a reflexive approach.

Rationale for the present study

In Chapter 4 I demonstrate that within the existing dominant medical and academic discourse, women's experiences of BTL have failed to receive the same level of attention or achieve the equivalent level of significance as other treatment side effects. This is reflected currently in the limited availability of patient information about BTL for women treated for breast cancer. Yet women clearly do have concerns: this is evident on the online patient platforms provided by breast cancer organisations such as *Breast Cancer Now*. The prevailing discourses which focus upon survival and optimism result in the marginalisation of these alternative experiences of treatment side effects. The result is the potential for an uninviting or even hostile environment in which women must negotiate how they respond to these side effects. Against this backdrop, it becomes clear why an understanding of these experiences needs to be located within the wider context of women's social and cultural influences.

An initial literature review in the following chapter will show that there is a dominance of research exploring women's experiences of developing arm rather than breast or trunk lymphoedema, leading to a bias in knowledge and understanding. Furthermore, the systematic literature review presented in Chapter 4 will verify the absence of women's experiences of BTL in the literature. It may be that women who have BTL have experiences which call for alternative forms of care and support. Thus, the overall aim of this study is to explore and give space to women's experiences of developing and living with breast or trunk lymphoedema following surgery and radiotherapy for breast cancer. The study recognises that women have remained unheard or have even been silenced about these experiences. Hence it acknowledges the importance of ensuring that this research not only generates awareness within academic contexts but creates tangible outcomes to improve the experiences of other women. In Chapter 3 I explain how The Silences Framework (TSF) guiding this study facilitates an exploration of those silences; and in Chapter 5 I place TSF in the context

of the epistemological and theoretical underpinnings of this study and how these aspects all contributed to the final study design.

The specific aims of the study are:

- to gain an in-depth understanding of women's experiences of developing and living with BTL following surgery and radiotherapy for breast cancer: that is, to explore what it means for women to develop and live with this treatment side effect and discover the impact upon them and their daily lives.
- to generate findings which will serve the educational needs of patients with breast cancer, the healthcare practitioners caring for them, patients' families and friends, and other charitable and non-charitable organisations supporting women who have had breast cancer.

As an exploratory study and one which seeks to provide women with the freedom to speak about aspects which are pertinent to them individually, the main research question has deliberately been kept very broad, namely:

What are women's experiences of developing and living with breast or trunk lymphoedema after surgery and radiotherapy for breast cancer?

Under this broad enquiry, there is a focus upon the following aspects:

- a) How do women describe their experiences of developing and living with breast or trunk lymphoedema?*
- b) What particular aspects of their lives do women describe in relation to living with breast or trunk lymphoedema?*

Accepting that women's experiences of BTL have remained unheard, the approach of this study seeks to provide agency and choice to participants and to produce findings which have some clinical relevance and are able to address women's needs.

Chapter summary

This introductory chapter began by providing a brief overview about breast cancer. The importance of a medical understanding about breast cancer was acknowledged as significant contextual information, and reference made to Appendix 1 which offers scientific and medical detail about breast cancer including epidemiology, diagnosis and staging, treatment, and treatment side effects. This chapter has presented BTL as a potential side effect of treatment; and it was discussed in relation to the need for an agreed definition; risk factors for its development; and assessment and treatment techniques. Next, I argued for the importance of understanding the patient experience. I described the present study's rationale, highlighting that this study is theoretically informed by The Silences Framework (Serrant-Green 2011) in view of the anticipated silences surrounding women's experiences of BTL.

In Chapter 2 an initial literature review of women's experiences of 'breast cancer-related lymphoedema' shows that women's experiences of lymphoedema of the arm (rather than the breast or trunk) have been extensively explored, hinting at an absence of literature about women's experiences of BTL. The review is presented as having relevance to the subject under investigation in this study as it indicates the range and type of women's experiences of arm lymphoedema. It also gives an opportunity to consider the applicability of the reported methodologies and methods to the present research.

Subsequent chapters are presented in line with each of the stages of The Silences Framework (TSF) (Serrant-Green 2011). TSF is described in Chapter 3 where I show how it is used throughout the research process. I explain how the adoption of TSF helps to gain a detailed, in-depth understanding about marginalised experiences, providing theoretical and practical guidance for illuminating silences surrounding the topic.

Chapter 4 equates to stage 1 of TSF, reporting the results of a systematic literature review which identifies the existing landscape in relation to what is known about women's experiences of BTL. In showing how women's experiences are represented, it demonstrates that they remain marginalised within the dominant medical-led discourse. Sources of information such as patient forums are also acknowledged.

In Chapter 5 I outline the methodology for this study. I discuss the epistemological and theoretical background which informs the use of TSF and which in turn informs the study design with which I propose to advance an understanding of women's experiences of BTL. Here I discuss in greater detail how the study is framed by The Silences Framework (TSF) (Serrant-Green 2011) which is based upon criticalist approaches. With reference to the examination of the research topic in the literature review at stage 1 of TSF, I re-emphasise how the nature of the evidence and type of experiences which are deemed legitimate are bound by their cultural and historical context. I explain how TSF positions individual experience – and particularly marginalised perspectives - as equally important forms of knowledge as those taken-for-granted, dominant ways of knowing. TSF's emphasis upon the effects of power upon experiences and the key role of the researcher is discussed. At stage 2 of TSF (which is explored in Chapter 5) I aim to reveal the potential silences surrounding the proposed research, located within my identity as the researcher, the research topic, and the research participants. In this chapter I also discuss the Voice-Centred Relational Method (VCRM) and its analytical tool known as the Listening Guide which I employ in the data analysis. I show how this method is applicable to research which aims to place the participant's voice centre-stage in the analysis, rather than being subsumed or obscured by the researcher's influence.

The research study design is also described in Chapter 5, including details of participant recruitment and the rationale for the techniques selected for data collection and analysis. This is also part of TSF stage 2 and aims to demonstrate how the methods selected intend to meet the aims and objectives of the study and facilitate an exploration of the silences previously identified. Stage 3 of TSF is presented in Chapter 6 in which I report on the process of data collection and analysis. This stage is continued into Chapter 7 in which I discuss the study findings. In exploring women's experiences, the findings will reveal the extent to which the voice of women with BTL remains absent and is silenced in practice.

Finally, the theoretical and practical implications of the findings are explored in the discussion which is provided in Chapter 8, and which encompasses the final stage of TSF (stage 4). I offer a reflection upon the status of the 'silences' that were uncovered at the beginning of the study: that is, I consider what has changed or indeed what new

silences may have been created because of the research. The chapter concludes with the implications of the findings for practice and recommendations for future research.

Chapter 2

Women's experiences of arm lymphoedema: an initial literature review

Chapter outline

Given the anticipated dearth of literature relating to women's experiences of lymphoedema in the breast or trunk after treatment for breast cancer, this chapter offers an initial literature review of women's experiences of lymphoedema in the *arm*, about which there is a substantial body of evidence. It is proposed that as a related phenomenon, women's experiences of arm lymphoedema bear some relevance to the current investigation. This chapter reports on the key findings of this review and considers their implications for this research, as well as reflecting on the methods used to inform the options for a suitable design for the current study.

Introduction

Chapter 4 presents a systematic literature review examining the evidence for women's experiences of developing and living with lymphoedema of the breast or trunk after treatment for breast cancer. However, an initial literature review of women's experiences of 'breast cancer-related lymphoedema' presented in this chapter will reveal that women's experiences of lymphoedema in the *arm* have been already extensively studied. It is acknowledged that concepts emerging from studies which have examined the impact of arm lymphoedema cannot be assumed to have direct relevance for women living with BTL. Clearly the arm is a visible part of the body which is used in many functional activities: the same cannot be said for the breast which carries associations with sexuality and motherhood (Nash 2014) and in Western cultures is generally a clothed area of the body. But inevitably there will be some similarities, such as in terms of women's experience of treatment for breast cancer. For this reason, in this chapter I report on the findings from an initial literature review of women's experiences of arm lymphoedema, describing the range and type of

women's experiences to provide some context for the present study. Establishing the scope and characteristics of the literature identified in this review has also helped me to clarify my research question and consider suitable methodological and methods choices for my own study. Specifically, it confirmed The Silences Framework (Serrant-Green 2011) as appropriate to exploring the apparent silence surrounding women's experiences of BTL. This framework is outlined in the next chapter; and it is explored in more detail in Chapter 5 when I discuss the methodology for this study and where I confirm the decision process for the final design approach.

It was explained earlier that the discourse around the term 'breast cancer-related lymphoedema' (BCRL) focusses almost exclusively on arm lymphoedema; and the fact that lymphoedema may occur in the breast or trunk is often not acknowledged. Even if these are listed as areas affected by lymphoedema after treatment for breast cancer, the tendency is for the focus to remain upon lymphoedema in the arm. For the purposes of this initial literature review, the terms BCRL and arm lymphoedema may be used interchangeably to reflect how they are used in the existing literature.

Search strategy and results

The database CINAHL was searched using terms including 'breast cancer', 'arm lymphoedema' or 'arm lymphedema', 'experience', 'body image' and 'living with'. The references for the articles identified were also checked. Twenty-six articles were included in this review; see Appendix 4 for details of the articles identified for the review. The studies discussed below were identified through the database CINAHL. They reveal a wide range of findings, demonstrating the scope of the impact of arm lymphoedema upon women's lives. Among the studies identified, several focussed upon women's experiences of managing their lymphoedema (Fu 2005; Greenslade and House 2006; Jeffs et al. 2016; Karlsson et al. 2015; McGrath 2013; Radina et al. 2014; Ridner, Sinclair et al. 2012). Management issues included work-related concerns (Fu 2008; Sun et al. 2020); how women coped (Heppner et al. 2009); how families coped (Radina and Armer 2001); and women's experiences of a complementary treatment (Whatley et al. 2018). One study (Honnor 2009) investigated the lymphoedema information needs of women who had had breast cancer. The meaning of living with

arm lymphoedema and the psychosocial consequences were explored by Hare (2000) and Johansson et al. (2003); similarly, Fu and Rosedale (2009) and Ridner, Bonner et al. (2012) reported on feelings and sense of self. Women's sexual experiences were investigated by Radina et al. (2008, 2015); while Whyte et al. (2010) reported on the experiences of younger women. The study by Anbari et al. (2019) is notable for its longitudinal nature, with data collected across a seven-year period. Considering a global perspective, a study by Maree and Beckmann (2016) was conducted in a developing country where most women rely on public health care services which appear to offer minimal lymphoedema treatment provision. Meanwhile, participants in Thomas-MacLean et al.'s (2005) study were from a predominantly rural area in Canada. Most recently, Acebedo et al. (2021) explored the lived experiences of Hispanic women of Mexican origin who have BCRL; and a study by Wanchai et al. (2012) also adopted a cross-cultural approach.

In relation to their methodological and theoretical context, all the studies identified in the initial literature review adopted a suitable approach for investigating human experience. Most of the articles were primary studies using a qualitative research design, apart from two which were mixed-methods studies (Radina et al. 2015; Ridner, Sinclair et al. 2012). Several of them adopted a phenomenological approach (Acebedo et al. 2021; Fu 2005; 2008; Fu and Rosedale 2009; Greenslade and House 2006; Johansson et al. 2003; McGrath 2013; Radina et al. 2015; Whyte 2010) in which the authors were seeking to understand the lived experience of participants. Meanwhile Karlsson et al. (2015) used 'phenomenography' as the theoretical framework for their study in Sweden, an approach which explores the variation in how individuals experience and interpret a phenomenon (Röing and Sanner 2015).

In Wanchai et al.'s (2012) study, women's experiences were located within the types of healthcare provision available to people of different incomes and circumstances within South Africa and USA. The authors described using an ethno-nursing research method to compare participants' experiences and lymphoedema management practices in the context of private and public healthcare. Maree and Beckmann (2016) also explored the experiences of women in South Africa living with BCRL. This study employed a profession-led model of nursing known as the 'Roy Adaptation Model' which adopts a biopsychosocial perspective and stresses the importance of environmental stimuli.

Other models used include the 'Family Adjustment and Adaptation Response' model which focusses specifically upon the family's response to stressors such as a chronic illness (Radina and Armer 2001). Using this model, the authors sought to interpret the findings from a range of data sources and used ethnographic methods to investigate how women and their families had been affected by BCRL. Meanwhile Radina et al. (2014) adopted feminist family theory as a framework to explore how women negotiate their self-care needs against the demands of family and work-related responsibilities. Using mixed methods, Ridner, Sinclair et al. (2012) examined women's factual accounts of their daily lives and behaviours to understand whether a disability model or a symptom management model may provide a better reflection of women living with arm lymphoedema.

Although identified as having a qualitative design, the reports of some of the studies were weakened as they did not offer an explicit theoretical framework or description of the methodology adopted. Aspects of the approach used could sometimes be inferred from a description of the methods, however. For example, Honnor (2009) commented on using constant comparison during data analysis to determine saturation point, which is a core feature of Grounded Theory (Creswell 2013), although there was no further reference to the theory underpinning the study. Elsewhere, Heppner et al. (2009) noted that the 'consensual qualitative research method' described by Hill et al. (1997) had been adopted for the analysis; while Thomas-Maclean et al. (2005) reported that the transcripts had been 'analyzed using established guidelines for qualitative research' (p. 250) which involved coding the data and generating categories and themes from the transcripts. Meanwhile Radina et al. (2008) adopted a 'co-operative, inductive approach' (p. 26) to their data analysis; and Whatley et al. (2018) reported using 'inductive content analysis' to examine the data.

Other studies made more explicit reference to the theoretical context for their study. For instance, in their descriptive qualitative analysis, Ridner, Bonner et al. (2012) drew upon Pennebaker's expressive writing paradigm (Pennebaker and Seagal 1999) to investigate participants' feelings about the impact of BCRL upon their lives and used content analysis to analyse the data. Hare (2000) and Jeffs et al. (2016) described using a Grounded Theory approach for their qualitative studies; while Anbari et al.'s (2019) longitudinal study employed the concept of quality of life to develop a-priori

categories for the analysis. A-priori theoretical concepts were also used in Sun et al.'s (2020) multiple-case study methodology to investigate the impact of BCRL on a sample of women in the USA who had returned to work after treatment for breast cancer.

Key findings from the initial literature review articles of arm lymphoedema

Burckhardt et al.'s (2014) meta-synthesis of qualitative studies, which used an integrative rather than an interpretative approach, detailed 94 findings from which four themes associated with women's experiences of living with arm lymphoedema were developed. The following section will show that several of the categories described by Burckhardt et al. (2014) are reflected in the findings from other studies which were identified in this initial literature review.

Theme: experience of everyday life

This theme encompassed the impact of BCRL treatment demands; financial implications of treatment; and the limitations that BCRL imposed upon women's work and personal roles, leading to a degree of dependence on others. It was also supported by the themes of *being bound to the chronic disease* (Johansson et al. 2003); *a sense of loss* (Acebedo et al. 2021) and the theme of *constancy* described by Greenslade and House (2006) to reflect the pervasiveness of the impact of arm lymphoedema across women's lives.

Theme: energy sapping

This theme included the categories *mourning*, *'it never goes away'*, *yearning for normalcy*, *loss of attractiveness*, *strains on relationships* and *lack of information*. Similar themes of *body image disturbances*, *adverse effects on relationships* and *yearning to return to normal* were reported by Ridner, Bonner et al. (2012). The theme *yearning for normalcy* also emerged in Greenslade and House's (2006) study. Participants wanted to have a normal size arm that did not draw attention and elicit questions from others; nor did they wish to have to purchase larger clothing to fit their

affected arm. This was reflected in participants' comments in Whatley et al.'s (2018) study. Unwanted attention could come from strangers; but in their desire to help it could also come from family and friends (Johansson et al. 2003).

Whatley et al.'s (2018) identification of the psychological impact of BCRL upon daily life referred to the physical restrictions imposed by BCRL upon everyday activities such as carrying heavy items and driving. Similar limitations on fulfilling everyday roles were highlighted in other studies (Anbari et al. 2019; Honnor 2009; Sun et al. 2020, for example). These limitations were either due to physical symptoms or to guidelines restricting some activities. Nevertheless, McGrath's (2013) study highlighted the importance to women's self-identity of maintaining familiar roles, such that most participants opted to risk harming their affected arms to maintain their occupational status. Hence, in attempting to overcome the negative feelings associated with impaired function, women reported trying to force their affected arm to perform normally. Such tension is reflected by Radina et al. (2014) under the theme *struggles with putting myself first* and the associated theme *making the time*. At the same time, participants in this study revealed a strong level of motivation to undertake self-care to reduce their risk of developing BCRL in the first instance. Participants were therefore shown to attempt to reconcile the need to undertake self-care routines while continuing to fulfil their roles within the family and at work.

An exception to the findings above is reported by Ridner, Sinclair et al. (2012) in a study investigating whether BCRL could be considered a disabling condition.

Participants were described as having stage 2 (ie moderate) arm lymphoedema, yet there was limited reporting of limitations in daily activities and the authors comment that participants were leading 'full, rich, busy lives' (Ridner, Sinclair et al. 2012, p. 609). Perhaps the method of data collection – women were guided to write 'objectively' about specific topics - restricted opportunities for participants to convey the full range of their experiences, including their feelings.

Theme: personal empowerment

This theme focussed upon ways of coping, including acceptance; adapting values; having a confident attitude; and drawing upon support from others or spiritual support. Despite the significant difficulties expressed by some participants, ways of coping with arm lymphoedema were also apparent in the literature. For instance, some women acknowledged that they felt 'lucky to be alive'; while support from family and friends was a feature for many participants (Acebedo et al. 2021; Hare 2000). The importance of religious or spiritual support was a particular feature in some studies conducted in the USA and South Africa (Fu 2005; Maree and Beckmann 2016; Ridner, Bonner et al. 2012a; Ridner, Sinclair et al. 2012; Wanchai et al 2012) and was reflected in the theme *uplifting resources* (Ridner, Bonner et al. 2012) and in *"I am grateful": coping with lymphoedema* (Maree and Beckmann 2016). *Coping* was also a theme in Johansson et al.'s (2003) study where there was evidence of seeking help from others or adapting activities (problem-focussed coping) as well as participants' use of emotion-focussed strategies, such as making favourable comparisons to other people. Similarly, Radina and Armer (2001) reported on women's modification of daily tasks to accommodate their BCRL, either by altering the task or seeking help from others. Adopting the perspective of the whole family, this study noted that the ability to adapt and to draw upon existing resources appeared to be positive indicators for successful coping. *Autonomy* and *safety* were themes relating to women's recognition of lymphoedema as a chronic condition and their ability to use management strategies, based upon either their own knowledge and understanding or access to specialist support.

Theme: contribution of others

A critical component of this theme was the ability of others to have empathy and understanding or information. Much of the literature revealed difficulties regarding information about lymphoedema; it was common for participants to have no prior lymphoedema knowledge. Under the theme of *searching*, Greenslade and House (2006) described women's reports of inconsistent or absent information from HCPs, compelling them to search for information themselves. This was reinforced by the

findings of Honnor's (2009) study in which most participants stated that they had not been made aware of lymphoedema prior to developing it. Significantly, none of the participants in this study could recall lymphoedema being raised as a possible side effect at the time when they provided their signed consent to surgery. Similarly, in Maree and Beckmann's (2016) and Acebedo et al.'s (2021) studies, participants reported that they had no preparation for the possibility of lymphoedema nor what action to take if it were to occur. Notably, the absence of a feeling of connection with HCPs was described in relation to *not knowing* about lymphoedema (Acebedo et al. 2021).

There was no consensus on how much information participants would prefer to receive and when to receive it (Honor 2009). While some reported that too much information could heighten anxiety, for others information was perceived to be helpful for coping. This was reflected by participants in Hare (2000)'s study where it was noted how information about lymphoedema had positive effects, including acceptance of the condition. Under the theme of *marginalisation and minimisation*, Ridner, Bonner et al. (2012) found that most participants felt unsupported and that their BCRL needs were largely ignored by HCPs. In South Africa in particular, Maree and Beckmann (2016) commented how BCRL is viewed by HCPs as a normal occurrence, leading to an unsympathetic response to patients' concerns.

Additional themes

Some additional themes which did not appear in Burckhardt et al.'s (2014) meta-synthesis of qualitative studies but were revealed in the initial literature review of women's experiences of arm lymphoedema are described below.

The theme of *uncertainty* identified by Karlsson et al. (2015) captures women's inability to foresee the future or to have a sense of treatment expectations. A lack of consistent information from healthcare providers contributed to this uncertainty.

Disappointment described women's feelings about the results of their lymphoedema treatment; while *guilt and shame* reflected the feelings of women who had been unable to adopt effective management strategies (Karlsson et al. 2015). The theme

resignation to a new self which was reported by Acebedo et al. (2021) emerged from interviews with Hispanic women and suggests a begrudging acceptance of their BCRL, although for some participants this resignation was associated with the belief that this was a part of their destiny. The importance of acceptance for women's ability to manage their BCRL was also highlighted by Jeffs et al. (2016). Additionally, participants valued having knowledge about BCRL and how to manage it successfully, with sources including lymphoedema practitioners, the national Lymphoedema Support Network, and information available online, in magazines and in newspapers.

Hare (2000)'s theme *suffering silently* captured the strength and impact of feelings experienced by women. Closely linked to feelings of anger was a sense of *abandonment* (Greenslade and House 2006), with reports of HCPs avoiding or minimising the subject of lymphoedema alongside an absence of education about lymphoedema prevention and management. For participants in countries such as the USA and South Africa, difficulties were often exacerbated by the financial costs of treatment (Greenslade and House 2006; Maree and Beckmann 2016).

Physical, emotional, and social consequences of arm lymphoedema

A range of symptoms were reported in the literature which included swelling, pain, pressure, tightness, tingling, numbness, reduced mobility, fatigue, and difficulty sleeping (Acebedo et al. 2021; Anbari et al. 2019; Greenslade and House 2006; Honnor 2009; Maree and Beckmann 2016; Ridner, Sinclair et al. 2012; Whatley et al. 2018). Emotions encompassed frustration, sadness, depression, anger, distress, disappointment, self-blame, helplessness, fear (of injury, for instance) and a lack of confidence (Acebedo et al. 2021; Anbari et al. 2019; Greenslade and House 2006; Hare 2000; Honnor 2009; Johansson et al. 2003; Jeffs et al. 2016; McGrath 2013; Maree and Beckmann 2016). In addition, there were reports of participants feeling self-conscious and believing that other people were afraid of their lymphoedema (Maree and Beckmann 2016). Concerns about body image and attractiveness were common among the studies. BCRL was noted to have a negative impact upon body image (Honor 2009), with women feeling embarrassed or wishing to avoid some social circumstances. Specifically, Radina et al.'s (2015) study exploring the way in which

BCRL symptoms affected women's sexual experiences revealed the negative impact of compression garments. Compression sleeves were experienced as a barrier to intimacy and reduced opportunities for spontaneity, in addition to reducing feelings of being sexy and attractive. Negative feelings about their intimate relationships were a feature of most participants' experiences in this study. Radina et al.'s earlier study (2008) reflected similar themes of not feeling sexy and of sexual and emotional changes within intimate relationships. However, it must be noted that this could be attributed at least in part to women's experiences of breast cancer more generally rather than specifically of BCRL.

Implications of the findings from the initial literature review for the present study

The themes identified from the initial literature review literature were wide-ranging and significant in the extent of influence of arm lymphoedema upon women's lives. Functional limitations caused by restricted movement or weakness of the arm or hand grip appeared to have wide-reaching implications. These included increased dependency on others and a need to manage the tension between attempting to maintain previous roles at home and at work with the need to manage time effectively to ensure that self-care activities were undertaken. The psychological impact was demonstrated in the range of emotions reported and the influence upon self-identity. The significance of relationships with others, including intimate and sexual relationships, was also evident. These experiences took place in the context of a lack of information about BCRL from HCPs, such that a potential opportunity for women to prepare for the development of arm lymphoedema was missed.

The findings from this review about women's experiences of arm lymphoedema raise many questions about the implications for women's experiences of living with lymphoedema of the breast or trunk. For instance, if patient information about arm lymphoedema is limited, what might this indicate about the availability of information about BTL, a condition which appears less visible in the academic literature? What practical, physical, psychological, or social concerns about BTL might women have? Is the experience of *suffering silently* (Hare 2000) shared amongst women with BTL as

well? What are women's experiences of developing and living with BTL that have not been heard?

Acknowledgement of women's knowledge about their lymphoedema as legitimate is exemplified in studies where the researchers did not seek formal confirmation of a medical diagnosis of lymphoedema: women's own accounts were accepted (Thomas-MacLean et al. 2005). Conversely, where the absence of a formal diagnosis was perceived as a limitation of the study (for example Acebedo et al. 2021), arguably this shows a disregard for women's knowledgeable status and is a form of silencing. Moreover, a recent prospective longitudinal cohort study (n = 647) provides an example of the significance of women's bodily knowledge as a reliable source of information in relation to arm lymphoedema (Collins et al. 2020). The findings showed that patients who reported an increase in arm size were more likely to develop arm lymphoedema than those who did not report it (hazard ratio (HR) = 3.09, 95% CI 1.62-5.89, p = 0.001).

Early reflections on the methods used in the initial literature review articles and their influence upon the design of this study

Unsurprisingly, qualitative research designs dominated the studies in this review; interviews (semi-structured or unstructured) and focus groups were the main methods of data collection. This confirms my expectations about a suitable research design and methods for the present study. Considering this study's aims and objectives, the methods used in initial literature review studies are evaluated in the light of their ability to draw out the voice of - or their risk of silencing - the participant.

In many of the studies, individual interviews were deemed to be the most appropriate method (Acebedo et al. 2021; Fu 2005; Fu 2008; Fu and Rosedale 2009; Greenslade and House 2006; Heppner et al. 2009; Honnor 2009; Jeffs et al. 2016; Johansson et al. 2003; Karlsson et al 2015; McGrath 2013; Maree and Beckmann 2016; Radina et al. 2008; Sun et al. 2020; Wanchai et al. 2012; Whatley et al. 2018). Although telephone interviews were employed in situations where geographical distance would otherwise have excluded participants, face-to-face interviews were the preferred option. Interviews are recognised as a valuable method for collecting rich and complex data

(Tod 2010) and are particularly suitable for drawing out individual experiences. The interviews were usually described as semi-structured, implying that a topic or question guide was used. However, on closer examination, the researchers often allowed participants free rein to steer the interview in their chosen direction (Fu 2008; Wanchai et al. 2012). This indicates that participants were given the authority to be in control of how they shared their story with the researcher. However, this needs to be weighed against the potential for participants to stray off-topic: indeed, at times, participants drew upon their wider experiences of breast cancer and needed prompting to attend specifically to their lymphoedema experiences (Johansson et al. 2003; Whyte 2010).

There is no consensus on an optimum method for exploring sensitive topics. Both interviews (Radina et al. 2008) and focus groups (Hare 2000) have been argued as appropriate methods for discussing issues such as sexual relationships (Radina et al. 2008). Focus groups are also claimed to be a suitable method for exploring subjects which are little understood (Thomas-MacLean et al. 2005), indicating their potential for the present study. However, it has also been suggested that women might feel more able to share sensitive experiences in relation to BCRL via an online survey (Radina et al. 2015) although the fixed and inevitably limited responses are recognised as a limitation of the method (Anbari et al. 2019; Radina et al. 2014).

While researchers have attempted to create the conditions to encourage participant disclosure, inevitably those women who agreed to participate were those who were already prepared to share personal information. Accordingly, women who were less willing to disclose will have excluded themselves from the research, resulting in a form of bias. Even among those women who do participate there will be varying degrees of self-censorship. For instance, Ridner, Sinclair et al. (2012) noted that participants who were asked to write about their daily activities did not specifically mention sexual activity. Similarly, researcher observation of a support group (Radina et al. 2001) carries the potential for women to alter their behaviour due to the researcher's presence as an outsider (Foster 2011), thereby inadvertently silencing them. Although expressive activities were only used in one of the studies identified (Ridner, Bonner et al. 2012) it alerted me to the potential of such techniques to offer a platform for the voice of participants to be heard. Nevertheless, this needs to be considered in the

light of the possibility that such techniques may not appeal to some women who may be deterred from participating or from expressing themselves fully.

In relation to data analysis, a range of techniques were employed in the studies. The techniques include content analysis which is used to provide a quantitative description of phenomena (Whatley et al. 2018), phenomenological approaches to determine individuals' lived experience (Karlsson et al. 2015), thematic analysis (Radina et al. 2015) and Grounded Theory approaches (Hare 2000; Jeffs et al. 2016). The diversity of methods used has led me to understand that there is no single suitable method for the present study. In accordance with the theoretical framework adopted for the study (see below and Chapter 3), however, I needed to identify a form of analysis which gave prominence to participants' voices. By this I mean that it was important not to silence participants' voices by imposing my own, i.e., researcher-led, interpretation upon the data analysis.

Chapter summary

This chapter described an initial review of the literature relating to women's experiences of arm lymphoedema after treatment for breast cancer, as a topic providing some context and therefore of relevance to the current investigation. Moreover, the methodologies and methods employed in these studies provide a useful reference when considering a suitable approach for this study.

The key findings of this review relate to the pervasive and limiting influence of arm lymphoedema in women's lives. A lack of patient information about lymphoedema was common, with women often having no preparation for this potential treatment side effect, compounded by a lack of support and empathy from HCPs. The threat to women's self-identity was seen in women's desire to return to normal and their attempts to use their affected arm normally to maintain their familiar roles. There were descriptions of participants' ways of coping and a developing acceptance. However, feelings of uncertainty, disappointment, guilt, and shame associated with treatment experiences, a sense of abandonment and suffering silently, were reported

themes. The review also revealed a range of physical, emotional, and social consequences for women.

I went on to discuss the implications of the findings from this initial literature review for the present study; and considered the methods used to inform the current study's design.

The next chapter is dedicated to a description and discussion of The Silences Framework (TSF) to facilitate the investigation into women's experiences of BTL after treatment for breast cancer.

Chapter 3

The theoretical framework for the study: The Silences Framework

Chapter outline

This chapter provides a rationale and description of the theoretical framework which was selected to guide the investigation into women's experiences of BTL after treatment for breast cancer. Known as The Silences Framework (TSF), it provides a series of sequential stages for addressing issues which are deemed to be marginalised.

Introduction

In the Introduction chapter, I explained that breast or trunk lymphoedema (BTL) can develop after treatment for breast cancer. The literature around BTL was described using the accepted forms of knowledge which dominate; that is, medical, technical, and statistical. I also showed in Chapter 2 that the discourse around the term 'breast cancer-related lymphoedema' (BCRL) focusses almost exclusively on arm lymphoedema, such that the fact that lymphoedema may occur in the breast or trunk is often not acknowledged. Therefore, in this thesis I propose that the voices of women with BTL remain unheard because their needs for an accurate diagnosis, information, and support if they develop the condition are at odds with the knowledge base and priorities of the health system which serves them. I also argue that the celebratory attitude towards survivorship promoted by the 'pink ribbon' culture obscures the fact that many individuals are living diminished lives because of treatment side effects (Balmer 2015a; Porroche-Escudero 2014). Furthermore, the sentiments of the 'pink ribbon' culture have an ability to silence and devalue those whose experiences do not conform to them.

The Silences Framework (Serrant-Green 2011) - hereafter referred to as TSF - offers a lens through which to understand women's experiences in the context of the 'silences' which surround them. This chapter discusses this framework to demonstrate how it

guides and underpins the study. The framework is presented at this early stage in the thesis to help the reader understand how it shapes the research process and informs each of the subsequent chapters.

The Silences Framework (TSF)

TSF was first introduced in a methodological paper (Serrant-Green 2011) where it was offered as a theoretical foundation for exploring under-researched, sensitive, or marginalised issues and experiences. TSF acts as a guide for the entire research process, from the development of the research question to planning for service change or community action. It is based upon anti-essentialist perspectives of social reality as constructed and fluctuating, according to the specific societal context at any specific point in time (Williams and May 1996), rather than pre-determined and fixed. At the framework's core is the concept of 'screaming silences' which is proposed to characterise those topics or experiences which are under-researched, undervalued or even ignored (Serrant-Green 2011). Issues are termed 'screaming silences' because it is reasoned that they resonate loudly for the individuals or groups experiencing them while simultaneously remaining absent from wider societal discourses and from the academic literature. Therefore 'screaming silences' are said to sit within the gaps in research. They reflect how power is played out by emphasising what is and what is not considered legitimate and accepted knowledge and understanding within a particular society at a particular time. In the present study, it is proposed that the 'screaming silences' are located within women's experiences of developing and living with BTL in the context of their healthcare, their personal and social networks, and the wider community.

TSF offers a four-stage process for investigating silenced issues.

Stage 1 - *working in silences* (Chapter 4 – Literature Review)

While TSF acknowledges the importance and value of individual experience and personal interpretations of events, it also recognises the significance of the wider

context. That is, experiences can only be understood by appreciating the wider social as well as personal context within which they occur, recognising that there are intrinsic inequalities within society. Hence at stage 1 of TSF, the researcher is required to establish and contextualise what is known about the research subject. Therefore, in the next chapter (Chapter 4) I will present a review of the current literature and the extent to which women's experiences are represented within the existing academic landscape. It will demonstrate that there is an absence in the literature of any in-depth qualitative exploration of women's experiences of BTL. I will argue that those experiences remain marginalised within the dominant medical-led discourse, and that the cultural and historical context determines the nature of evidence and the form of experience which count as legitimate knowledge. Meanwhile, TSF positions individual experience- and in particular marginalised perspectives - as equally important forms of knowledge as those taken-for-granted, dominant ways of knowing. In undertaking TSF stage 1, the absence of women's voices from accepted discourses will be shown to provide a justification for researching this subject at this time. The potential gains to individual women, to care practices and to health knowledge by conducting this research will also be emphasised at this stage.

In the previous chapter, I showed that existing research about women's experiences after treatment for breast cancer have not explored BTL specifically (Fu 2008; Hare 2000; McGrath 2013; Radina et al. 2014; Thomas-MacLean et al. 2005) or at least not exclusively (Radina et al. 2015). I recognised that while it cannot be assumed that the experiences of women who experience lymphoedema in their arm following treatment for breast cancer are directly comparable to those who develop lymphoedema in their breast or trunk, aspects of experience such as HCPs' understanding, impact upon body image and impact upon emotional wellbeing are areas which could bear some similarities. Thus, I believe that concepts from the existing literature around women's experiences of developing and living with arm lymphoedema offer a useful benchmark against which to examine women's experiences with BTL.

Stage 2 - *hearing silences* (Chapter 5 – Methodology and Methods)

The theoretical concept of 'screaming silences' reflects the notion that individual experiences are open to multiple interpretations since it recognises that each of us 'hears' distinct silences. That is, we each adopt a particular perspective or filter through which we organise and understand those silences. Consequently, it is important to note that it is the researcher as the *primary listener* of the silences who inevitably influences the research. Notably, there is a dynamic interrelationship between the researcher, research participants and the research topic. It is these three key interdependent influences which must be examined by the researcher in order to reveal the silences which emerge as a consequence of this researcher conducting this particular research at this specific time. These influences and their inherent silences will be explored in Chapter 5 in which I will outline the methodology and the research design developed to advance an understanding of women's experiences of BTL. Examining these influences also allows the reader to 'hear' the silences from the perspective of the researcher and how they influence the research at each stage of the study: that is, at the point of the research design, data collection, data analysis, findings, and final recommendations. Chapter 5 will include details of the research process from the development of the study materials (such as the recruitment and consent paperwork) to dissemination and storage issues.

Stage 3 - *voicing silences* (Chapter 6 – Data collection & analysis; Chapter 7 – Findings)

The intention of this stage is to explore the silences in context by collecting and analysing data to meet the study's aims and objectives. Chapter 6 will report on how the data collection and analysis methods were employed in this study. The introduction to the analysis will set out again my researcher identity, including the influences and biases that were present at data collection which determine the results of the analysis. Any other limitations, such as those resulting from the silences which were previously identified, will also be reported.

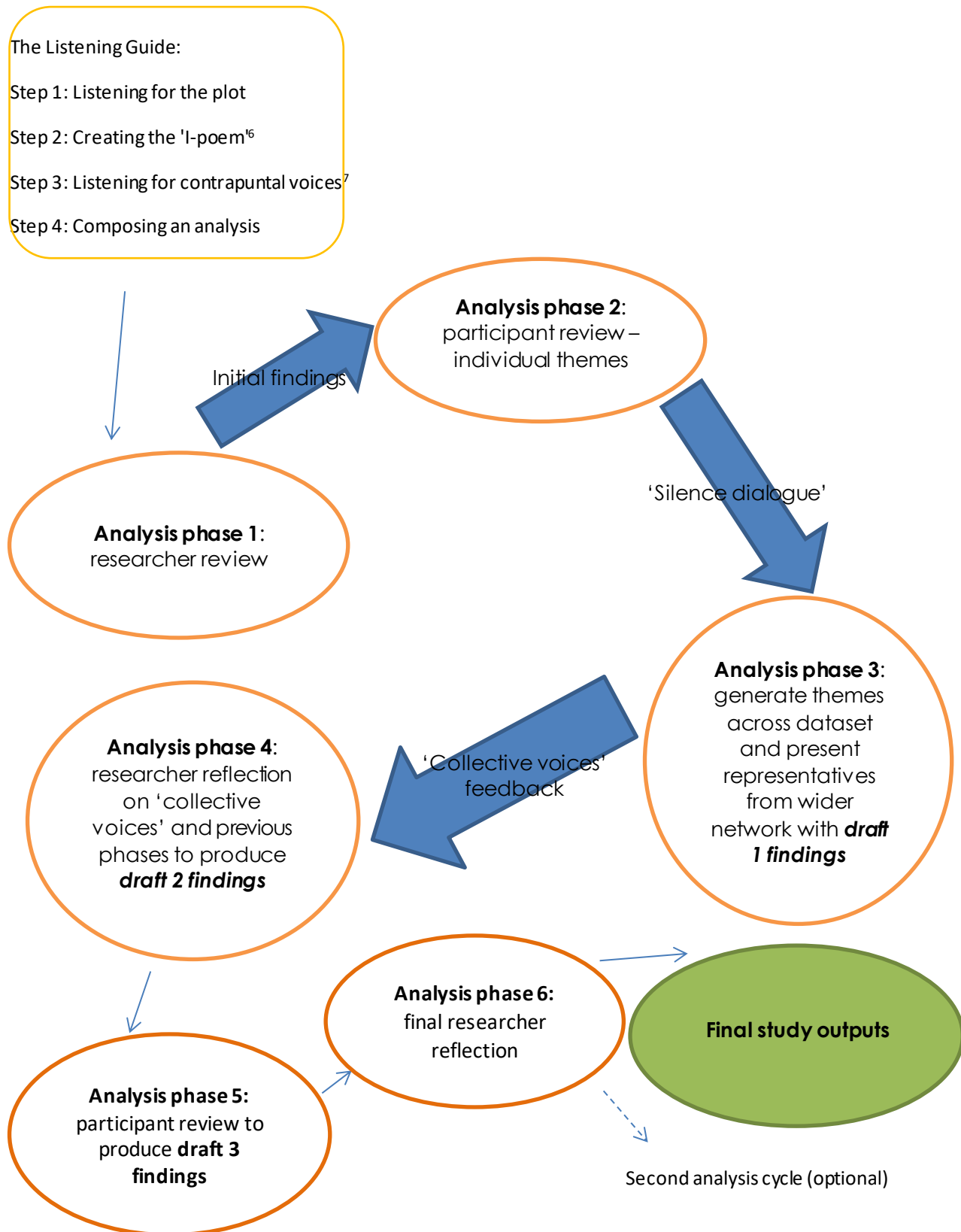
Figure 1 is based upon an adaptation by Janes et al. (2019) of the four cyclical analytic phases as they were originally depicted by Serrant-Green (2011), in which Janes et al.

included some further detail to the diagrammatic representation. I have further amended Janes et al.'s (2019) adaptation to incorporate an additional two phases (shown in Figure 1); this means that the phases as numbered are different from those in Serrant-Green's (2011) original depiction. The two additional phases represent two (rather than one) participant review of the draft findings and subsequent researcher reflection. Figure 1 also shows how the stages of my own chosen analytical method fit with TSF's analytic phases.

In **phase 1** of the analysis, the researcher analyses the data while considering the research question alongside any limitations resulting from any identified silences. This enables the research and its findings to be positioned within context. For my research, phase 1 incorporates the four stages of the Voice-Centred Relational Method (VCRM) of analysis using its tool known as the Listening Guide. This will be discussed in detail in Chapter 5 (methodology and methods) but essentially is a narrative-led method which uses a series of transcript readings - or 'listenings' - through which the researcher responds to the transcript in specific ways. The method makes transparent the researcher's reactions, assumptions and biases and uses strategies to ensure that the voice of the participant is paramount in the analysis. The fourth step of the Listening Guide results in the production of a synthesis of the previous three 'listenings', from which themes are developed. The culmination of this stage is what constitute the *initial findings* within the TSF cyclical process, which are then presented for participant review (**phase 2**). Chapter 6 (data collection and analysis) contains an illustration of the analysis process.

TSF's data analysis cycle is designed to promote the integration of the participants' perspectives into the research findings. In particular, the purpose is to avoid further silencing participants' voices by seeking verification or amendment of the researcher's interpretation of the data. Participant feedback is reflected in the *silence dialogue* which the researcher integrates into the initial findings to create the *draft 1 findings*. In the present study, the intention was not only to demonstrate commonalities among participants but also to highlight diversity among women's experiences and perspectives: therefore, both common and contrasting experiences will be presented. This attention to individual experience will also be reflected in Chapter 5 (methodology and methods).

Figure 1: The Silences Framework data analysis cycle (adapted from Janes et al. 2019), incorporating the four analytical steps of the Listening Guide



⁶ I-poem = poem created from chronological documentation of first-person 'I' phrases in the transcript.

⁷ Contrapuntal voices = contrasting voices in which we all speak, such as those that may encapsulate an aspect of attitude, tone, or emotion.

The *draft 1 findings* are subsequently presented in **phase 3** of the analysis to representatives of those individuals or organisations that may have some bearing upon the research question. These may be from within participants' social networks; or they may be related to the research topic for professional or cultural reasons. In the present study the women who were participants in the pilot study and those in the advisory group were invited to provide feedback. In addition, lymphoedema specialists at two clinics in different geographical areas of the country also agreed to comment upon the draft findings. They were legitimate members of what TSF terms *collective voices* (Serrant-Green 2011) either because of their direct or indirect experiences of living with lymphoedema (whether breast, trunk, or arm), or due to their experiences of treating lymphoedema after treatment for breast cancer. Some were targeted as they were believed to be a part of the context for the pre-identified silences (Serrant-Green 2011). Hence the *collective voices* included women who had developed lymphoedema after treatment for breast cancer; and HCPs who were witness to evidence of silences among other healthcare colleagues as well as the impact of those silences upon their patients. I chose not to include HCPs who may themselves have contributed to the silences experienced by participants. These HCPs may have felt uncomfortable being presented with the silences suggested in the proposed themes and attempted to refute them. As the participant voice was paramount in this study, inclusion of these HCPs would have risked silencing participants even further. Rather, the purpose of obtaining the *collective voices* dialogue is to establish whether the draft findings resonate with the wider context, beyond the experiences of the participants interviewed for the study. This may give an indication about whether the findings could transfer to similar settings or contexts. The active engagement with participants and the wider network also allows the data analysis to remain aligned with a socially constructed and contextual view of reality. It provides different perspectives upon the 'screaming silences' which are central to TSF. Examination and critical reflection by the researcher upon the feedback from the *collective voices*, together with the *silence dialogue* and *draft 1 findings*, become the *draft 2 findings* at **phase 4** of the analysis.

In the present study, the analysis was extended to incorporate two further stages. In **phase 5**, participants were presented with the draft final analysis, with participant

feedback considered in generating the *draft 3 findings*. Finally, **phase 6** of the analysis represented my (the researcher's) final reflection before the findings were presented as the *final study outputs* in the form of themes (see Chapter 7).

TSF also prompts the researcher to consider repeating this cycle of analysis until all feedback has been integrated and the information is deemed to be complete.

Stage 4 - *working with silences* (Chapter 8 - Discussion)

This stage of TSF re-contextualises the study findings. The core question for the researcher at this stage is to ask what has changed as a consequence of conducting this study (Serrant-Green 2011). TSF accepts that silences can be revealed, altered, or even generated through the research. This may be seen in the *silence dialogue*, the *collective voices* dialogue or within the final study outputs. In Chapter 8, I will discuss the findings in relation to the original aims of the study and the related literature. I will consider the implications of the findings in relation to the anticipated benefits of addressing the silences around women's experiences of BTL and make recommendations for future research. This chapter will also address the study limitations and include the adoption of a reflexive approach to examine my own influence.

Stage 5 - *planning for silences*

This fifth stage was proposed by Serrant-Green (2011) for use in studies such as action research which seek to change practice. However, like Janes et al. (2019), the present study aims to raise awareness and identify rather than implement potential improvements to practice; therefore, this stage was not implemented. Nevertheless, Chapter 8: *working with silences* will conclude by considering the opportunities and limitations for changing practice in the light of any remaining or newly created silences from this study.

Application of TSF

In her article, Serrant-Green (2011) invited other researchers to explore the utility of TSF for examining issues that are under-researched, undervalued, or silenced. The available empirical and methodological literature about TSF is largely positive about its usefulness for exploring such issues (Eshareturi and Serrant 2018; Janes et al. 2019; Rossetto et al. 2018). The present study aims to contribute to the knowledge base about TSF and its applicability.

Eshareturi and Serrant (2018) provided an example of the use of TSF to guide a qualitative, collective case study exploring the silences surrounding the physical health needs of eight ex-offenders. The *collective voices* were drawn from a wide range of professionals within the ex-offenders' network and were able to set the findings in the context of service provision without further silencing the voices of participants. Notably, TSF made possible the creation of a study design which generated the conditions for more equal power relations between the researcher and the participant. For instance, participants were able to self-identify as having a health problem rather than relying on a formal diagnosis. Meanwhile, Janes et al. (2019) offered a critique of the value and contribution of TSF in research investigating the experiences of people under 60 years old who had a 'fragility hip fracture.' This injury occurs because of mechanical forces which would not normally result in a fracture. The researchers drew attention to the alignment of features of TSF with the ethos of good nursing care, including prioritising the views and experiences of patients. They also noted the benefits of the cyclical method of data analysis which ensured that participant and *collective voices* were heard, promoting the authenticity of the findings. The lead author and researcher Gillian Janes pointed out that the lack of definitive guidelines for using TSF may not appeal to less experienced researchers. For instance, she admitted that she had found it quite challenging to develop an understanding of the cyclical data analysis stages. From a personal perspective, the publication of Janes et al.'s (2019) critique was timely. Her learning about TSF in conducting her own research, including a diagram of her adaptation of the data analysis process, helped to increase my confidence in applying TSF to my own study.

Chapter summary

This chapter has briefly outlined The Silences Framework (TSF) as the theoretical framework underpinning this study. In describing its stages and analytical phases, I have also demonstrated my adaptation of the analysis cycle.

In the next chapter, a literature review of the existing evidence for women's experiences of BTL is provided as stage 1 of TSF: *working in silences*. It will show that while BTL is recognised as a potential consequence of breast-conserving surgery, mastectomy, or radiotherapy for breast cancer, it has been far less extensively researched than arm lymphoedema. Specifically, it will show that there is a dearth of knowledge and understanding about women's experiences of BTL. This is intended to be addressed by the present study.

Chapter 4

Literature Review

[TSF Stage 1 - Working in silences]

Chapter outline

I begin this chapter by reiterating the importance of understanding patients' perspectives for optimising the quality of their healthcare experiences. This is followed by a description of the key aspects of the protocol devised for a systematic review of the literature relating to women's experiences of BTL. A description and critique of the 24 articles identified for inclusion in the review is provided, followed by an evaluation of the patient-reported outcome measures (PROMs) for breast lymphoedema that were employed in the identified studies. Given the limitations of these PROMs, I go on to discuss instruments which are sensitive to QoL issues for individuals with lymphoedema and particularly BTL. Other forms of representation of women's experiences of BTL are then discussed, including numerical ratings for physical symptoms. Finally, I propose that qualitative methods of investigation will provide a deeper understanding of women's experiences and the interplay of individual and contextual influences.

Introduction

This chapter represents TSF Stage 1 in which the context for the research topic is established, allowing for a greater understanding of the silences surrounding it. In this study, Stage 1 is achieved through a review of the literature of women's experiences of breast and trunk lymphoedema (BTL). The chapter begins by addressing what is meant by the term 'patient experience'. It goes on to describe details of the systematic search strategy employed and reports on the features of the literature identified for the review. This is followed by an examination of the study findings and a critique of the methods used to capture women's experiences within this body of literature,

beginning with a review of quality of life (QoL) measures before examining alternative representations of women's experiences. Finally, support for a qualitative approach in this study is presented.

As mentioned in Chapter 1, while there is an argument that the term 'oedema' more accurately describes the acute oedematous response to treatment, it has also been used in the literature when referring to lymphoedema (Young-Afat et al. 2019). Hence both terms may be used within the chapter.

Understanding 'patient experience'

The importance of understanding the patient experience for improving the quality of care and treatment is well recognised (Pusic et al. 2013; Ziebland and Coulter 2013). Specifically, in the absence of knowledge about women's experiences of developing and living with BTL after treatment for breast cancer, it will not be clear whether their needs are being met by existing healthcare services. In relation to health, patient experience may be said to include experience of disease and illness, its treatment and side effects, and of the healthcare system including interaction with healthcare staff. Experience is a multidimensional concept and is often associated with quality of life (QoL), a term reflecting a range of basic and higher human needs including material wellbeing, safety, opportunities for creativity and for helping others [Letellier et al. 2015]. Other aspects of QoL relevant to women's experiences of BTL, including body image and feminine identity, have also been identified [Nguyen et al. 2015]. The World Health Organisation has adopted an expansive definition of QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [WHO 2021]. Consequently, it could be argued that an understanding of women's experiences of any health condition needs to be situated in the wider context of all aspects of their lives.

Systematic literature search and review

The full protocol for this systematic literature review is outlined in Appendix 5 and is

registered with PROSPERO (CRD42019149223), but the key aspects are described here:

Aim

To understand women's experiences of breast or trunk lymphoedema following treatment for breast cancer

Objectives

To establish how women's experiences are measured in the literature (including narratives and numerical measures)

To examine what those experiences are (for instance, whether they are related to home life, work, leisure activities, appearance, or women's emotional response)

To identify & critique (positive and negative) factors that impact upon women's experiences

Where possible, to critique any theoretical frameworks used to explain those experiences

The strategy for searching the literature was refined over time (see Appendix 6). A search for relevant articles was completed using the terms outlined in the databases listed in Table 2. Studies from 1999 onwards were included to ensure a focus upon the most modern surgical techniques. Only English language articles were eligible for inclusion. Search terms were informed by identifying a 'pearl', an article (or more) already sourced from the literature about experiences of the related phenomenon of women's experiences of developing and living with arm lymphoedema after treatment for breast cancer. Articles by key authors identified in the literature relating to women's experiences of arm lymphoedema were also searched. The journal *Psychosocial Oncology* was hand-searched for relevant articles published in the last five years. Forward citation tracking was undertaken to search for more recent articles; and the reference lists of the key articles identified were also checked.

Table 2: Sources and search terms for the systematic literature review

Databases	Search terms
CINAHL (EBSCO)	<p>Title or Abstract searched: the following were combined (the operator 'N12' was used for spelling variations of 'lymphoedema' combined with variations on 'breast'):</p> <p>'lymphoedema' or 'oedema' or their alternative spellings or 'swelling'</p> <p>'breast' or 'trun*' (ie trunk or truncal) or 'chest' or 'upper body'</p> <p>'breast cancer' or 'breast neoplasms' (MeSH term) or</p> <p>'carcinoma, ductal, breast' (MeSH term).</p> <p>'experience*' or 'quality of life' or 'satisfaction' or 'body image' or 'perception*' or 'living with' or 'patient N1 outcome' or 'self-report*' or 'impact' or 'symptom*' or 'pain' or 'distress'</p>
MEDLINE (EBSCO)	
Web of Science (Clarivate Analytics)	
Scopus (Elsevier)	
PSYCINFO	
AMED (Ovid)	
Cochrane Central Register of Controlled Trials (CENTRAL) (Wiley)	
Proquest Dissertations and Theses: UK and Ireland	
<i>(abridged search terms used)</i>	
www.opengrey.eu/	
<i>(abridged search terms used)</i>	

Systematic literature search and review: findings

In total, 5811 articles retrieved in September and October 2019 were assessed by title and abstract for eligibility; 5754 were excluded at this stage, with 57 full texts being assessed. Thirty-seven studies were excluded, with 20 articles remaining for critical appraisal. Four additional articles were identified from database search alerts and reference searches. For full details, see the PRISMA diagram in Appendix 7.

The 24 articles which were identified for inclusion (see Appendix 8) contain the following study designs: one cross-sectional observational study (Haen 2012); one retrospective cross-sectional study (Goffman et al. 2004); one prospective, cross-sectional study (Adriaenssens, Verbelen et al. 2012), four prospective, longitudinal studies (Degnim et al. 2012; Gregorowitsch et al. 2019; Wennman-Larsen et al. 2015; Young -Afat et al. 2019), five case studies (Giacalone and Yamamoto 2017; Jacob and Bracha 2019; Linnitt and Young 2007; Scaglioni et al. 2021; Tan and Wilson 2019), one case series (Hammond and Mayrovitz 2010), six experimental studies (Collins et al. 2018; Hansdorfer-Korzon et al. 2016; Jahr et al 2008; Johansson et al. 2019; Kilbreath et al 2020; Petkov et al. 2016) including one feasibility RCT (Collins et al. 2018) and one pilot randomised controlled study (Johansson et al. 2019), two pre-treatment/post treatment studies (Ridner et al. 2010; Teguh et al. 2016), two surveys (Finnerty et al. 2010; Sierla et al. 2013), and one qualitative study (Probst et al. 2021). Reasons for study exclusion included not being related to the topic of BTL; unclear about the extent to which the findings related to BTL; experiences of BTL were not a clear focus of the study or were not reported at all; not primary studies; or published prior to 1999 (see Appendix 7).

The rationale for the selection of the tools used to assess the quality of the identified articles is reported in Appendix 5; Table 3 summarises the outcome. Examples of the data extraction and quality assessment process can be seen in Appendix 9. Table 3 demonstrates that the quality of the studies was mixed; however generally they carried a high or moderate risk of bias. Only three studies (Probst et al. 2021; Scaglioni et al. 2021; Young-Afat et al. 2019) were assessed as being of high quality. There were

Table 3: Summary of evidence and quality assessment outcome

Authors and year	Adriaenssens, Verbelen et al. 2012	Collins et al. 2018	Degnim et al. 2012	Finnerty et al. 2010	Giacalone & Yamamoto 2017	Goffman et al. 2004	Gregorowitsch et al. 2019	Haen 2012	Hammond & Mayrovitz 2010	Hansdorfer-Korzon et al. 2016	Jacob & Bracha 2019	Jahr et al. 2008
Study type and critical appraisal tool applied (where none listed, a self-devised checklist was used)	Prospective cross-sectional study	Feasibility RCT	Prospective longitudinal study	Audit, including a questionnaire <i>CEBM critical appraisal of a survey checklist</i>	Case study <i>JBIC case report checklist</i>	Retrospective cross-sectional study	Prospective longitudinal pilot study	Cross-sectional, observational study	Case series <i>IHE case series checklist</i>	Experimental study <i>RoB 2.0</i>	Case study <i>JBIC case report checklist</i>	Randomised controlled pilot study <i>RoB 2.0</i>
How are women's experiences measured?	EORTC QLQ BR23 Self-devised questionnaire	Visual analogue scale for breast symptoms	Rating scale for breast symptoms FACT-B	Self-devised questionnaire	Descriptive comments about patient's experiences	Detail derived from case notes about symptoms and treatment outcomes	EORTC QLQ C30 and BR23 Brief Pain Inventory	Includes self-report questionnaire – numerical scales – pain; other breast symptoms; treatment success; satisfaction with clinic	Description of patient experiences	Visual analogue scale - pain	Description of patient symptom experiences Visual analogue scale - pain	Visual analogue scale – pain, swelling, treatment effectiveness
Outcome of quality assessment	Some concerns	Some concerns	Some concerns	Some concerns	Some concerns	Some concerns	Some concerns	Some concerns	Some concerns	High risk	Some concerns	High risk

Table 3 (continued): Summary of evidence and quality assessment outcome

Authors and year	Johansson et al. 2019	Kilbreath et al. 2020	Linnitt and Young 2007	Petkov et al. 2016	Probst et al. 2021	Ridner et al. 2010	Scaglioni et al. 2021	Sierla et al. 2013	Tan and Wilson 2019	Teguh et al. 2016	Wennman-Larsen et al. 2015	Young-Afat et al. 2019
Study type <i>and critical appraisal tool applied (where none listed, a self-devised checklist was used)</i>	Randomised controlled pilot study <i>RoB 2.0</i>	Randomised controlled trial <i>RoB 2.0</i>	Case study <i>JBIC case report checklist</i>	Randomised controlled study <i>Rob 2.0</i>	Qualitative study <i>JBIC checklist for qualitative studies</i>	'Quasi-experimental' pre-and post-treatment uncontrolled study	Case report <i>JBIC case report checklist</i>	Cross-sectional descriptive survey <i>CEBM critical appraisal of a survey checklist</i>	Case report <i>JBIC case report checklist</i>	Pre- and post-treatment study	Prospective cohort study	Prospective cohort study
How are women's experiences measured?	Visual analogue scale – breast symptoms Patient reports of discomfort	EORTC QLQ BR23 LSIDS (breast or chest wall interchanged for arm)	Description of impact; patient's feelings	Total Life Quality Scale, including visual analogue scale - pain	Patient experience of radiotherapy is reported	LSIDS (Arm and Trunk) Functional Assessment Screening Questionnaire Participant responses to device and compliance	Reference to patient distress and subsequent improvement in patient's quality of life	Validated questionnaire – multiple choice and occasions to provide additional comments. Rating scales for discomfort/other sensations and treatment effectiveness	Reference to patient's 'subjective remarks'; authors' interpretation of impact upon patient	EORTC QLQ BR23 EORTC QLQ C30 EQ 5D Numerical rating scale - pain	EORTC QLQ BR23	EORTC QLQ C30
Outcome of quality assessment	Some concerns	Some concerns	Some concerns	High risk	Low risk	High risk	Low risk	Some concerns	Some concerns	High risk	Some concerns	Low risk

some concerns about a risk of bias in fourteen studies (Adriaenssens, Verbelen et al. 2012; Collins et al. 2018; Degnim et al 2012; Finnerty et al. 2010; Giacalone and Yamamoto 2017; Goffman et al. 2004; Gregorowitsch et al. 2019; Haen 2012; Hammond and Mayrovitz 2010; Jacob and Bracha 2019; Johansson et al. 2019; Kilbreath et al. 2020; Linnitt and Young 2007; Sierla et al. 2013; Wennman-Larsen et al. 2015); and five studies were deemed to be at high risk of bias (Hansdorfer-Korzon et al. 2016; Jahr et al. 2008; Petkov et al. 2016; Ridner et al. 2010; Tan and Wilson 2019; Teguh et al. 2016). Hence the proportion of studies at high or moderate risk of bias is large.

Due to the heterogeneity of the included studies a narrative synthesis will be provided, offering a descriptive evaluation of the appraised literature in relation to questions relevant to the review.

Articles describing the impact of BTL upon quality of life (QoL)

This section will provide a brief description and critique of each study which explores the impact of BTL upon QoL. It will examine how QoL has been measured as well as discuss and critique the instruments used.

Overwhelmingly, those articles which addressed participants' QoL found that BTL had a negative impact; all these articles addressed breast rather than trunk lymphoedema. In Probst et al.'s (2021) qualitative study (n = 9) which reported on participants' experiences of the radiotherapy pathway, women were found to have been unprepared for the development of breast lymphoedema. The study also found that women's experiences were worsened by poor understanding and recognition of breast lymphoedema among HCPs. Meanwhile, Young-Afat et al. (2019) concluded that breast oedema was independently associated with increased breast pain and reduced QoL, body image and physical functioning. In this study, scores for breast pain remained higher for participants with breast oedema than those without at all timepoints, with the greatest difference at 12 months after the start of radiotherapy (mean score differences of 30.9 out of 100). Women with breast oedema also had consistently lower QoL scores, as well as lower body image scores at all timepoints

other than at three months, where the mean scores were almost identical (mean score difference = 0.2). Similarly, Adriaenssens, Verbelen et al. (2012) found a significant negative correlation between the degree of breast oedema and body image ($p < .001$, $r = -.443$). Mean body image scores were 70.8 compared to 91.4 (out of 100, where higher scores denote a higher level of functioning) for participants with and without breast oedema, respectively. This is also reflected in findings by Degnim et al. (2012); and while these researchers reported (on an 11-point scale) low levels of distress associated with breast symptoms, it was found that higher levels of distress were associated with more severe breast lymphoedema (mean = 2.7 for moderate versus mean = 1.0 for mild lymphoedema, $p = 0.03$). Meanwhile Sierla et al. (2013) found that 35% of survey respondents with lymphoedema ($n = 149$) reported having swelling in their breast or chest area and were more likely to report moderate or severe discomfort ($p = 0.003$) than women who had arm or hand lymphoedema. Feelings of discomfort were also described by Goffman et al. (2004); specifically, feelings of heaviness, redness, pain, and perceptions of poor cosmesis which "were all worrisome for patients" ($p. 409$); and Wennman-Larsen et al. (2015) noted wide individual variation of breast symptoms after surgery, with some women reporting severe symptoms up to two years after treatment.

Six of the articles retrieved from the search described the use of patient-reported outcomes (PROs) to provide a quantitative assessment of one or more aspects of patients' QoL or health status. Of these, two used validated PROMs only (Wennman-Larsen et al. 2015; Young-Afat et al. 2019); while two studies employed both validated and non-validated measures (Adriaenssens, Verbelen et al. 2012; Degnim et al. 2012). Although Kilbreath et al. (2020) used two validated tools, the instrument used to determine symptom intensity and distress relating to the breast or chest wall had been validated for the arm. Likewise, the instrument used in the study by Sierla et al. (2013) was developed for arm lymphoedema although 35% of participants described breast or chest wall swelling. Meanwhile, Goffman et al. (2004) merely documented both clinician and patient-reported signs and symptoms. The next section describes and critiques the measures used.

In their prospective cross-sectional study including 131 women who had been treated with surgery and radiotherapy for breast cancer, Adriaenssens, Verbelen et al. (2012)

used all domains of the EORTC QLQ-BR23 to establish a correlation with subjectively rated symptoms of breast lymphoedema. They found that the degree of breast lymphoedema was negatively correlated with body image ($p < 0.001$, $r = -0.443$) and future perspective ($p < 0.001$, $r = -0.476$); and positively correlated with breast symptoms ($p < 0.001$, $r = 0.693$), arm symptoms ($p < 0.001$, $r = 0.571$) and systemic therapy side effects ($p < 0.001$, $r = 0.264$). Meanwhile, Wennman-Larsen and colleagues (2015) sought to assess the development and severity of both breast and arm symptoms in the two years following surgery for breast cancer using the four items specific to breast symptoms in the EORTC QLQ-BR23: that is, pain, swelling, oversensitivity and skin problems in the affected breast. The results of this study demonstrated different patterns for breast symptoms and arm symptoms and significantly higher mean levels of breast than arm symptoms, although some selection bias is possible as only 54% of participants completed the study due to drop-out. Kilbreath et al. (2020) also relied upon the items in the EORTC QLQ BR23 relating to breast pain, swelling, oversensitivity and skin problems to calculate a score for the breast in a randomised controlled trial of an exercise intervention ($n = 89$). The researchers used the median scores to determine change from baseline to 12 weeks after the exercise intervention, demonstrating a significant between-group difference, i.e., a reduction in symptoms, (non-parametric analysis, $p < 0.01$) in favour of the intervention group. Specifically, they found no change in scores for breast symptoms between baseline and 12 weeks for the control group ($n=44$), but a change of -16.7 for the exercise group ($n=40$), with scores at baseline of 25.0 [interquartile range 16.7-41.7] for the control group versus 33.3 [25.0-33.3] for the exercise group.

However, Wennman-Larsen et al. (2015) raise some legitimate concerns about the usefulness of the EORTC QLQ BR23, arguing that the last twenty to thirty years have seen advances in treatments for breast cancer such that the scales may no longer be valid measures. For the purposes of this review, it is also questionable whether scores for all four breast symptoms is a meaningful way to access women's experiences of breast lymphoedema since some items may be unrelated to the condition. An arguably more precise indicator of breast lymphoedema was adopted by Young-Afat et al. (2019) who used only the two items in the EORTC QLQ BR23 relating to breast pain and breast swelling. This prospective cohort study sought to establish the prevalence and

causes of breast lymphoedema as well as its impact upon QoL and breast pain. QoL was determined using the EORTC QLQ C30 alongside the breast cancer-specific module BR23; scores relating to physical functioning, sexual functioning and body image were also generated from these measures. The study was strengthened by its success in recruiting a large cohort of 836 patients using wide inclusion criteria; and in the analysis the researchers have attempted to account for confounding variables such as age, type of axillary surgery and tumour size. However, a potential criticism is the dichotomising of the four-point breast swelling scale (to create a distinction between either the presence or absence of breast oedema) which could be viewed as a rather crude and possibly invalid method. Thus, while this study has been clearly described and appears well-designed overall, the method of data collection enabled only limited access to the patient perspective. Given the study's focus upon QoL there are ways in which further detail could have been elicited. For instance, it is unclear why other QoL-related domains, such as emotional functioning, social functioning, role functioning or future perspective, were not included in the analysis of independent associations with breast oedema. Furthermore, the researchers' key finding that breast oedema was independently associated with increased breast pain and reduced QoL, body image and physical functioning could have been enriched by interviews with participants to gain a deeper understanding of the meaning of these outcomes for them.

The EORTC QLQ BR23 was also used to measure the severity of breast symptoms in a pre-treatment, post-treatment study of hyperbaric oxygen (HBO₂) therapy (Teguh et al. 2016). Like Young-Afat et al. (2019), the scores were dichotomised, reporting either 'no problems' or 'severe problems'. As well as potentially invalidating the instrument's use, it further diminishes the limited reporting of women's experiences by removing from the data altogether those reports from women who selected '2' ('a little'), for example, to describe each breast symptom.

Several studies have addressed forms of compression therapy for the treatment of breast lymphoedema and have included some element of the patient experience (Gregorowitsch et al. 2019; Hammond and Mayrovitz 2010; Hansdorfer-Korzon et al. 2016; Johansson et al. 2019; Ridner et al. 2010). In their prospective, longitudinal pilot study, Gregorowitsch and colleagues reported on the impact on a sample of 25 participants of wearing a compression vest in reducing breast or chest wall oedema.

They used a series of validated instruments to determine patient-reported outcomes for health-related QoL and pain (the EORTC QLQ C30 & BR23); and pain severity and its impact upon daily living (the Brief Pain Inventory). Specifically, the breast pain and breast swelling items of the EORTC QLQ BR23 were employed. However, a risk of bias is evident in this study for reasons such as the limited inter-rater reliability of the assessment of breast lymphoedema, with the researchers reporting poor agreement between clinicians assessing for breast or chest wall oedema as measured by Common Terminology for Adverse Events (CTCAE) v4 ($k = 0.066$, 95% CI - 0.098 – 0.230) which only improved to fair ($k = 0.248$, 95% CI 0.068-0.428) following consensus and observer training. This may be an argument for the superiority of PROMs in terms of signs and symptoms which are meaningful to patients themselves. While the researchers asserted that patient perceptions are the most valuable outcomes, they noted that to date, data for breast oedema was unavailable from patient-reported Common Terminology Criteria for Adverse Events (CTCAE) scores (PRO-CTCAE) which were developed to integrate the patient perspective into adverse event reporting. The researchers also conceded that breast pain could be caused by other factors and not solely breast lymphoedema. This provides a rationale for deeper exploration of patients' experiences through qualitative means, to avoid making associations that may be incorrect. Indeed, one strength of the study is the presentation of quotations from participants about their reasons for non-compliance in wearing the compression vest.

In a prospective, longitudinal study (Degnim et al. 2012), 124 women (74% of whom were diagnosed with breast cancer) evaluated breast symptoms, i.e., degree of heaviness, redness and swelling, together with the accompanying level of distress, using 11-point rating scales. On this occasion, QoL was measured using the Functional Assessment of Cancer Therapy (FACT-B) scale although this validated tool is not specific to measuring the impact of breast lymphoedema. Of note is the fact that the clinician's assessment of whether a participant had breast lymphoedema did not always match the participants' perception of breast swelling: only 59% of participants reported breast swelling in those deemed to have breast lymphoedema; while amongst those for which breast lymphoedema was reported to be absent, 22% reported having breast swelling. This opens a debate about the perceived legitimacy of

the testimony of individual women; that is, the value of self-reported as well as clinician-assessed breast swelling. For instance, clinicians can only assess for the presence or absence of breast lymphoedema at the time that they are with the patient; whereas a patient is able to consider fluctuations in swelling.

Petkov et al. (2016) incorporated participants' visual analogue scale (VAS) scores in a Total Life Quality scale which included several other physical symptom indicators, such as breast volume, limb swelling and range of motion at the shoulder and neck. While purporting to measure QoL, it is unclear whether the instrument had undergone psychometric testing, so that the impact upon QoL cannot be assumed for any of these physical indicators. Furthermore, experience is reduced to quantification such that a score of between 4 and 7, for instance, translates into a 'good' improvement in the quality of the participant's life.

Only three of the studies provided any detail about participants' ethnic background and two referred to their employment status. For their study conducted in the USA, Goffman et al. (2004) reported their sample according to the percentage of White, Black, and Asian participants. Ridner et al. (2010) acknowledged that the sample in their study was 'primarily well-educated, female Caucasians' although they did not offer further ethnicity details; while Sierla et al. (2013) acknowledged that their survey sample failed to reflect the ethnic make-up of the wider population and had attained a higher level of education than the Australian national average. Both Ridner et al. (2010) and Sierla et al. (2013) provided a breakdown of participants' employment status. These findings are relevant in the context of recent evidence from a cross-sectional, observational study in the USA revealing African American women are significantly more likely than White women to report having breast lymphoedema ($p = 0.0016$), as are women with a lower income ($p = 0.0074$) (Flores et al. 2020). The demographic details of participants suggest that among women who are more likely to report having breast lymphoedema, disproportionately few have been recruited to the reviewed studies.

Quality of life (QoL) reporting - evaluation of the measures used

In this section, criteria published by Terwee and colleagues (2007) will be used to

evaluate the quality of the PROMs for breast lymphoedema identified in the previous section, recognising that the extent to which this information is available is often limited. When available, the main criteria against which quality can be assessed include elements of validity (content, criterion, and construct) and internal consistency.

European Organisation for Research and Treatment of Cancer (EORTC) QLQ BR23

The most common instrument was the European Organisation for Research and Treatment of Cancer (EORTC) QoL breast cancer-specific module, the EORTC QLQ BR23, which was used in three studies. This tool was designed to supplement the generic cancer questionnaire EORTC QLQ C30. While the validity of the EORTC QLQ BR23 has been well established (Nguyen et al. 2015), the symptom scales have been demonstrated to have weaker internal consistency (Cronbach's alpha < 0.70). However, given the wide range of issues covered by the physical symptom scales of the EORTC QLQ BR23, a low degree of internal consistency is to be expected. Recognising changes in treatment for breast cancer and the consequent side effects since its development in 1996, an update of the EORTC QLQ BR23 is being developed (EORTC Quality of Life, n.d.). Known as the EORTC QLQ BR45, this expanded module is currently undergoing validation. In the meantime, the current version contains 23 questions and includes two functional scales (body image and sexuality), three symptom scales (breast symptoms, arm symptoms and systemic therapy side effects) and one item evaluating future perspective. The new expanded version includes an additional 22 items; and respondents can identify up to two additional symptoms or problems that are not already listed (Bjelic-Radisic et al. 2020), representing an improvement over the current version as it enhances the priority afforded to the patient experience.

Despite its emphasis on physical function over social or emotional aspects, the EORTC QLQ BR23 has been shown to indicate that having breast lymphoedema may be negatively associated with psychosocial as well as physical aspects of QoL. As reported earlier, Adriaenssens, Verbelen and colleagues (2012) found that the self-rated severity of breast lymphoedema was negatively correlated with body image ($r = -$

0.443, $p < 0.001$) and future perspective ($r = -0.476$, $p < 0.001$). In addition, there were significant differences in QoL on several dimensions for those patients with and without breast lymphoedema, including body image ($p = 0.001$) and future perspective ($p = 0.048$), although the findings are limited by the study's use of a non-validated instrument to rate symptoms of breast lymphoedema.

Functional Assessment of Cancer Therapy – Breast (FACT-B)

Incorporating the Breast Cancer Subscale (BCS) alongside the FACT-G (Functional Assessment of Cancer Therapy - General) scale, the FACT-B (Breast) - unlike the EORTC QLQ BR23 - explores how bothersome side effects are to patients, rather than simply addressing whether side effects are present. Its emphasis is upon the social and emotional aspects of QoL as opposed to physical function. This instrument has been shown to have good internal consistency (Cronbach's $\alpha = 0.9$) and test-retest reliability (Cronbach's $\alpha = 0.85$) (Brady et al. 1997).

It is unclear whether Degnim and colleagues' (2012) finding of non-significant differences in QoL scores between women with and without breast lymphoedema using the FACT-B reflects a true finding or whether it is a function of a confounding characteristic of the study. For instance, it may be that the FACT-B lacks sensitivity to issues specific to breast lymphoedema, although as higher levels of distress (as reported on an 11-point scale) were reported to be associated with a higher degree of breast lymphoedema, differentiating participants by subgroup may have revealed QoL differences. There is also insufficient information to determine any bias among patient characteristics in this study. For instance, women in the study sample may have been predominantly smaller-breasted and so may have experienced less discomfort and subsequently a higher QoL.

Summary critique

Fayers and Machin (2007) discuss how the initial concepts upon which an instrument is based will influence the direction in which the tool is developed. Thus, despite its validation and widespread use, it has been argued that the EORTC QLQ BR23 cannot be

considered an instrument for measuring QoL (Letellier et al. 2015). Mapping the items in the instrument against codes in the International Classification of Functioning, Disability and Health (ICF), it was concluded that the EORTC QLQ BR23 merely acts as an “impairment inventory” (Letellier et al. 2015, p.767) since it does not focus upon QoL beyond its indirect measurement via symptoms of functioning and retains a focus upon physical symptoms.

Both the FACT-B and the EORTC QLQ BR23 have been noted for their emphasis upon chemotherapy-related treatment (Nguyen et al. 2015), implying that they have limited usefulness in determining QoL after surgery or radiotherapy, although an updated version of EORTC QLQ BR23 was noted earlier to be in development. None of the studies identified made use of the BREAST-Q, a validated instrument for use with women who have had surgery for breast cancer (Fuzesi et al. 2017). The conceptual framework underpinning the BREAST-Q questionnaire is arguably broader than that for most instruments as it distinguishes QoL (conceived as aspects of wellbeing) from satisfaction (ie with care, with their breasts, and with the overall outcome), indicating that there is the potential to identify aspects of women’s experiences that may go uncaptured using other existing instruments.

It is notable that both the EORTC QLQ BR23 and the FACT-B are designed to address issues specific to patients who have been treated for breast cancer but are limited in their ability to reflect QoL issues of concern to women who develop lymphoedema, beyond registering the presence of physical symptoms. This is significant in an era where changes to treatment for breast cancer have resulted in side effects such as lymphoedema. Within the EORTC QLQ BR23, four items relate to physical symptoms of the breast, but none are designed to elicit the impact of these symptoms upon patients. Similarly, although the FACT-B’s supplementary scale (FACT-B+4) recognises the potential for arm symptoms, breast lymphoedema is excluded in terms of either its symptoms or its impact.

Instruments sensitive to QoL for individuals with lymphoedema

Several instruments have been developed specifically to measure QoL in patients who

have lymphoedema. They include the Wesley Clinic Lymphedema Scale (WCLS) which was designed to measure QoL within the last two weeks and contains five items rated on a seven-point scale. However, there appear to be no published details of the instrument's psychometric robustness; in fact, it is reportedly an adaptation of the Functional Living Index-Cancer (FLIC) in which the word 'lymphoedema' has merely been substituted for other terms (Pusic et al. 2013). Meanwhile the Upper Limb Lymphoedema 27 (ULL-27) instrument has been measured against criteria established by Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) and demonstrated to have undergone sound psychometric development (Pusic et al. 2013). Despite this, the ULL-27 has been open to some criticism: although its content validity was gained by interviewing patients to identify relevant concepts and issues for inclusion in the instrument, it arguably fails to address the full range of symptoms reported by women who have BCRL (Davies et al. 2014). In its favour, it is noteworthy that the ULL-27 has been developed with people who have had cancer, unlike the development of many PROMs which are intended to be used with patients who are receiving active treatment for cancer and therefore may not be valid for other patient groups (Pusic et al. 2013). As its name suggests, the ULL-27 is designed to investigate QoL amongst women who have arm lymphoedema and this is most explicitly reflected in the physical functioning items (Launois 2002). Similarly, the Lymphedema Functioning, Disability and Health Questionnaire for Upper Limb Lymphedema (Lymph-ICF-UL), a recent revision of the Lymph-ICF (De Vrieze et al. 2019), can be considered to capture elements of QoL with its focus upon functional ability and respondents' capacity to participate in everyday activities. However, these tools inevitably have limited applicability for capturing the QoL of women who have developed BTL.

Instruments sensitive to QoL for individuals with BTL

While there are many examples of published, validated measurement tools within the field of cancer intended to capture patients' QoL using quantifiable means, few are designed to explore breast lymphoedema specifically even though they may document breast and chest swelling. This is reflected in diagnostic measures, such as the

Lymphedema Breast Cancer Questionnaire (LBCQ) which has been used to diagnose lymphoedema of the arm rather than the breast or trunk (Armer et al. 2003). Meanwhile, a measure of symptoms and related distress levels known as the Breast Cancer and Lymphedema Symptom Experience Index (BCLE SEI) includes breast and chest wall swelling, although Fu et al. (2015) report psychometric testing of the instrument for use with arm lymphoedema. Similarly, Chen et al.'s (2010) systematic review of PROMs used with patients treated for breast cancer did not distinguish between arm or breast swelling. In another example, Bhattacharya et al.'s (2019) longitudinal examination of patient-reported outcomes across five years following whole or partial breast radiotherapy included items such as 'problem getting bra to fit' and 'breast smaller,' which do not necessarily relate to changes associated with breast lymphoedema. The same can be said for items such as breast size, breast texture and breast pain within the patient-report instrument the Breast Cancer Treatment Outcome Scale (BCTOS) (Stanton et al. 2001). In fact, this instrument was not designed to address breast lymphoedema; and the absence of patient involvement in its development weakens its psychometric robustness. More recently, the validation of shorter measures including the BCTOS-12 (Hennigs et al. 2018) and the BCTOS-13 (Struik et al. 2018) have been described. Once again, although these items may indicate breast lymphoedema and its effect on QoL, it cannot be assumed that this is being assessed.

The development of an instrument specific to breast lymphoedema has recently been reported, however. Known as the Dutch Breast Edema Questionnaire (BrEQ-Dutch), it includes a section addressing the impact of breast lymphoedema upon daily functioning. Although further validation is required on this section, it appears to have the potential to improve QoL monitoring with its inclusion of items such as sleeping, wearing a bra, and taking part in sports. The questionnaire also includes a section designed to assess breast lymphoedema symptoms and can be used as a diagnostic tool. The tool has demonstrated good content validity (for example, 90.7% of the sample [n=54] agreed that the questions were "relevant for your current situation"); moderate convergent validity for individual symptoms of breast lymphoedema (Spearman correlation co-efficient of between 0.303 and 0.422, all achieving statistical significance); and good test-retest reliability (Cronbach's alpha scores between 0.631

and 0.807 for individual symptoms, all $p < 0.001$) (Verbelen et al. 2020). However, the English translation is yet to undergo psychometric testing.

Other forms of representation of women's experience of BTL within the literature

So far, this chapter has examined the QoL and lymphoedema-specific instruments which provide some limited information about women's experiences of BTL. This section will examine the alternative ways in which women's experiences have been represented in the selected studies.

Numerical ratings of patient perceptions of bodily symptoms are frequently used in the literature, offering a similarly narrow perspective of women's experiences, although the scales are not always validated. In his masters thesis measuring tissue water changes in the breast and arm, Haen (2012) used a self-report questionnaire to compare objective and subjective measures of lymphoedema. A series of numerical scales were used to establish participants' perceptions of pain, discomfort, heaviness, increased size, and skin changes as well as ratings of perceived treatment success and satisfaction with the lymphoedema clinic. In addition, tissue dielectric constant (TDC) measures for each quadrant of the treated breast were compared to measures for the untreated breast to produce a TDC ratio. The results showed that higher TDC ratios were related to self-reported pain, discomfort, and perception of increased size. However, while there was a particular trend for the lower lateral quadrant of the breast towards an association between reported symptoms and higher TDC ratios, this trend varied across breast quadrants and depth measurements. It is also unclear whether the self-report questionnaire has been validated, limiting the credibility of the findings.

Several of the studies identified in the review employed a case study design. Although the limited, indirect style of reporting typical of case studies may be appropriate for such scientific papers, it lacks any scope to provide the patient's experiences and thoughts or feelings. Consequently, only glimpses are provided of what may be a challenging episode for some women following treatment for breast cancer. For example, Giacalone and Yamamoto (2017) described a successful surgical treatment known as supermicrosurgical lymphaticovenous anastomosis (LVA) for a patient with

severe, long-term breast lymphoedema. The treatment was evidently life-changing for this individual although her experiences were peripheral in the reporting of it.

Scaglioni et al. (2021) also described the use of LVA to treat breast lymphoedema. In this case study, the patient was merely reported to be caused "severe distress" by her pain associated with breast swelling, tension, and erythema, although an improved QoL is reported at follow-up. Similarly, Tan and Wilson's (2019) case report of physiotherapy for a patient with arm and breast lymphoedema offered minimal reference to the patient's thoughts and feelings. However, a more detailed description of the subjective experiences of a patient experiencing symptoms including breast swelling was provided in a case report by Jacob and Bracha (2019), such as reports of her feeling 'calmer' and 'stronger' after a treatment session. This case study also benefitted from highlighting the evident complexity of separating breast lymphoedema from other, co-existing conditions. Finally, Linnitt's (2007) case study also offered some limited evidence for the physical and psychological consequences of breast lymphoedema, describing how MLD was successfully used to relieve chronic swelling in the patient's treated breast. However, references to worry and frustration at her 'ugly' breast, are only able to hint at the potential distress that may be experienced by some women.

Some studies used alternatives to measuring QoL, although limitations around the suitability of their application to BTL are sometimes evident. Kilbreath et al. (2020) employed the Lymphedema Symptom Intensity and Distress Survey (LSIDS) to determine breast or chest wall measures; however, there are concerns about the validity of its use as this tool is validated for arm lymphoedema. Although the results indicated no significant differences in symptom intensity and distress between the group receiving the exercise intervention and the control group, this may be a feature of the measures used. Similarly, alongside the EORTC QLQ BR23, participants in Adriaenssens, Verbelen et al.'s (2012) prospective, cross-sectional study completed a 'self-devised' questionnaire designed to elicit detail about women's experiences of physical symptoms associated with breast lymphoedema. Participants rated their symptoms of 'heaviness, swelling, redness, peau d'orange, numbness, tingling, stabbing pain, and skin twitching of the breast' (p. 156) on an 11-point scale (0-10). While having the potential to offer more detail about women's self-reported

symptoms, again it reduces the expression of women's experiences to numerical scores. In addition, the use of this unvalidated tool raises questions; for instance, it is unclear whether the symptoms each carry the same weight in the overall score. The researchers also appear to conflate symptom occurrence and symptom distress, as they report a score of zero as representing the absence of a symptom; whereas a score of ten denoted the symptom as 'currently unbearable.'

The use of compression therapy to treat trunk lymphoedema has been addressed in several small studies such as a small pre- and post-treatment uncontrolled study conducted by Ridner et al. (2010). Numerical rating scores were obtained for symptoms and their burden using the Lymphedema Symptom Intensity and Distress Survey - Arm and Trunk (LSIDS-AT); and comments about compliance and participants' responses to the equipment were also documented. In addition, the study employed the Functional Assessment Screening Questionnaire (FASQ) to generate a score designed to reflect the respondent's functional abilities and limitations. Both these tools have undergone psychometric testing; and there is evidence of an attempt to achieve reliability by ensuring that staff were trained to measure trunk circumference to within 0.2 cm variation. Nevertheless, there are several reasons to suggest that there is a high risk of bias in this study. For example, the FASQ may not be sensitive to functional issues affected by trunk lymphoedema. The researchers also question whether there could have been a placebo effect since this small, non-randomised study with no control group demonstrated no significant reduction in girth size (i.e., reduction in trunk oedema) which was at odds with participants' self-reported improvement. This is valuable information because it provides a rationale for investigating the degree of improvement in the circumference of the trunk that is meaningful to patients themselves.

In Hammond and Mayrovitz's (2010) case series of pneumatic compression therapy for trunk (and arm) lymphoedema, the authors detailed patients' impressions about their experiences. This includes participants' explanations about instances of non-compliance with self-MLD; the physical benefits experienced from the treatment, including reduced pain and stiffness; and participants' increased ability to adhere to other self-care aspects and engage in everyday activities. Yet there is a potential risk of bias in this study for reasons such as variation in the treatment history of participants

and length of time with lymphoedema. In addition, it is unclear whether the outcomes are all attributable to the intervention as participants were also guided to adopt other aspects of self-care such as exercises and dietary advice. Despite these limitations, this study has offered some priority to women's reports of their experiences alongside objective measures.

The absence of a wider patient perspective to establish the impact of compression therapy for BTL is evident in other studies. A small (N=37) experimental randomised study by Hansdorfer-Korzon et al. (2016) sought only to obtain patient reports of pain using a VAS. The study also suffered from a high risk of bias due to the absence of information about the reliability of the objective (ultrasound) measurements and blinding of assessors. Meanwhile Johansson et al. (2019) also employed a VAS in their small randomised controlled pilot study of compression therapy (N=56), in this instance to determine participants' perceptions of breast pain, heaviness and tightness. Participants' reports of any discomfort from using the compression bras were documented as mild adverse events. Some concerns of bias were revealed including the potential for participants in the control group to have been wearing bras with compression properties, although using assessors blinded to group status demonstrates an attempt by the researchers to reduce this.

Originally used for sports injuries, kinesiology tape (KT) has become recognised as a potentially effective treatment for lymphoedema. It is applied to stretched skin which is lifted away from the underlying tissues, enabling lymph fluid to move more freely (Mortimer and Levine 2017). Finnerty and colleagues (2010) reported on a small audit (N =10) which incorporated questionnaires to investigate women's experiences and their feelings associated with using KT to treat BTL. As part of the audit, questionnaires invited participants to make open-ended comments alongside some yes/no responses about their experience of KT which were reflected in the direct quotations used in the report. However, the data from the questionnaires was undermined by the fact that they had not been validated; and the patient-reported data was confounded by the suggestion to respondents that their views 'can be combined with those of your therapist.' Although objectively the overall effectiveness of the KT was uncertain due to challenges in obtaining accurate and reliable chest wall measurements, the researchers suggested that a more valuable outcome was the patient's perception

alongside examination by a clinician. One patient reported a decrease in her breast oedema although it was discovered that she had an objective increase in the circumference of her abdomen. This example contributes to the debate about what may constitute change which is meaningful to patients.

Collins et al. (2018) also investigated KT by undertaking a feasibility study to establish the case for a future randomised controlled trial to evaluate its effectiveness in addition to usual care. Like other studies, participants' experiences were restricted to their responses on a VAS for breast heaviness or fullness, discomfort, and redness, the researchers admitting that no QoL measures were used to capture the impact upon participants. This study also revealed some concerns about a risk of bias: for instance, as a part of usual care, participants were reported to have been given information on how to obtain compression bras, the use of which may have confounded the results for the effectiveness of KT specifically. There could also have been some bias from the inclusion of participants with breast oedema which was acute swelling rather than actual lymphoedema as the study design permitted participants who were a minimum of six weeks post-surgery and four weeks post radiotherapy; although in fact, the time between surgery or radiotherapy and recruitment to the trial was a minimum of five months for all participants.

Therapy intended to promote the flow of lymph fluid using an electrostatic technique to produce deep vibration (Jahr et al. 2008; Petkov et al. 2016) was also reported, although the studies identified indicated a high risk of bias, including the possibility of a placebo effect (Jahr et al. 2008). The studies used a VAS (on a scale of 0-10) measuring pain, swelling and the effectiveness of lymphoedema treatment (Jahr et al. 2008) or pain as a sole indicator (Petkov et al. 2016).

The study by Goffman et al. (2004) employed a retrospective design, hence was inevitably limited in the extent of the researchers' control over the variables of interest. Case notes were used to derive information about symptoms and treatment outcomes; and no specific tool was used to elicit participants' experiences. Patient experience was limited to referring to patients' 'worrisome' experiences of breast pain, heaviness, and a poor cosmetic outcome.

Finally, in a cross-sectional, descriptive study, Sierla et al. (2013) used an electronic

questionnaire to gain responses from 444 participants about the presentation of breast cancer-related lymphoedema (BCRL), the severity of their swelling, the degree of their discomfort, and information about the treatments used and their reported effectiveness. A measure to assess swelling which was reported to be validated (details not known) was incorporated into the questionnaire. Although the questionnaire was created specifically for the study, some psychometric testing was reported which lends it some validity. However, it did employ the rather ambiguous concept 'discomfort and other sensations' which, although deemed sufficient by women during psychometric testing of the measure, is notable as different from the terms used in other studies. In addition, the survey was inconsistent in providing respondents with an opportunity to offer further detail regarding their experiences of different treatments: not all items included this open question. Given that for some women, reports of mild swelling were accompanied by reports of moderate-to-severe discomfort, analysis of the free-text boxes on the survey could have provided a greater understanding of women's perception of discomfort.

Summary evaluation and conclusion

Drawing on the evidence from existing measures, the literature indicated that having breast or trunk lymphoedema has a negative impact upon the QoL, body image and physical functioning of many women, with experiences including pain, discomfort, and distress. Only one small qualitative study with nine participants could be identified that highlighted aspects of women's experiences of breast lymphoedema. Quantitative methodologies and the use of outcome measures eliciting numerical data dominate the academic landscape in relation to patient-reported aspects of breast lymphoedema, thereby largely obscuring the patient voice. Frequently women's experiences have tended to be defined within these narrow parameters which are dictated by yes/no forced responses or numerical scales to determine aspects of QoL or physical symptoms. Of concern is the translation of numerical outcomes into apparently arbitrary categories such as 'good' in relation to QoL. While such measures are valuable for reporting on incidence and severity of symptoms within studies, inevitably they are unable to provide rich data about how women experience BTL. Moreover, the high proportion of studies estimated to be at high or moderate risk of

bias has implications for research and practice, impacting upon the healthcare experiences of women who have BTL as well as undermining those instances where patient reports were afforded some priority.

Of the six studies in this review which used PROMs, two studies used self-devised tools which had not been validated, reducing the credibility of the sparse available patient-reported information. Moreover, current validated tools are recognised to be outdated or not specific to breast lymphoedema, although there are developments such as the current revision and expansion of the domains in the EORTC QLQ BR23 and tools such as the BrEQ, for which the English translation is awaiting validation.

The review has revealed limited representation of ethnic diversity in the populations which have been sampled and little reference to participants' economic status. This is relevant as there is evidence to demonstrate that African American women are significantly more likely to report having breast lymphoedema than White women, as are women in low-income groups (Flores et al. 2020).

The lack of emphasis upon women's experiences demonstrates a gap in knowledge about the impact of BTL on women's lives. While it is acknowledged that the limited way in which women's experiences are represented in some of the existing studies may in fact be quite appropriate for that type of research, what is at issue is the lack of alternative, qualitative studies that can provide richer detail by eliciting those aspects of experience which are priorities for women themselves.

Other methods used for documenting the patient experience

The case for qualitative methods of inquiry

This chapter has shown that studies using quantitative instruments suggest that there are some negative psychosocial consequences for women living with BTL (Adriaenssens, Verbelen et al. 2012; Degnim et al. 2012; Goffman et al. 2004; Sierla et al. 2013; Wennman-Larsen et al. 2015; Young-Afat et al. 2019). Nevertheless, patient-report instruments are unable to capture aspects of experience that may have significance for individual women, nor offer any explanatory power for the item

responses or situate the information in a wider psychosocial or cultural environment. The findings from quantitative studies often raise questions and issues that demand a qualitative inquiry to deepen understanding and provide explanations. In their systematic review of the literature of qualitative research completed alongside clinical trials, O'Cathain et al. (2013) identified 22 ways in which qualitative research has been used, recognising its potential to inform healthcare research and practice. For example, the finding by Mukesh et al. (2016) that clinician assessment did not agree with patients' subjective reports of breast oedema (23% versus 2% respectively, for moderate-severe breast oedema, according to the EORTC QLQ BR23) led the authors to speculate that patient adjustment to their bodily changes resulted in their underplaying symptoms. The apparent mismatch between clinicians' and patients' impressions also lends support to promoting an understanding of the patient experience to determine outcomes which have clinical relevance. Additional context could also help to provide the reasons why some women experience moderate or severe discomfort when they have mild breast swelling, for instance. Hence the adoption of qualitative data gathering techniques alongside quantitative data would provide more insights and enrich the findings.

Only one of the studies retrieved in the systematic literature review gathered qualitative data, using workshops in which the views of patient representatives were elicited (Probst et al. 2021). This study used quotations to support the presentation of findings, so that women's voices were central to reporting them. However, in the two studies which surveyed women's experiences as a central feature of the data, women's voices remained unclear as the detail was mainly confined to numerical scales or pre-set multiple choice answers with variable opportunities for accompanying free-text explanations. Meanwhile, Gregorowitsch et al.'s (2019) pilot study of compression vest treatment was unusual in presenting quotations from participants about their reasons for non-compliance with the treatment.

Qualitative investigation of women's experiences of BTL

The wider healthcare context remains one in which scientific understanding usurps patient experience; but recognition of the patient perspective is gaining traction in

different arenas. For example, Elizabeth O’Riordan’s positioning as both consultant breast surgeon and patient enabled her to share lessons from her own treatment for breast cancer in *Annals of Surgical Oncology* (O’Riordan 2021). Meanwhile, The Patient Experience Library – established in recognition of the failure by the NHS to consistently maintain and archive records of patient experience - currently contains more than 60,000 items on its database.

This review has demonstrated that there is an absence in the literature of any in-depth qualitative exploration of women’s experiences of BTL. The reliance on quantitative evidence leaves women’s experiences marginalised. Existing studies investigating women’s experiences after treatment for breast cancer have not explored BTL (Fu 2008; Hare 2000; McGrath 2013; Radina et al. 2014; Thomas-MacLean et al. 2005) or at least not exclusively (Radina et al. 2015), instead focussing upon arm lymphoedema. For instance, in a study of women’s perceptions of treatment for lymphoedema, only one out of sixteen participants in a qualitative study by Karlsson et al. (2015) reported having developed breast lymphoedema, the remainder having arm lymphoedema. Evidence of psychological distress emerged from Hare’s (2000) study which employed focus groups to explore the impact of living with arm lymphoedema and in which feelings of isolation, sadness and anxiety were described. More recently, Barlow and colleagues reported on the qualitative aspects of a mixed-methods study in which most participants appeared to have BCRL (Barlow et al. 2014). They found that HCPs often had limited knowledge about lymphoedema which left many women unprepared for developing and managing this side effect, findings which are supported elsewhere (Conway 2016). The discovery that women’s concerns have been frequently ignored or underplayed is also reflected in several studies (Conway 2016; Jeffs 2006; Williams et al. 2004), with negative consequences for women of feeling criticised and of being marginalised (Ridner et al. 2016). Additionally, the complexity for women of attempting to reconcile the need to undertake self-care routines for their arm lymphoedema while continuing to fulfil their roles within the family and at work has been shown (McGrath 2013; Radina et al. 2014). Studies based upon quantitative research methods cannot fully take account of such contextual influences and patients’ responses to these.

While it cannot be assumed that the experiences of women who develop lymphoedema in their arm following treatment for breast cancer is directly comparable to those who develop breast or trunk lymphoedema, aspects of experience such as HCPs' understanding, impact upon body image, and influence upon emotional wellbeing are areas which seem likely to bear some similarities. Hence, concepts from the existing literature around women's experiences of developing and living with arm lymphoedema may offer a useful framework for beginning to explore women's experiences with BTL.

Research that takes account of the influence of variables such as ethnicity and age on QoL is also warranted. A systematic review of studies of younger Black women who had been treated for breast cancer concluded that young Black women appeared to have poorer QoL outcomes than older Black, younger White, and older White women (Samuel et al. 2016). This was reflected in Ashing-Giwa and colleagues' univariate analyses which revealed differences in several QoL dimensions between African American and White women who had been treated several years previously for breast cancer (Ashing-Giwa et al. 1999). However, these differences were not supported by multivariate analyses, hence other factors such as poorer socioeconomic status (Flores et al. 2020) and higher comorbidity levels may be important mediating influences.

Exploration using qualitative research methods may illuminate the interplay of these and other variables and their impact upon women's experiences. For example, the findings of a phenomenological study which explored the lived experiences of 13 Hispanic women who had BCRL (Acebedo et al. 2021) demonstrated the cultural significance of relationship with family (or other supportive ties) and HCPs. In-depth qualitative research could also provide insight into the significance on QoL of spiritual beliefs. Such beliefs have been found to be important among African American, Asian American, and Latina women during their recovery from breast cancer (Ashing-Giwa et al. 2004) and among Muslim women living with BCRL (Dönmez et al. 2021). They have also been reported to influence life satisfaction among African American women who underwent treatment for breast cancer ($p = 0.01$, Pearson correlation between scores on the validated Spiritual Health Locus of Control (SHLOC) scale and those on the Satisfaction with Life Scale (SWLS)) (Meadows et al. 2020). Moreover, women who had lower incomes were over three times more likely to have higher life satisfaction scores

(OR = 3.42; 95% CI = 1.38, 8.52) if their SHLOC scores were higher, suggesting the importance of spiritual beliefs among poorer and thus marginalised groups of women. This may be worthy of further investigation using qualitative methods. Exploring women's experiences using more in-depth methods may also help to explain the finding that stronger religious beliefs among young Black women did not appear to mitigate their greater fear of dying (Samuel et al. 2016). Likewise, the finding that spiritual and religious beliefs may change over time and may interact with mood (Gall and Bilodeau 2020) lends further support to this area for investigation.

Chapter summary

In this chapter, I explained how I undertook a systematic search of the literature about women's experiences of BTL and identified 24 articles. I reported that a critical appraisal had revealed that the studies were of mixed quality, with most raising some concerns about the robustness of the findings. In considering how women's experiences were represented, I began by examining how QoL was explored in the selected literature, evaluating the QoL measures used and noting their limitations in addressing BTL. I then discussed available QoL instruments which are sensitive to lymphoedema and particularly to BTL, of which there are few. I went on to explore the alternative methods of representation of women's experiences in the literature, demonstrating how qualitative data is predominantly absent from the research evidence base on BTL. The limited ethnic diversity reported among the study samples was noted as a limitation. As this review revealed a clear gap in the evidence about women's experiences of BTL, I ended by arguing for more in-depth, qualitative methods of investigation to counter the way in which women's experiences are currently obscured.

In the next chapter, I describe stage 2 of The Silences Framework (TSF): *hearing silences*, in which I explain the epistemological and theoretical underpinnings of this study and discuss TSF as my chosen theoretical framework. I also offer a rationale for the study design and selected methods of data collection and analysis. I highlight the silences which already existed prior to conducting this research so that the reader may 'hear' them and understand how they might have influenced the study.

Chapter 5

Methodology and methods

[TSF Stage 2: Hearing silences]

Chapter outline

This chapter explains the methodological approach that I have developed and how the study's theoretical underpinnings intend to support the study aims. I describe the influences upon the study's research design, including the epistemology and theory, my professional background, and my personal beliefs about the nature of knowledge. This leads me to demonstrate why this study is framed by The Silences Framework (TSF) (Serrant-Green 2011) which was introduced in Chapter 3. I go on to explain my choice of qualitative methods of inquiry to illuminate women's perspectives and the interplay of contextual influences, methods that are intended to encourage participants to provide in-depth information about what it means to develop and live with BTL. Finally, I provide detail about the research process, such as participant identification, recruitment, and the interview procedure. The Voice-Centred Relational Method (VCRM) of data analysis, using its tool the Listening Guide (LG), is discussed and critiqued, including the extent to which it is theoretically aligned with TSF.

Introduction

In previous chapters I discussed how the sentiments of the 'pink ribbon' culture that emphasise celebration and positivity have an ability to devalue and silence those whose experiences do not conform. This celebratory attitude maintains its authority as the dominant discourse because it emphasises the success and competency of the powerful institution of medicine. Meanwhile, the silence surrounding treatment side-effects is maintained if these effects remain poorly understood, inconsistently monitored and unrecognised among HCPs. This creates an environment which stifles

opportunities for women's experiences to be heard. One task of this research, therefore, is to offer a space for women to share those experiences.

In Chapter 4: *working in silences*, the review of the literature showed how medical, technical, and statistical forms of knowledge about breast and trunk lymphoedema (BTL) dominate our current understanding of the condition. The review revealed that our understanding of the patient experience has been largely reduced to yes/no forced responses or numerical data, so that the patient voice is largely obscured. Hence although the literature suggests that having BTL has a negative impact upon the QoL of many women, there is a lack of qualitative studies which could provide a richer understanding of women's experiences. This would enhance the visibility of the perspectives of women (as patients) which is currently situated outside academic contexts, remaining side-lined within comments on online patient forums, for example, where they constitute marginalised forms of evidence. Women's experiences therefore remain silenced in the sense that silences "reflect viewpoints and information that are not openly said, heard or evidenced in the available (mainstream or easily accessible) bodies of literature related to a specific subject." (Serrant-Green 2011, p. 2).

Gaining an understanding of women's experiences - and setting it within the broader social and cultural context of breast cancer - illuminates an important form of evidence about BTL. This evidence offers women's testimonies as a legitimate form of knowledge with the potential to inform and improve clinical practice, thereby enhancing women's healthcare experience. I argue that women's unheard experiences require a particular investigative approach: one that is sympathetic to women's apparent marginalised and disempowered status in relation to the diagnosis and treatment of BTL.

While remaining open to all aspects of experience that participants choose to disclose, by applying the theoretical notion of silences to this research the intention is that the study is attuned to exploring the evidence for silences that surround women's experiences of BTL. Other underlying processes or theories that may illuminate the

data will also be explored in the discussion chapter, since the area under investigation remains poorly understood.

To recap, the aims of the study which I first outlined in the Chapter 1 are as follows:

- to gain an in-depth understanding of women's experiences of developing and living with BTL following surgery and radiotherapy for breast cancer: that is, to explore what it means for women to develop and live with this treatment side effect and discover the impact upon them and their daily lives.
- to create conditions for change by generating findings which will serve the educational needs of patients with breast cancer, the healthcare practitioners caring for them, patients' families and friends, and other charitable and non-charitable organisations supporting women who have had breast cancer.

The main research question is intentionally broad to allow participants to identify issues pertinent to them rather than to the researcher. The question is simply: what are women's experiences of developing and living with BTL after surgery and radiotherapy for breast cancer?

There is a focus upon the following aspects: a) How do women describe their experiences of developing and living with BTL? b) What particular aspects of their lives do women describe in relation to living with BTL?

In the next section, I will explain the philosophical approach underpinning the study in the light of my personal values. The chapter will go on to discuss the selection of TSF as the theoretical framework guiding the research design and the subsequent selection of methods.

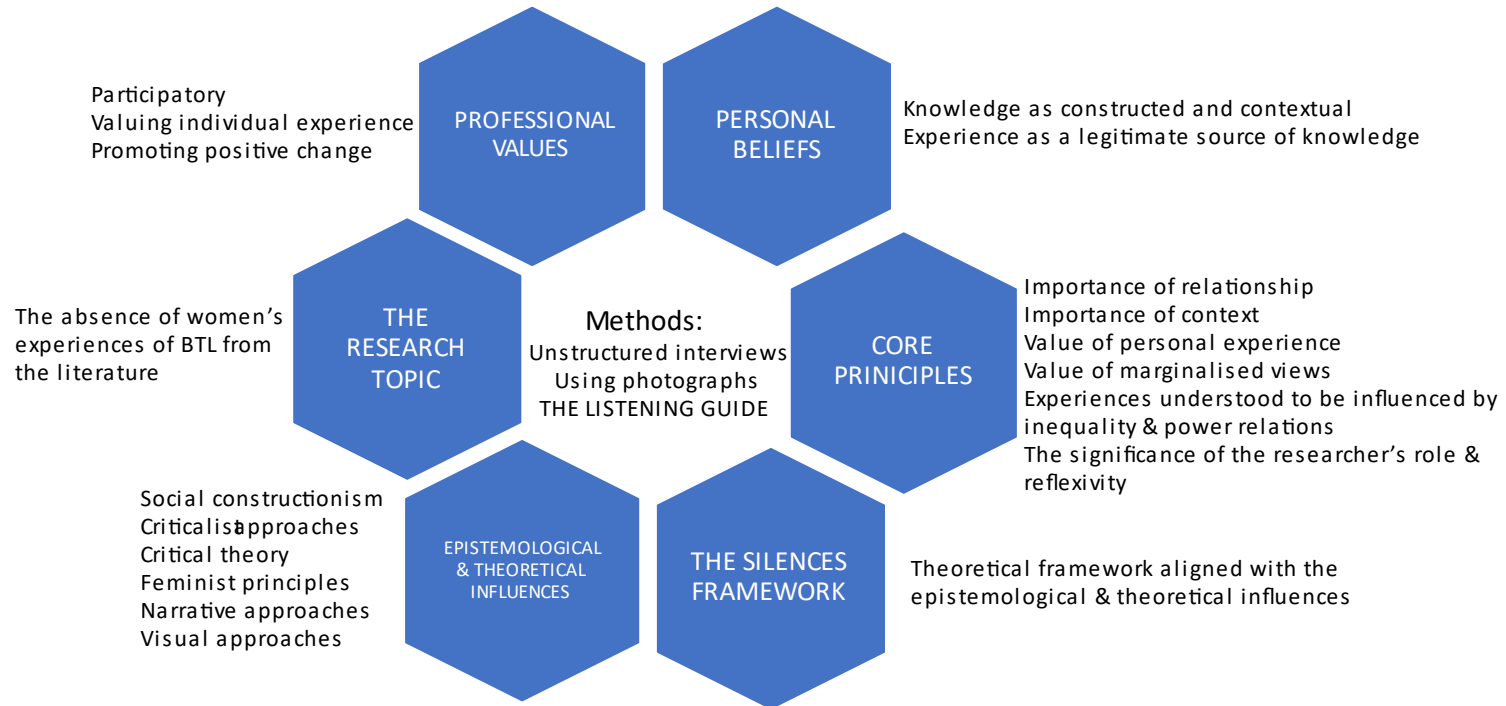
[The epistemological and theoretical approach underpinning the study](#)

All research is located within a particular world view, bringing with it assumptions about the nature of reality (ontology) and the nature of knowledge (epistemology). In adopting and making explicit a chosen perspective, a researcher can justify their choice of theory and methods selected to answer the research question (Crotty 1998). The

positivist perspective - that there is one single reality which can be understood through observable or deducible phenomena (Waller et al. 2016) – remains influential in medical and scientific communities; yet it allows no space for human experience and beliefs. The idea that objects hold meaning independent of human consciousness is firmly rooted in objectivist thought. From this perspective the researcher is presumed to remain impartial and have no influence over the findings, which are deemed to be objective. Importantly, the subjective perspective is considered to have no value in understanding reality. Meanwhile, although post-positivists may acknowledge there is no precise way of measuring reality and accept that objectivity is untenable (Crotty 1998), post-positivist thought remains aligned with positivist beliefs in using the scientific method of inquiry. Reality is maintained as independent from human consciousness using quantitative methods of investigation. As the literature review in Chapter 4 confirmed, the dominance of such ideas remains evident within the health sciences (Creswell 2013). In contrast, this study adopts an interpretive approach to explore in-depth a topic about which little is known to facilitate an understanding of women's experiences (Creswell 2013; Morrow 2016).

Figure 2 offers a diagrammatic representation of the influences upon the study research design, including the epistemology and theory underpinning this study (including The Silences Framework as the study's theoretical basis), my professional background, and my personal beliefs about the nature of knowledge. It shows the core principles deriving from all these aspects and, together with the research topic, how they inform the chosen methods. In researching human experience, my perspective views individuals as social beings who make meaning during interaction with others (Burr 2015). This emphasis upon relationship is a key feature of my background and training as an occupational therapist. Collaborative working, acknowledging individual experience, and promoting positive change were all features of my clinical role. These values guided me towards two epistemological approaches informing my understanding of what constitutes knowledge: social constructionist and criticalist, which I will address separately.

Figure 2: Epistemological, theoretical, personal and research topic influences upon the research design



Social constructionism

The term 'social construction' is commonly used to describe the way in which knowledge and understanding is created in human relationships and influenced by cultural and historical context (Gergen and Gergen 2015). The construction of knowledge through social interaction implies that what we know is changeable: that is, what constitutes 'truth' is a particular way of understanding the world, accepted at a particular time within a given set of circumstances. An individual's myriad experiences are reflected in multiple interpretations of events. This approach recognises that this study offers a particular perspective of women's experiences of BTL which is generated from women's own views and experiences, me as the researcher and the interaction between us. Accepting the notion of oneself as being in-relation-to others, the mutual influence of researcher and participant becomes evident. The approach also accounts for the social, cultural, and historical influences that provide the current context for this research. It recognises that both participant and researcher will be affected by circumstances outside as well as inside the research context and that these effects will differ between individuals.

Although the terms are sometimes used as if they hold the same meaning, social constructionism can be considered as distinct from social *constructivism* where people's understanding begins within their own mind rather than through their relationship with others (Gergen and Gergen 2015). This study's emphasis upon relationship, the central significance of the researcher and the importance of cultural and historical context is reflected in a social constructionist rather than social constructivist epistemology. Not only do the participant and the researcher interactions influence each other in an interview context, the researcher inevitably plays a role in 're-storying' participant's narratives during the analysis (Jones et al. 2006). While not inherently critical, modern social constructionist beliefs are influenced by a shift towards critical thinking (Gergen and Gergen 2015). These include the significance of the social, cultural, and historical context in shaping what is accepted knowledge.

Criticalist thought

Criticalism embodies a critical evaluation of the conditions that create and maintain accepted beliefs and produce inequalities such as those based upon ethnicity, gender, class, or economic status. Such inequalities are understood to be the result of domination, discrimination, and unequal access to opportunities. It is considered that knowledge is bound within power relations which influence what is viewed as legitimate at any given time; hence criticalist approaches examine how power operates in knowledge creation. Foucault's beliefs are useful in providing a language to think about these ideas, such as his ideas about scientific discourse as "subject to the rules that come into play in the very existence of such discourse" (Foucault 2002, p. xiv). Similarly, his notion of power as performative rather than something owned by individuals or institutions is pertinent: power may be enacted at the macro and the micro level of society, promoting some forms of knowledge and excluding or marginalising others. Power also manifests itself within the research process and particularly within the participant-researcher relationship. Of significance to this study is the way in which power is performed within participants (as patients)' relationships with HCPs and the wider health system. Here, power is influenced by the patient's knowledge of their health condition such that as expert, a patient may have some command within healthcare encounters (Åsbring and Närvänen 2004). This is important for this study given the apparent lack of knowledge about BTL among both patients and many of the HCPs they encounter.

I have drawn upon the term 'discourse' which in this context refers to Foucault's focus upon the specific rules underpinning statements made which maintain the authority of some ideas or beliefs and marginalise others. In this way, it can be seen how discourse relates to power; that is, what is deemed to be 'true' in any given society at a particular time will be governed by those processes driving dominant discourses which either legitimise ideas and statements as 'facts' or discount them. Criticalist thinking scrutinises the taken-for-granted nature of ideas and examines the power relations and contextual influences underpinning them. This approach is used in health research; adopting a critical viewpoint to address marginalisation is recognised among healthcare professions including occupational therapy (Gerlach 2015; Hammell and Iwama 2012).

Considering theoretical perspectives for this study

There is no single theoretical framework to explore women's experiences of BTL.

Honan et al. (2000) demonstrated how "each framework generates a different way of reading the data, a different sense of what can be found in it" (Honan et al. 2000, p. 10). This is important as the theoretical approach "can be experienced as either sharpening sensitivity to research participants' voices, or as shaping and silencing those voices" (Parr 1998, p. 87). Considering the epistemological framework for this research, this study requires theoretical support for the following principles:

- recognising the role and influence of the researcher in the research process
- promoting an equal relationship between the researcher and the participant
- enabling participants to voice their experiences
- empowering participants through the act of being heard and valuing their experiences as unique
- recognising the unequal power relations which influence women's experiences and their ability to be heard
- considering the contextual nature (i.e., social, historical, political and cultural context) of experience

Several theoretical approaches were considered for the extent to which they were congruent and compatible with the study's underpinning epistemological perspective and assumptions. Early in my doctoral studies I considered Grounded Theory as offering a systematic approach to data analysis, which is undoubtedly helpful to novice researchers. As its name suggests, however, it is intended for studies that seek to generate a theory grounded in the data. Theory-generation is not the intention of this study; the philosophical underpinnings of this research imply some clear a-priori theoretical assumptions which would be incompatible with a Grounded Theory approach. For example, the present study begins with clear assumptions about women's experiences of BTL being unheard and unrecognised. I had also become aware of some of the potential pitfalls of using Grounded Theory as a form of analysis.

Riessman (1993) and Jankowska (2014) both noted their desire to avoid breaking up participants' transcripts into codes and themes - a feature of Grounded Theory - to preserve the integrity of the narrative and retain its meaning. Thus, I understood that appreciating the larger "narrative-like chunks of text" (Janowska 2014, p. 7) during the analysis - at least in the early stages - would facilitate an increased understanding of participants' experiences that would likely be missed by coding methods alone. Furthermore, Grounded Theory's approach of seeking patterns in data potentially excludes any examples of variation in the dataset and risks silencing those aspects of experience. A similar claim can be made of phenomenological approaches which seek to elicit the collective meanings of lived experiences (Creswell 2013), so that phenomenology's intention to derive some shared understanding of the experience under study is contrary to this study's aim to capture diversity as well as common themes.

Critical theory

In acknowledging the influence of cultural, social, and historical contexts upon experience, researchers adopting a critical approach often seek to change practice by questioning those taken-for-granted beliefs and norms (Crotty 1998) and revealing unequal power relations which impact on the individual level. This emancipatory intent is aligned with the aims of this study. Critical approaches seek "to avoid the uncritical reproduction or reinforcement of dominant ideas and interests" (Alvesson and Skoldberg 2018, p. 203). However critical theory has been noted to offer little guidance for conducting research studies (Alvesson and Skoldberg 2018). I have been influenced by participatory action research (PAR) as an approach underpinned by critical theory (Koch and Kralik 2006) in my own study. PAR has focussed on addressing real-life issues rather than contributing to theory development. In this study, I adopt a participatory stance by allowing participants to choose how to tell and share their story, promoting a sense of empowerment. As well as valuing participants' stories, experience and knowledge, this study reflects PAR's attention to the researcher-participant relationship. Moreover, although this exploratory research

cannot claim to raise consciousness (Gaventa and Cornwall 2015), it aims to contribute to raising awareness in health education and healthcare around BTL.

Critical theory's emphasis upon the significance of context has implications for the data collection and analysis methods adopted for this study. Contextual influences both within the participant-researcher relationship and outside the research context are relevant. Hence the need for researcher reflexivity "in which we turn our gaze inward and question how we are individually located historically, politically and socially" (Gerlach 2015, p. 250). The nature of this research topic means that all participants are female, guiding me to consider how feminist thought may be relevant to the investigation.

Feminist thinking

Feminism is the adoption of a female or gender lens in addressing social issues. It perceives gender as "a dominating organizing principle in society, discriminating or in other ways disadvantaging females, in public and private spheres" (Alvesson and Sköldbberg 2018, p. 290). While recognising that there are many forms of feminism, it has been suggested that there are three key features which represent 'mainstream' feminism (Alvesson and Sköldbberg 2018). First, there is a focus upon gender in any consideration of the social world and its mechanisms. Second, gender is viewed as the site of unequal power relations. The third aspect emphasises the influence of the social, cultural, and historical context upon the construction of gender relations which are impermanent and open to change. While this study is not grounded in feminism - in the sense that it does not set out to establish gender as a key aspect of the investigation - the fact that all participants are women makes it inevitable that gender may be a significant feature; therefore, I remain sensitive to gender in the analysis.

This study is also aligned with other features of feminist inquiry, including facilitating non-hierarchical relationships and empowering participants through enabling their voice to be heard, validating their experiences expressed on their terms: "the process of creating the space to give voice to the voiceless" (Koch and Kralik 2006, p. 19). There is an acknowledgement that no individual woman speaks for others because this

would further marginalise them; hence diversity of experience is embraced. Moreover, the notion of relationship is a key feature of feminist research which recognises the importance of maintaining a reflexive attitude and being attuned to the researcher's influence throughout the research process (Mauthner and Doucet 1998). These features of feminist thinking have influenced my decisions about the methods of data collection and analysis for this study. Of central importance, however, is the broader theoretical framework guiding its development.

The Silences Framework (TSF)

TSF was selected as the best theoretical fit with the aims of the study and my own beliefs. TSF - and the chosen analytical method (described below) - allows me to foreground participants' experiences, upholding their diversity as well as common aspects of experience. It guides me to examine the social and cultural context within and beyond the research setting.

Chapter 3 outlined the structure and stages of TSF; they will be used to frame the discussion below. As a reminder, TSF provides a four-stage process for exploring silenced issues. The stages are:

Stage 1 – *working in silences*: The researcher establishes what is already known about the research topic to appreciate the wider context for individual experiences. This enables the researcher to understand the silences which affect those experiences. In this study, it was achieved through a review of the existing evidence about women's experiences of BTL. Stage 1 was presented through a literature review in Chapter 4.

Stage 2 – *hearing silences*: The researcher explores three elements of the silences to help the reader 'hear' them and appreciate how they influence the conduct of this research at this moment by this researcher. The nature of and interdependence between the researcher identity, the research topic, and research participants is examined to reveal these silences; it will be detailed later in this chapter. By declaring the philosophical and theoretical position of the research, the nature of the silences

surrounding the study at its inception, and the rationale for the selected study design, the reader is encouraged to understand the researcher's decision-making processes.

Stage 3 – *voicing silences*: At this stage, the researcher investigates the silences from the viewpoint of key stakeholders. This is achieved through collecting and analysing data to meet the aims of the study and gaining feedback on the developing analysis from participants and the wider network⁸. This stage is presented in two parts, in Chapters 5 (data collection and analysis) and 6 (findings).

Stage 4 – *working with silences*: Here the researcher addresses the impact of the study and the likelihood of any expected gains, having considered the silences which were revealed at Stage 1. The contribution or gains from attending to the silences revealed at Stage 1 are presented alongside the study limitations. This stage is presented in Chapter 8 (discussion).

Theoretical basis for TSF and implications for this study

TSF reflects the core features of feminist, ethnicities-based and criticalist approaches which I will summarise and discuss to demonstrate how they are applied in this research. TSF perceives social phenomenon as constructed: experience and knowledge are shaped by context. This means that the narrative presented by each participant is one created in relationship with the researcher: it is one of many possible narratives. The significance of relationship will be evident in locating the silences inherent in the researcher identity (Stage 2 of TSF) and in the chosen analytical method.

The implications of TSF for my study are that I adopt a critical approach which considers the broader cultural, medical, and academic context within which women's experiences of BTL are understood. I also recognise that in creating a narrative about their experiences, participants are constrained by the discourses available to them at this specific moment in time. Hence, the construction of knowledge does not occur at

⁸ The wider network of *collective voices* is constituted of representatives from those individuals or organisations that may have some bearing upon the research question, such as those with an understanding of living with lymphoedema after breast cancer treatment either personally or professionally.

a fixed point and is open to re-interpretation (Dharamsi and Charles 2011). The interview data and findings are themselves open to re-interpretation during the research process - that is, during the iterative analytical process involving participants and other stakeholders.

TSF guides research which seeks to give voice to people who have remained unheard or whose experiences are undervalued or under-researched. In the Introduction chapter I spoke of the significance of counter-narratives of the experience of breast cancer which challenge the dominant 'pink ribbon' discourse around positivity and survivorship. However, in "the allure of the transgressive" (Shapiro 2011, p. 69), Shapiro reminds us that the focus on counter-narratives may unintentionally undervalue accounts which conform to the dominant discourse. It serves as a reminder of the importance of adopting "narrative humility" (Shapiro 2011), accepting that the story told to the researcher is the story the participant chooses to tell. This will be shaped by a combination of personal motivations and the influence of the dominant discourses prevailing in society at that time. It can be argued that within a research relationship it is through our stories that we know each other; and that all that we can hope to know is what is presented to us through our participant's narrative. I therefore strive to employ critical thinking "that acknowledges that patients' tellings are ...dynamic entities that we approach and engage with, while simultaneously remaining open to their ambiguity and contradiction" (Shapiro 2011, pp. 70-71).

The notion of construction implies the type of research - and type of knowledge generated - that is deemed in society to have value and hold authority is influenced by the social, cultural, and political climate. Accepting that experiences are influenced by inequalities and power relations, the dominance of biomedical knowledge about BTL over women's narratives reveals the location of power that places women's experiences as marginalised. This taken-for-granted dominance is sustained when power retains an "ability to hide its own mechanisms" (Foucault 1998, p. 86). Foucault argues that the structures placed upon thinking through discourse manifest in a way that is not always conscious, resulting in certain discourses remaining unchallenged. His writings urge us to examine accepted ways of knowing: to trace their origins and consider alternative, marginalised discourses. Foucault had, as Cain (1993) describes, "a passionate concern for those whose ways of being cannot be spoken" (p. 84), either

because those individuals cannot articulate them, or they are suppressed by dominant discourses. 'Subjugated knowledges' are those that are suppressed or deemed invalid in the context of dominant ways of knowing and understanding (Nicholls et al. 2010). In Western cultures, medical knowledge is given authority and 'truth' status by processes which deny the legitimacy of alternatives. Women's testimonies about their experiences of BTL are therefore a form of subjugated knowledge and power is expressed in the form of silencing. TSF equips and guides research practice to explore these silences and address the power inequalities in participants' relationships with me, the researcher. In examining the potential silences surrounding the topic, BTL will also be shown to be further marginalised by its status as sensitive as it deals with the breast and its sexual and maternal associations.

The feminist principles which broadly underpin this study are aligned both with TSF and the Voice-Centred Relational Method (VCRM) as the chosen method of analysis (discussed later in this chapter). Therefore, I remain open to the possibility that notions of oppression and empowerment may be relevant to exploring women's experiences of developing BTL (Paliadelis and Cruickshank 2008). Key features of this study include enabling women to have a voice and speak on their terms (Mauthner and Doucet 1998), promoting a more equal relationship with the researcher.

Undoubtedly power relationships are pertinent not just during the interview but throughout the whole research process. For instance, power can take different forms in the research findings: Karnieli-Miller et al. (2009) note the "discrepancy between the informal, private (intimate) talk of the early stages of the research and the later, more formal, structured, public use of these data ..." (p. 280). Arguably neither the participant nor researcher can envisage the nature of the findings arising from the interview nor the nature of power influences at play, which is arguably disempowering and potentially exposing for the participant. Using TSF helps to mitigate against this by engaging with participants during the analysis and incorporating their feedback into the findings.

It is acknowledged the researcher is not simply a neutral observer but influences the study throughout the process. A reflexive approach is recognised as an important characteristic of the research process within a social constructionist paradigm, not

least to reveal the researcher's power relationship with participants (Finlay 2002) and influences upon knowledge construction (Doucet 2008). Adopting a reflexive attitude, I will demonstrate how I have attempted to position myself within the social and cultural influences I bring to the research process, including an emphasis on privilege and experience. The notion of intersectionality, based upon the premise that aspects of identity such as gender, race, class, and religion are interlinked, can reveal processes of unequal power and dominance that might otherwise have remained unrecognised both within the researcher-participant relationship and beyond (Carstensen-Egwuom 2014). Hence examining how gender, race or class influence the research encounter increases understanding, potentially illuminating the 'blind spots' related to power in the construction of knowledge. This type of exploration is manifest in stage 2 of TSF when the researcher identity is discussed. Under *Researcher identity* below I offer my personal reasons for undertaking this research at this time in my life to reveal my personal inherent biases and guide the reader to consider which silences may be present.

It is also the case that during the interview both the researcher and the participant are continually making decisions about how far to pursue a particular issue, which direction to take and which topics to avoid, demonstrating the social features of the interview process and co-construction of data which are key features of TSF. Guillemin and Heggen (2009) comment on the need for researchers "to negotiate a fine ethical balance between building sufficient trust to be able to probe participants for potential rich data, while at the same time maintaining sufficient distance in respect for the participant" (Guillemin and Heggen 2009, p. 292). Promoting a more equal researcher-participant relationship can arguably be assisted by the researcher being open to sharing personal information, although as Parr (1998) notes this carries the risk of silencing participants: "I felt that my background and experiences could be a double-edged sword, both enabling and limiting the women's voices" (Parr 1998, p. 91). This is pertinent to my own study as some participants could be inhibited from sharing their views if they felt that they conflicted with or were critical of my position as a health professional. I attempt to address this in the analysis in making explicit my perceived influence on the interview; it is also one of the tensions to be addressed in Stage 4 of TSF: *working with silences*.

Serrant-Green (2011) suggested a potential devaluing of individual experiences which challenge the dominant norm and the accepted societal discourse at a particular moment in time. Conversely, marginalised perspectives are championed by criticalist approaches. TSF places individual experience as central to understanding, creating an opportunity to challenge or counter the dominant perspective. I have suggested the limited reference to BTL in patient information and poor awareness about women's experiences as reflected by the absence of academic literature, accord participants the status of marginalised. This indicates that a participatory approach which empowers women to share their understandings on their own terms would be appropriate. By foregrounding women's experiences, the research question demands an approach that acknowledges each participant as expert, enabling them to advance their own meanings and interpretations. This participatory stance is intended to encourage participants to be active in the research process.

One of this study's intended outcomes is for its findings to be shared with healthcare practitioners, healthcare students, patients and their families, and organisations which support women who have had breast cancer. In alignment with criticalist approaches which advocate some form of positive action, sharing the findings in this way is hoped to increase awareness and inform future clinical practice, thereby improving patients' experience.

In summary, accepting that women's experiences of BTL have remained unheard and that in this respect women's voices are therefore marginalised, this study seeks to provide agency and choice to participants and to produce findings with clinical relevance. This is reflected in the study objectives which are:

- To enable participants to share their stories of their experiences of BTL on their terms by undertaking individual, unstructured, audio-taped interviews with them at a location of their choice.
- To facilitate discussion and encourage alternative ways of thinking by providing participants with the option to use images in their interview.
- To promote an active style of participation facilitating a more equal relationship with the researcher.

- To employ an analytical method that positions participants' voices and testimonies at the centre of the analysis.
- To create an environment for raising awareness and promote the conditions for positive change for women with BTL by producing outputs such as an exhibition, talks, peer-reviewed articles and videos and/or podcasts which meet the needs of diverse patient and professional audiences.

The next section will address TSF Stage 2: *hearing silences* to reveal the silences which exist because this study is undertaken by me at this particular time.

TSF Stage 2- Hearing silences

At this stage, TSF guides the researcher to identify the potential silences located within the researcher, the research topic, and the study participants, to understand their influence within the investigation.

Researcher identity

A key requirement of stage 2 of TSF is for the researcher to make explicit their association with the research topic including their motivations for undertaking the study, since the researcher's presentation of the study will inform the reader's understanding. As stated earlier, a reflexive attitude is recognised as an important characteristic of the research process within a social constructionist paradigm, not least revealing the power relationship with participants (Finlay 2002) and influences upon knowledge construction (Doucet 2008). Aspects of self, including gender, race, class, and educational background, have been highlighted as significant (Berger 2015; Doucet 2008; Mauthner and Doucet 2003). Given the importance of intersectionality in addressing potential 'blind spots', as part of Stage 2 of TSF, therefore, I offer my personal motivations for research at this time in my life.

I grew up in a north-eastern city in a White, middle-class family of Scottish heritage. I lived in several cities before settling in Sheffield where I finally married into a Yorkshire

working class family. Consequently, I view myself as having a foot in both the middle and working classes. Although childless, I have been surrounded by children throughout my adult life through my network of family and friends.

My interest in health issues stems from childhood when I was influenced by my mother's work as a nurse. Motivated to understand the patient's viewpoint and how their health and illness impact upon their daily life and their ability to cope, I trained as an occupational therapist. My lifelong curiosity and thirst for learning have resulted in opportunities to return to academic life on several occasions. Most recently I completed the National Institute for Health Research (NIHR)-funded master's degree in clinical research at the University of Sheffield prior to undertaking this doctoral study.

In the years immediately before beginning my doctoral studies, however, my professional and academic careers were disrupted due to sudden and dramatic episodes of ill-health among the people closest to me, requiring me to take on a caring role. I cared for my mother for a few short months until her death after she was unexpectedly diagnosed with a rare and aggressive form of cancer; and in the years since I have tried to fill the gap she left behind in the form of emotional and practical support provided to my father. Two years after my mother died, my husband was unexpectedly diagnosed with a large, benign but nevertheless life-threatening brain tumour. The tumour required prompt, complex and lengthy surgery which has left him deaf in one ear and with some balance issues. These intense events, bringing into sharp focus the fragility of the life of the people who mattered to me, clarified my professional and academic purpose. My career in occupational therapy was valuable but I felt stifled and unable to use my clinical research training. Hence, I sought out doctoral training for a project that held some personal meaning. Providing a space to hear from women who have endured cancer and are living with a side effect of their treatment has felt like a part of my mother's legacy and provided an opportunity to continue the care and attention I could no longer give to her. Nevertheless, I knew nothing about BTL - or indeed lymphoedema generally - until I began my PhD.

In thinking about researcher influence, Berger (2015) argues for the significance of their insider or outsider status - that is, whether the researcher has experience of the phenomenon under study. The extent to which I can be considered an outsider or an insider in this research is multifaceted. I have not experienced breast cancer and began

my PhD with minimal knowledge and understanding of breast cancer care for women; in these respects, I am clearly an outsider. Dwyer and Buckle (2009) argue, however, that the insider-outsider dichotomy is potentially unhelpful and instead advocate 'the space between' in which researchers can inhabit aspects of both positions. While there may be variation between participants and myself in terms of backgrounds, lifestyles and values, my experiences as a woman with some appreciation of loss and bereavement will contain some common features with the experiences of my study participants. The extent to which participants have disclosed their experiences is likely to be influenced by their sense of my willingness and ability to understand the stories they tell. This means that I would answer personal questions from participants in an endeavour to establish some rapport. I argue that a strength of my position as outsider in relation to developing BTL after treatment for breast cancer is that it draws participants towards the position of expert, thereby supporting a more equal relationship with the researcher (Berger 2015). Furthermore, my own inexperience means I have not attempted to impose any preconceived ideas or expectations onto the study. Nevertheless, I remain conscious of the potential power of my researcher status relative to participants. I also note some silences that could have been generated by my undertaking this research at this time. For instance, would my lack of experience of breast cancer - and specifically BTL - maintain or create silences in the participants? Were there likely to be questions I could have asked that did not occur to me? I acknowledge that participants may have felt reluctant to talk about this sensitive topic because of my lack of first-hand experience.

In addition to the reflexive account offered here, later in this chapter I make explicit my thinking and rationale regarding choices in the design and execution of this study to help the reader evaluate this research.

Research subject

As a part of hearing the potential silences surrounding the study, the researcher must acknowledge those features of the study topic that render it sensitive or unexplored in research, either because of the topic itself or the time at which it is being investigated. BTL can be considered a sensitive or undervalued topic on several grounds. First, I

mentioned previously that it relates to an area of the body which is generally clothed and perceived as private in our culture; the breast is associated with both sexuality and motherhood, although these realms tend to be seen as separate such that "breasts sit in an uncomfortable territory historically and culturally" (Nash 2014, p. 40). Second, women who have received treatment for breast cancer may already experience negative feelings due to changes to their body image (Kang et al. 2018). Third, evidence from studies of women who have developed lymphoedema in their arm after treatment for breast cancer suggests some HCPs expect that women should simply learn to live with the side effects (Maree and Beckmann 2016; Greenslade and House 2006; Ridner, Bonner et al. 2012). This attitude implies that women should be grateful they have survived cancer and should deal with the consequences of their treatment without complaint. Hence in the context of others' responses to their BTL, women are at risk of being marginalised.

Melanie Mauthner (1998) wrote about 'silent voices' in her exploration of the challenges she encountered in her research about relationships between sisters. The marginalisation and absence of knowledge about sister relationships in both public and academic fields seem to mirror the situation for women's experiences of BTL.

Mauthner (1998) observed there are risks inherent in the act of making public - within academia or established organisations - those experiences which have been hitherto private, undisclosed, and unheard, to generate new forms of knowledge. In particular, she noted there may be participant and researcher ambivalence about disclosing or remaining silent within the interview as a semi-public location. This highlights a form of silencing which can occur during the research process, and the need for the researcher to be sensitive to the potential for selective nondisclosure by participants.

Research participants

Finally, the researcher seeks to identify the absent evidence: the silences arising from the "missing voices" (Serrant-Green 2011, p. 354) or unheard perspectives. There is anecdotal evidence and comments on breast cancer forums from women who express their disappointment and sadness at having developed BTL. For instance, a recent post on a *Breast Cancer Now* forum includes comments from one woman having to "really

push" for treatment for her breast and arm lymphoedema; and that she had been refused when she had asked to be referred to a specialist. She felt that there was "not enough care or support" for treatment side effects. Yet Stage 1 of TSF: *working in silences* showed that women's experiences of BTL remain silenced and absent from academic discourse. Women as patients receiving care for breast cancer, within an institution largely operating on a biomedical model, provides context for why silences exist. Furthermore, the cultural representation of breasts in our society as private, intimate, and sensitive creates a potential barrier to sharing experiences, further fostering silence.

At the time of writing, there has been a global pandemic and the UK remains under some restrictions to control the spread of COVID-19. While this has not impacted upon either data collection or analysis for the study, there may be limitations on dissemination activities which are yet to be realised and which could thereby create further silences. Alternatively, more online and virtual events may present opportunities previously unacknowledged, such that further silencing is avoided.

Study design

The previous sections have discussed the potential silences which are characteristic of three key features of the study: that is, me as the researcher; the research topic, and the research participants. These included my status as an outsider in relation to women's experiences of BTL; the sensitivity of the topic due to its association with intimacy, sexuality, and motherhood; and the apparent marginalised status of women's experiences of BTL in healthcare settings. A study design was required which would counter women's experiences of being marginalised by offering them some authority and prioritising their voices over that of the researcher. I sought methods of data collection and analysis which would encourage participants to provide rich detail about their experiences and would offer the scope for a more equal partnership within the research process between the participant and the researcher.

The study's intention to foreground women's accounts of their experiences suggests elements of a narrative approach (Thomas et al. 2009). Listening to patient stories is a fundamental aspect of healthcare practice and sits well with my way of relating to people, both as a healthcare practitioner and a researcher. Individual, unstructured, open interviews - in which the participant sets the content and delivery of her story - were therefore chosen for this study. They are a suitable data collection method for giving some control to participants and allow in-depth exploration of a topic, enabling participants "to tell their own stories in their own words" (Bowling 2014, p. 392) and are suitable for exploring topics about which little is previously known (Tod 2010). They provide an opportunity for levelling the potential researcher-participant power imbalance by handing over some control to the participant. In seeking to find out about individuals' sensitive health issues, researchers are 'entering the lives of others' (Dickson-Swift et al. 2007, p. 330), indicating the intensely personal nature which can be characteristic of interviewing. It suggests that this method is particularly appropriate for exploring human experience. Similarities between research interviews and therapeutic interviews have also been noted, particularly the opportunity to be listened to which is provided by an open style of interviewing, as well as the importance of relationship (Colbourne and Sque 2005). This relationship can be considered "fluid and changing, but ... always jointly constructed" (Collins 1998, p.4). Hence even though the interview style is unstructured - lacking a series of questions to prompt the participant's storytelling - the interview data is shaped by the participant and researcher's mutual responses.

My motivation to hear participants' stories also led me to consider ways to encourage women to articulate them. While not a skilled artist, I have always enjoyed artistic pursuits including drawing, painting, and poetry. Photography is ubiquitous in our society through the availability of high-quality mobile phone cameras; hence it is likely to be a familiar resource to participants (Bell 2006). To help elicit rich accounts of their experiences from participants I was drawn to using visual methods in my research, inspired by a colleague's successful use of photography as a method in her own studies (Craig 2009, 2014, 2016a, 2016b). I kept in mind my intended research outcomes and the need to engage with audiences through dissemination activities for optimal

impact. I had several meetings with Dr Claire Craig which enabled me to gain insight into the theoretical and practical applications of including images and how to use the technique of 'photo-elicitation'. This technique was first used to describe the use of photographs within interviews (Collier 1957). However, rather than using researcher-produced photographs, the technique has since been extended to include and is dominated by studies using participant-produced photographs as the basis of individual interviews. Meanwhile 'photo-voice' employs similar methods by inviting participants to document aspects of their lives through photographs, although it differs in emphasising social change (Wang and Burris 1997).

Although traditionally researchers have used verbal means to gain understanding of others' experiences, visual imagery has been widely used to make illnesses visible and heard. For instance, the socialist feminist and photographer Jo Spence created images that powerfully represented her experiences of breast cancer and its treatment (Spence 1995). Her photographs exemplify her struggle to be heard by the medical profession (Bolaki 2011), drawing the viewer's attention to her silenced status and relative position of powerlessness within the medical system. There has been an increasing uptake of the use of visual methods in research; and the use of photographs in health research has grown over the last two decades (Balmer et al. 2015b; Frith and Harcourt 2007; Guillemin 2004; Lorenz 2010; Poudrier and Mac-Lean 2009; Radley and Taylor 2003; Yi and Zebrack 2010).

Several studies have employed photographs to explore participants' experiences of cancer. Balmer et al. (2015a) invited individuals with a poor prognostic cancer to take photographs which represented 'living with and after cancer'; while in a study by Frith and Harcourt (2007) participating women took photographs of their experiences during chemotherapy. Men with prostate cancer were the focus of a study where participants were asked to envisage that they were being commissioned to put on a 'Living with my prostate cancer' exhibition (Oliffe and Bottorff 2007). Notably, this latter study drew attention to the suitability of the method to increase understanding of people deemed to be marginalised, in this instance by patriarchal notions of masculine behaviour.

Many authors have commented upon the potential for visual methods to enrich data collection (Balmer et al 2015a; Mannay 2010; Oliffe and Bottorff 2007; Pain 2012; Rose

2016); and participants themselves have echoed this assertion (Burles and Thomas 2014). Images can be used to express experiences in a literal, concrete way or a symbolic or abstract manner (Frith and Harcourt 2007; Papaloukas et al. 2017; Radley 2010). In a study with adults who have a brain injury, Lorenz (2010) found that participants frequently presented their experiences through visual metaphor; similarly, Balmer et al. (2015a) demonstrated the use of an image of a battery by a participant with a poor prognostic cancer to convey fatigue as a sense of being drained. This is an example of Radley's comment that "what the photograph means is something that cannot be pointed to on the photographic print" (Radley 2010, p. 273). A deeper engagement with the topic can become a means to raise awareness not only in the researcher but within the participant, in a way that might not have been possible by a traditional interview alone (Pauwels 2013; Balmer et al. 2015b). It can also encourage the expression of thoughts and feelings that may be difficult to articulate using words (Gillies et al. 2005; Guillemin & Drew 2010; Papaloukas et al. 2017).

Data enrichment may come from the relational benefits of a visual approach. According to Pain's (2012) literature review, using visual images is believed to enhance the researcher-researched relationship by engendering a relaxed atmosphere. For example, in a study with adolescents who self-managed chronic disease, examining and discussing photographs during the interview helped facilitate rapport-building between researcher and participant (Drew et al. 2010). Some authors argue that visual approaches give authority to the participant (Pain 2012; Pauwels 2013) since the technique positions participants as the expert, with control over the production or presentation of images within the interview. This is particularly significant for participants who have felt diminished by their experiences with illness (Frith and Harcourt 2007).

Nevertheless, it cannot be assumed that using photography will empower participants. Rather than giving participants a voice they may be silenced if the researcher chooses not to use images in the way participants expected (Fairey 2017). This type of silencing will be explored in Chapter 8: *working with silences* when I consider the extent to which I have achieved my intention to give voice to my participants. Although I have developed a consent process for the inclusion of participants' images in dissemination activities, ultimately decisions about curating and disseminating the material will be

mine and influenced by my beliefs about the nature of the imagined audiences. This is an instance where my own biases might influence decisions, promoting or silencing participants' stories. As the researcher I become the primary listener who 'hears' silences according to my own biases as a part of a "politics of listening" (Fairey 2007, p. 2) in which giving voice is determined by who, how and under what conditions the listening takes place.

Some participants may not engage with producing photographs for a range of reasons including their health status, the value they attribute to the project, and their ability to capture their experiences in images (Burles and Thomas 2014; Frith and Harcourt 2007; Drew et al. 2010; Radley 2010). Possibly they may need reassurance that they need not produce photographs they anticipate will please or interest the researcher (Frith and Harcourt 2007). It could be argued that creating photographs does not require a high degree of artistic or technical skill, avoiding engendering feelings of inadequacy or intimidation (Guillemin 2004; Saarelainen 2015). In their examination of the experiences of individuals with a poor prognostic cancer, Balmer et al. (2015a) reported that participants found the method 'straightforward', suggesting that it was not a burdensome task for participants.

In this study, it was important not to exclude potential participants who may not want to use photographs, thus maintaining an inclusive approach and avoiding further participant silencing. An attempt was made to engender control and empowerment among participants by providing the option of using photographs; it was not a requirement for participation. Following Burles and Thomas's (2014) finding that some participants drew on existing photographs (rather than creating their own), I also extended the choice of photographs that could be used. Hence the following options were available to those women who chose to use photographs to convey or represent their experiences:

- Photographs created by participants for the study. Participants were offered the option of a disposable camera for this purpose. They were also provided with some prompts, guidelines and cautions as part of the study information pack (including advice about potential restrictions on taking photographs in places such as hospitals; see Appendix 14);

- Existing photographs or pictures (such as family photographs or photographs in magazines or newspapers) sourced by the participant;
- A set of photographs provided by me as the researcher. Participants could select photographs from the set to use in their interview, the images acting as prompts for the participant to tell their story. Examples included scenes from nature; of people displaying emotion; and of particular activities. A description of the photographs and my reasons for choosing each one is provided in Appendix 17. One was a photograph I took myself; the remainder of the 59 photographs were copyright-free images from the website *Pixabay*, containing a combination of what I perceived to be positive, negative, and potentially 'neutral' images, some of which could have either a literal or symbolic meaning. I am aware that this is my own assessment and so heavily biased. My justification for the inclusion of more negative images is that by its very nature, I was investigating a condition that is a negative feature of women's lives. Arguably, therefore, there was a need for more such images to access women's experiences of BTL.

Mitigating against personal bias

To gain a range of opinion on my ideas for recruitment and data collection - and thereby aim to prevent my own biases from dominating - a small advisory group was convened. The purpose of the group was to obtain the views of women who had developed lymphoedema following treatment for breast cancer to agree on a) the design and content of the recruitment material for my study to reach potential participants most effectively; and b) a suitable method of data collection, given the sensitivity of the topic. The advisory group consisted of a purposive selection of three women who lived locally and who had developed lymphoedema in their breast, trunk, or arm after treatment for breast cancer. I drew upon the network of women known

to my academic colleagues to identify suitable women who might be willing to help due to my own inexperience of the field under investigation. These choices were pragmatic, and I believe the small, local group was commensurate with the scale of my PhD project.

I facilitated the meetings of the group which met on two occasions. Members contributed to the design of the recruitment material and provided feedback on the research questions, participant documentation and some examples of the researcher-provided photographs for the study. Examples of feedback included the suggestion to give women the *option* of taking photographs rather than making it a requirement (as reflected in the *data collection* section earlier) and ideas for making the Participant Information Sheet (PIS) more appealing using colour and imagery. In addition, they all expressed an interest in providing feedback on the draft study findings (as part of the wider network of collective voices⁸ in phase 3 of TSF Stage 3).

Some additional personal learning gained from this group included the following aspects, which improved my confidence to make decisions about the study methods and clarified my expectations of recruitment:

- It was quickly evident that the women were very willing to share their own experiences of lymphoedema, as they did unprompted during the first meeting. I was aware that participants may also feel empowered if they had a sense of contributing to raising awareness, in this instance among other women who have BTL and among healthcare practitioners who treat them (Burles and Thomas 2014);
- The group felt that women would be interested in participating in the study as it could be viewed as therapeutic to share their experiences;
- They believed that participants would feel confident in voicing their opinion regarding their willingness to meet with the researcher twice (as my original intention was to conduct two interviews with each participant). This was due to their perception that the experience of having breast cancer made women more able to assert themselves;

- They felt that not all women would be drawn to using photographic images: it was recommended that instead I made this an option for participation;
- While individual interviews were viewed as a suitable method of data collection, the group also suggested that participants could benefit from meeting together, such as at the point of sharing the study findings. I did not pursue this suggestion, in large part for logistical reasons due to participants' potentially diverse geographical locations. It may be, however, that there will be future opportunities for some participants to meet each other if they wish to participate in dissemination activities.

At the point of meeting with the advisory group, I had already drawn upon my previous knowledge and understanding of research methods to arrive at the choices described above. While it could be claimed that I was wielding power over the advisory group members by asserting my pre-formed proposal for the research methods, I remained open to alternative suggestions from the group if my proposal was met with opposition. Moreover, my contact with the advisory group at an early stage in planning the study located me as a relatively inexperienced researcher, with the potential to level the power difference between us. Members may therefore have felt more able to challenge my proposed research methods if they felt that alternatives would be better.

Participant identification and recruitment

Inclusion and exclusion criteria

Eligible participants were female and aged 18 years and over. They had undergone breast-conserving surgery or mastectomy for breast cancer and had developed lymphoedema in their breast or trunk after surgery or radiotherapy. Eligible women identified through the recruitment avenues which were sanctioned through the

Integrated Research Application System (IRAS) were invited to participate. It was recognised that some women may come forward to participate who did not yet have a formal diagnosis of BTL. Such women were recognised as having an important and valuable contribution to make to the study and were eligible to participate. Women without a diagnosis would be encouraged to seek one to ensure that they received appropriate guidance and treatment.

To allow for the resolution of any temporary swelling associated with the trauma of treatment, participants were required to have completed radiotherapy a minimum of two months prior to recruitment.

Women who were receiving active medical treatment⁹ for breast cancer were to be excluded from the study; the rationale for this was that participation may have been burdensome for women at that time.

Participants were required to be able to give written informed consent and to communicate in English during in-depth interviews.

Men were excluded from the study as they constitute 1% of the population of people in the UK who develop breast cancer: between 2016 and 2018 there were an average of 375 cases of men versus 55,545 cases of women with breast cancer (Cancer Research UK 2021). This justifies a focus upon women for this early, exploratory research.

Access to participants

As somebody with no personal or professional background in lymphoedema, I relied upon my network of academic colleagues with a clinical background in radiotherapy and oncology to signpost me to potential gatekeepers for participant recruitment. My immediate colleagues had strong links with a lymphoedema service in the region which was identified as a potential primary recruitment site. Therefore, I visited the service to establish a working relationship with the lymphoedema nurse specialists. I

⁹ Those patients in continuing hormone therapy or other maintenance therapy (ie lbandronate) were eligible to participate.

also made links with a local support centre for people who have cancer which had hosted the advisory group meetings, and which became an additional recruitment site.

Ethics approval

University ethics approval was gained prior to undertaking the pilot study (Appendix 10a). For the main study, however, it transpired that the research governance process was not straightforward in view of the recruiting lymphoedema service's status as a charitable rather than an NHS organisation. This meant that it took some time to establish with the associated NHS Foundation Trust whether recruitment through the lymphoedema service constituted NHS activity or not. Ultimately it was determined that IRAS approval would be required; and NHS ethics approval was gained from Yorkshire & the Humber - South Yorkshire Research Ethics Committee (REC) and the Health Research Authority via IRAS in July 2018 (IRAS project ID 225878; see Appendix 10b for the approval documentation). Amendments (non-substantial and substantial) to the original application were required and are detailed below; they are summarised in Appendix 11.

Recruitment

A purposive sample of women with BTL following treatment for breast cancer was chosen to target individuals who had insight into the research topic, rather than being representative of the entire study population (Procter et al. 2010). Thirteen women were recruited to the main study between July 2018 and July 2019. Women who had undergone either breast-conserving surgery or a mastectomy were both represented in the sample, allowing for an exploration of women's experiences of breast and trunk (including chest wall) lymphoedema (see Chapter 6 for further details).

Most of the recruitment (eight women) took place via the lymphoedema service identified for this purpose. This was undertaken on behalf of the associated NHS Trust

acting as the Participant Identification Centre (PIC)¹⁰, as a proportion of patients seen through the recruiting site constitute NHS activity. During appointments the lymphoedema nurse specialists acted as gatekeepers, screening and identifying women who were eligible to take part in the study and providing those who expressed an interest with a study information pack (Appendices 12-15). The pack contained a covering letter, the PIS, an additional sheet containing guidance and prompts for taking photographs, and the study consent form. The covering letter invited potential participants to contact either an independent person at the recruiting site or the researcher directly for a discussion about taking part in the study or in research generally. Posters advertising the study were also displayed at the recruiting site; and the study was advertised via the organisation's social media accounts. In addition, posters about the study were displayed at a local support centre for people who have cancer; one eligible woman was identified by a staff member (who is also a Health and Care Professions Council-registered therapeutic radiographer) who had put up the poster at the centre on my behalf. The poster and social media invitation invited interested women to contact the researcher directly. Two participants were identified by word of mouth. In alignment with the values underpinning TSF, women who were recruited in the absence of a gatekeeper were able to participate if they had self-identified as having BTL.

Widening recruitment

Due to the limited number of women who pursued their initial expression of interest in the study, a non-substantial amendment was submitted and approved in November 2018 to enable reminder letters to be sent out to potential participants identified at the recruiting lymphoedema service (Appendix 16).

I had initially anticipated using the social media accounts of charity organisations to recruit potential participants, believing that this would be non-NHS recruitment activity. However, I realised that this would in fact require a further amendment to the IRAS ethic approval already obtained. Therefore, I withdrew one of the organisations'

¹⁰ A Participant Identification Centre (PIC) is an NHS organisation which identifies patients who are potential research participants; it is not a research site.

social media posts prepared for recruitment and removed this as a recruitment strategy; no participants were recruited via social media at this stage.

Clearly it is important to gain an understanding of the experiences of women from diverse backgrounds. In response to the heterogeneity of the sample achieved using these sampling techniques – in relation to ethnicity and age - alternative methods of recruitment were required. Specifically, there was a need to encourage participants from a wider range of ethnic backgrounds and younger women. The recruitment strategy was formally broadened through a substantial amendment which was approved via IRAS in January 2019 (Appendix 11). The amendment detailed a list of proposed organisations or individuals to be invited to advertise the study, which after approval was actioned as follows.

The charity previously known as *Breast Cancer Care* agreed to advertise the study, as did the administrators for the Facebook pages of organisations which had been suggested to me via word-of-mouth. These included the Lymphoedema Support Network (LSN) and the closed group *Ladies Living with Lymphoedema*. A closed Facebook group representing younger women with breast cancer declined to post my study invitation due to the reported volume of requests that they receive. The absence of the perspective of women from Black and minority ethnic background in the first recruitment round had represented a significant area of silence in my study. I sought to address this by advertising the study via a mixture of public, charitable, and voluntary organisations such as a local Asian women's resource centre; the Asian Breast Cancer Support group and on their Twitter feed; a social group for the local South Asian community hosted by a charitable organisation; and a local community health organisation via its community engagement worker. Finally, a local charitable centre offering complementary therapies and support for people who have had cancer and local practitioners of manual lymphatic drainage (MLD) were also approached to ask whether they could mention the study to any clients who had BTL.

Potential participants identified via the routes listed above were posted the study information pack. They were invited to contact me as the researcher directly by e-mail or telephone, at which point their eligibility to be included in the study was confirmed. During the initial phone call with every potential participant, a verbal explanation of

the study was offered to support the detail in the information pack. Women were given the opportunity to ask questions about the study. Some basic demographic data was obtained either during the initial phone call or at the time of and prior to the interview, to establish the characteristics and diversity of the sample. Participants' GP details were also obtained at the time of interview; however, it was impressed upon participants that this information would only be used if I had concerns about their welfare and that it would be destroyed immediately after the interview.

Sampling

Since a lymphoedema service was the primary recruitment source, inevitably women whose BTL was of a sufficient severity to warrant treatment were invited to participate in the first recruitment drive. Snowball sampling (i.e., through word-of-mouth) was also adopted which may have resulted in the recruitment of some women with less severe BTL; however, the degree of BTL was not an aspect of the inclusion criteria and so women were not explicitly asked about this.

I intended to recruit a sample of between fifteen and twenty participants: that is, a sufficiently large sample to reveal patterns across the whole dataset but small enough to maintain a focus upon individual participants' experiences (Braun and Clarke 2013). Data from 14 women is included in the final analysis which includes data from one woman who participated in the pilot study and who fitted the inclusion criteria for the main study. Fourteen was the total number of women I was able to recruit in a reasonable timescale within the constraints of my PhD. As I believe that the data provided by this sample is sufficiently rich and diverse so as not to compromise the aims of the study, the fact that I did not quite reach my proposed sample size is not deemed to be problematic. I am guided by Malterud et al.'s (2016) suggestion about the concept of "information power" to aid decision-making about sample size. This concept includes features such as the quality of the communication between the participant and the researcher together with the resultant degree of richness of the data. As participants tended to offer detailed information in their interviews with me, this lends weight to an argument for a smaller sample size as being sufficient.

Preparing participants for data collection and the interview process

Those women who consented to participate were invited to take part in an interview with me at a mutually convenient time and location. Initially I considered that two meetings with each participant would be optimum. The first meeting would be a preliminary one prior to the interview proper in which I would explain and discuss the options for using images in their subsequent interview with me. It would also provide an opportunity to build rapport. It quickly became apparent, however, that a telephone call was sufficient in place of a preliminary face-to-face meeting. In my clinical career as an occupational therapist, I have extensive experience of interviewing people and I believed that I had gained sufficient skill to enable me to develop a rapport with participants quite easily. I readily disclosed personal information if I felt that it would engender a more equal relationship. Information shared included my professional status as a qualified occupational therapist and when appropriate the fact that I had lost my mother to cancer.

At the beginning of each interview, participants were simply invited to “tell me everything and anything you’d like to tell me about developing and living with breast or trunk lymphoedema” so that they could tell their story in their own way. In conducting open interviews, participants were able to set the topic agenda. I interjected with questions if I was prompted by something said by the participant, mindful that it was important “not to intrude into areas that the narrator has chosen to hold back” (Anderson and Jack 1991, p. 25). On occasion I asked about or commented upon their emotional state if they appeared upset. In general, however, the intention was to allow each participant to raise those issues which she chose to bring to the interview and to follow her own lines of thought.

At the end of the interview, once participants appeared to have finished giving their account, I posed three pre-set questions:

- 1. How would you describe your experiences of health services in developing and living with breast or trunk lymphoedema?
- 2. Do you think that there is anything specific about living in today's society that has affected your experience of breast or trunk lymphoedema?
- 3. What do you want other people to know about living with breast or trunk lymphoedema?

These questions were intended to reflect TSF underpinning this study in seeking to give voice to women's experiences and acknowledging the cultural and social context in which their experiences are taking place.

Listening to silenced stories: data analysis

In TSF Stage 3: *voicing silences*, the researcher restates their identity and associated biases prior to the analysis since these will influence the entire analytical process. In Chapter 3, I outlined the six cyclical phases of analysis which I presented as my adaptation of the original process (Serrant-Green 2011); a diagrammatic representation of my adapted version of the data analysis cycle was informed by Janes et al. (2019) (see Figure 1, Chapter 3). The additional two phases in my adaptation constitute two rather than one participant review and subsequent researcher reflection as part of one cycle of analysis. The analytical cycle is described here:

In this study, **phase 1** of TSF is constituted by a review of the data by me as the researcher using my chosen analytical method (described below) to produce the *initial findings*. The initial findings were then shared with participants for review (**phase 2**). In its original form, TSF offered participants the draft findings from across the dataset at this stage, but in the present study participants' *individual themes* were presented in this phase. The *silences dialogue* generated from participants' feedback was then

integrated by me as the researcher into the analysis to develop *overall themes* as *draft one findings*. In **phase 3**, these findings were presented to the wider network, or *collective voices*, of individuals or organisations whose status has relevance to the research question for their feedback. In the light of feedback from the *collective voices*, the draft one findings were then reviewed to become the *draft two findings* (**phase 4**). In this study, in a **further phase (5)** the draft two findings were then presented to participants so that they could see the overall themes (which also incorporated feedback from the *collective voices*) and have their 'final say' on the findings. In the last stage of the analysis (in this instance, **phase 6**), I reflected upon participants' feedback on the draft two findings. Serrant-Green (2011)'s original formulation provided the option of repeated cycles of analysis until all information and feedback relevant to the research question had been elicited and integrated. This could be particularly important if there were changes or additional aspects to the findings as the cycle progresses.

In this study I do not attempt to generalise the findings to all women who have experienced BTL but recognise that the findings capture the perspective of a group of women at a specific point in time. Nevertheless, as well as presenting an opportunity to gain insight into the wider social and cultural context for participants' experiences, offering the draft analysis for review and feedback does help to establish the extent to which the interpretations resonate both with participants and the wider network. This may provide some indication of the findings' broader relevance (Serrant-Green 2011) and the extent to which inferences about the general scope and nature of their experiences could be applied to the wider population of women with BTL.

Ideally the wider network of *collective voices* should include individuals or organisations that are sufficiently close in profile to have knowledge or experience of the context of the pre-existing silences identified at stage 1 of TSF: *working in silences*. For this study, I invited members of the advisory group, some of whom had arm rather than breast or trunk lymphoedema. Two lymphoedema clinics were also chosen due to their unique position as healthcare providers who are knowledgeable about the topic area and have the potential to empower women to manage their condition. As a result, they may stand in contrast to their health service professional peers outside of the clinics who may have limited understanding of BTL. The 'wider network' therefore

included the women in the study advisory group, the lymphoedema nurse specialist team at the recruiting lymphoedema service, and the Lymphoedema Support Network (LSN) (a charity providing information and support to people with lymphoedema). In fact, the LSN was approached¹¹ after the lymphoedema service in the North-East of England which had originally agreed to provide feedback was unable to do so; this may have been partly because of the additional pressures upon the service caused by COVID-19. Feedback was also sought from the pilot participant whose data was not included in the analysis because she did not fit all the eligibility criteria (i.e., she had arm and not breast or trunk lymphoedema).

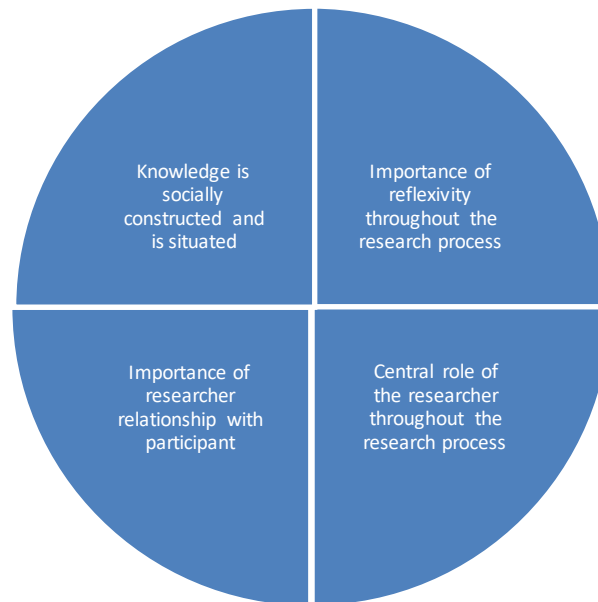
Phase 1 TSF: Method of researcher review

The Listening Guide (LG)

There is no prescribed method of data analysis in phase 1 of TSF's Stage 3. For this study I adopted the Voice-Centred Relational Method (VCRM) and its analytical tool as I believe them to be congruent with TSF (see Figure 3). The VCRM draws upon relational social constructionist beliefs: that is, that our sense of self and our social environment is generated through interacting with other people. Hence interviews are "mutually constructed social events" (Collins 1998), the method drawing upon a relational ontology which frames the self and our experiences as in-relation-to-others as opposed to independent cognitive processes (Brown and Gilligan 1992; Nortvedt et al. 2011). This perspective is captured in The Listening Guide (LG), a tool for data analysis which draws upon this thinking. The LG was originally developed by Lyn Mikel Brown and Carol Gilligan (1992) during their exploration of girls negotiating adolescence as a form of psychological inquiry. It acknowledges the importance of the researcher's influence, their relationship with the participant, and the positionality of both; and is described as "designed to amplify voices that have been marginalized or silenced by dominant cultural frameworks" (Coglan and Brydon-Miller 2014, p. 2). At the same time, it "recognizes the weighty significance of the research encounter as a site where some voices may be enhanced while others are silenced" (Mauthner and

¹¹ Following a non-substantial amendment via IRAS (see Appendix 11)

Figure 3: Common features of TSF and VCRM



Doucet 2003, p. 423). This relational perspective has implications for the analysis, prompting the researcher to adopt a reflexive approach and appreciate their potential to illuminate and incur silences.

Brown and Gilligan (1992) were prompted to develop the VCRM after feeling constrained by established analytic procedures. The result was a method which focuses not just upon what is said but the way in which individuals use many 'voices' (representing an attitude, tone or emotion) to talk about their experiences. The LG has four sequential steps, involving a series of 'listenings' or "passes through the data" (Gilligan 2015), each contributing to a multi-layered appreciation of the participant's account by attending to the various 'voices' in which we speak. The term 'listening' captures the literal form of listening to the interview recordings; but it also refers to reading the transcripts in a way which "transforms the act of reading into an act of listening, as the reader takes in different voices and follows their movement through

the interview" (Brown and Gilligan 1992, p. 25). This attention to the collection of 'voices' in which we speak is a fundamental aspect of the LG as a method "that tunes our ear to the multiplicity of voices that speak within and around us, including voices that speak at the margins" (Hutton and Lystor 2020, p. 3). The concept of 'voices' will be elaborated upon with examples in the next chapter.

The VCRM is also theoretically aligned with the criticalist approach underpinning TSF. This is evident in studies that draw on relational and feminist theories to use the method to give voice to participants deemed to be marginalised (Brown and Gilligan 1993; Mauthner and Doucet 1998, 2003). Through carefully attending to participants' voices, the method reduces the risk of silencing by preventing the researcher's voice to dominate. This is potentially empowering for the participant as it levels power relations with the researcher during the analysis.

I was drawn to this method for its use of re-telling participants' stories, highlighting points of crisis or reflection which is a feature of narrative approaches (Creswell 2013). Hence this study's method draws upon elements of narrative analysis as well as thematic analysis. The VCRM has been used in a range of contexts including studies of women's experiences of motherhood and postnatal depression (Mauthner 2002); disabled University student experiences (Hopkins 2011); workplace transitions (Balan 2005); communication rehabilitation for people after stroke (Bright et al. 2018); community policing (Giwa et al. 2014); and older women with dementia (Proctor 2001). The VCRM was also attractive to me as a novice researcher for several reasons. It has been described as straightforward to learn and offers a more explicit means of interpretation than some methods (Byrne et al. 2009). Its focus upon listening to the voices of unheard individuals was fundamentally aligned with TSF. Using the VCRM would respect the integrity of participants' individual accounts of their experiences and attend to their social and cultural contexts. Different researchers have adapted the method and focussed their 'listening' to meet their own needs and areas of interest (Byrne et al. 2009). This is particularly the case for the third and fourth 'listening' which allow for some flexibility; the first and second readings remain more prescriptive. While this degree of flexibility may be challenging for a novice researcher, overall it imposes a helpful level of discipline in the analytical process.

Critique of the Listening Guide (LG)

The depth of analysis promoted by using the LG enables the creation of a multi-faceted account of each participant's experiences, reflecting my intention to appreciate diversity and uphold the value of individual and varied experience as a legitimate form of knowledge. The preservation of participants' unique stories which is a feature of the approach avoids silencing women further by distilling or selecting from the narratives of different participants in the early stages of analysis. In their retrospective examination of their doctoral studies, Mauthner and Doucet (1998) comment upon how they resisted and delayed a 'reductionistic' approach in which transcripts are carved up into themes and compared across the whole dataset. Nevertheless, Gilligan and Eddy (2017) admit that "it takes a certain discipline or restraint to listen without immediately categorizing or coding what one is taking in ..." (Gilligan and Eddy 2017, p. 7), and the LG offers some protection against moulding the data to fit pre-formed categories.

The LG process enables the researcher's workings to be made transparent, allowing others to assess them and consider alternative interpretations. However, it is a time-consuming method of analysis (Hutton and Lystor 2020). The outcome is a series of documents created from undertaking each of its four steps, which has implications for what to share with participants in obtaining feedback on the analysis. While it is possible to provide participants with detailed information (Balan 2005), challenges include the extensive time required to read all the documents. This could have the effect of excluding and so further silencing some potential participants. In addition, the degree of immersion in the interview data and analysis has the potential to be overwhelming if participants are required to re-visit emotionally difficult content. Thus, the researcher employing the LG must consider the level of analytical detail to share with the participant and their degree of involvement.

Users of the LG are encouraged to engage with an 'interpretive community' (Coghlan and Brydon-Miller 2014) so that the researcher's emerging analysis can be interrogated. This process can help reveal the researcher's 'blind spots' and expose

silences that could have been ignored or created if the researcher were developing the analysis in isolation. An 'interpretive community' may not always be available to researchers, but the ability of the researcher to seek the views of academic colleagues on the developing analysis – in this case, my supervisory team - contributes to the process of verification.

Integration of TSF with VCRM and the LG

While Bright et al. (2018) highlight the way in which research undertaken using the VCRM creates a 'relational interpretation' of the data (p. 37), Byrne et al. (2009) argue that the method can produce numerous different interpretations. Using this approach does mean that the narrative presented by each participant is created in relationship with the researcher, as one of many possible narratives. However, the series of 'listening' afforded by the LG creates opportunities to prioritise the voice of the participant and consider unheard, newly identified, or potentially created silences. In these respects, the VCRM appears compatible with TSF.

I have described ways in which participants can be placed in the role of expert, for instance by being invited to share their previously unheard and unknown experiences. I have also referred to what may be meant by giving voice to participants. However, by adopting the epistemological perspective that social phenomena are constructed between the researcher and participant, there may be a tension created in simultaneously claiming to provide a space for each participant's voice to be heard. In their description of the VCRM, Mauthner and Doucet (1998) offer a perspective which reconciles this tension. They propose that their research participants have agency within the interview, engaging in a process of making decisions about levels of disclosure. Nevertheless, Mauthner and Doucet (1998) caution against "making grand statements about just who this person or 'voice' is." (Mauthner and Doucet 1998, p. 137).

Tension can also be detected in how the LG's emphasis upon listening to the participant may be at odds with TSF's intention for researchers to obtain feedback on the analysis from the wider community in which the silences occur; it may be seen to risk obscuring participants' voices. However, it can be argued that the role of

obtaining the views of the wider network is to demonstrate the network's influence upon participants' experiences as part of their contextualisation: "research that simply describes experiences provides insufficient information for it to be fully judged" (Serrant-Green 2011, p. 350). Additionally, by returning to participants with the final version of the draft findings to have a 'final say', it can also be argued that I have mitigated against further silencing of the women who have participated in this study.

Chapter summary

I began this chapter by discussing the philosophical approach to this study. I explained that the research question required a qualitative approach to gain an in-depth understanding of individuals' experiences of a topic about which little is known. Knowledge was argued to be socially constructed, positioning this study as offering a particular perspective on women's experiences which is generated between participants, myself as the researcher and the interaction between us at a particular point in time. I demonstrated that this research is also informed by critical approaches and highlighted the importance of considering social and cultural context and the role of power in legitimising particular forms of knowledge. I also argued that women's experiences of BTL currently sit within the silences located outside of accepted forms of knowledge. TSF was therefore proposed as the best theoretical fit for this study, reflecting core features of criticalist approaches.

While the previous chapter presented stage 1 of TSF: *working in silences* through a literature review of women's experiences of BTL, this chapter has represented stage 2: *hearing silences* by identifying those potential silences which are a feature of undertaking this research by me as the researcher at this time. By presenting my researcher identity, I hope that the reader can appreciate the lens through which other silences are 'heard', including the 'blind spots' I bring and the subsequent risks of further silencing participants. The research subject was also examined for the silences surrounding those aspects that render it sensitive and unexplored. Finally, in focussing upon research participants, I sought to identify the absent evidence: the silences

arising from the "missing voices" (Serrant-Green 2011, p. 354) or unheard perspectives.

This was followed by a consideration of and rationale for the research design and methods of data collection and analysis. I explained the suitability of open, unstructured interviews for providing participants with some agency; and described the use of visual methods, particularly photography, as an option for participants to use within their interview. I reported on the involvement of an advisory group in refining my ideas for recruitment and data collection. Next, I described the process of participant identification and recruitment. I went on to explain the selection of the voice-centred relational method (VCRM) as the chosen approach to data analysis, with the Listening Guide (LG) as the analytical tool used to create the *initial findings* in phase 1 of TSF stage 2's analysis cycle (Figure 1, Chapter 3). Finally, I considered the ways TSF and VCRM are theoretically aligned and integrated in this study, highlighting some potential tensions inherent in adopting these approaches.

Stage 3 of TSF: *voicing silences* will be reported over the next two chapters. Chapter 6 will describe how the research was conducted, including data collection and analysis; and Chapter 7 will report the study findings in the form of themes supported by quotations and images.

Chapter 6

Data collection and analysis

[TSF Stage 3 - Voicing silences]

If the only true pathway out of silence is voice, then we need space, opportunity and trusting relationships to have our voices heard

(Hutton and Lystor 2020, p. 11).

Chapter outline

This chapter represents the first part of stage 3 of TSF: *voicing silences*, demonstrating the conduct of the methods used to allow women's experiences to be heard. I describe the pilot study and its impact on the main study before providing information about recruitment and participant demographics. I go on to describe the data collection process, including details about the interviews and their management. I then explain how I applied the analytical steps of the Listening Guide and provide an illustration of the data analysis process. This is followed by an explanation of how the individual themes were developed and refined, and the overarching themes identified. Details of good practice including methods to enhance the credibility and trustworthiness of the findings; data confidentiality; ethical considerations; dissemination of the findings; and data storage are discussed next. Finally, I provide some further reflections upon the data collection and analysis process such as participant responses to their research tasks (using images and providing feedback on the analysis) and the researcher-participant relationship.

Introduction

In the introduction chapter I argued that women's experiences of BTL after treatment for breast cancer have failed to receive the same degree of interest in the academic or clinical communities as have women's experiences of lymphoedema of the arm. It was evident in Chapter 2 from an initial literature review of women's experiences of breast

cancer-related lymphoedema in the *arm* that this patient perspective has been relatively well documented in the literature (Fu 2005,2008; Greenslade and House 2006; Jeffs et al. 2016; Karlsson et al. 2015; McGrath 2013; Radina et al. 2008, 2014,2015). However, a systematic review of the literature about women's experiences of BTL in Chapter 4 demonstrated minimal attention to the topic, such that women's experiences remain unclear. In addition, there is evidence to suggest that HCPs may have limited or no knowledge of lymphoedema after treatment for breast cancer (Conway 2016) and this is reflected in the limited availability of patient information about BTL. Hence the voice of women who have BTL appears to be absent in the literature and it seems to be silenced in practice.

In the last chapter which discussed stage 2 of TSF: *hearing silences*, I located the silences which are an inevitable feature of this research conducted by me at this particular time. I acknowledged my outsider status in relation to the research topic - both personally and professionally - and therefore the potential to inadvertently silence participants by failing to pick up on what women say – or omit to say. In addition, I considered that participants may feel inhibited to talk to me about a topic relating to a sensitive body part if they perceive me to lack an understanding about the subject. In relation to the research subject, I acknowledged several ways in which it could be described as sensitive or undervalued. These included a perception of the breast as a sensitive body part (Nash 2014); the potential for negative feelings experienced by women due to body image changes (Kang et al. 2018); and the indication that side effects after treatment for breast cancer may simply be dismissed by HCPs (Maree and Beckmann 2016; Greenslade and House 2006; Ridner, Bonner et al. 2012). In relation to research participants, silences were acknowledged as located within the experiences of women as patients living with a neglected condition. In attending to the silences, I also gave an example of some anecdotal evidence of the difficulties women with BTL encounter such as having to "really push" for treatment and having a request to be referred for assistance turned down.

In the light of these silences, this study aims to explore the experiences of women who have BTL and its impact upon them and their daily lives. It may be that women with BTL have experiences which call for specific forms of care and support that are distinct from those for women who have arm lymphoedema. This research is also intended to

generate findings which will serve the educational needs of patients with breast cancer and healthcare practitioners, to improve the lives of future patients.

Research question

As I commented in the last chapter, given the absence of knowledge about women's experiences of BTL, this study is exploratory and deliberately broad in nature. It seeks to answer the questions:

- How do women describe their experiences of developing and living with BTL?
- What particular aspects of their lives do women describe in relation to living with BTL?

I have argued that women's experiences of BTL remain unheard and therefore those women are marginalised. For this reason, the approach of this study seeks to redress this by providing agency and choice to participants as well as by producing findings with some clinical relevance. This is reflected in my choice of data collection and analysis methods.

Pilot study

A small pilot study was required to establish the acceptability of the study protocol and procedures to women who would be targeted for the study. It also provided an opportunity to reflect upon both my interview style and method of analysis, ensuring that I used open questioning during the interview and reviewing potential areas of researcher bias. It was also intended to identify any flaws or the need for any adaptations to the protocol and the study materials such as the recruitment invitation, the format for the interview or the options for using photographs. Two women participated in the pilot study, recruited via informal networks. One did not strictly meet the full eligibility criteria for the main study as she had lymphoedema in her arm but not in her breast or trunk. However, in discussion with my supervisory team it was felt that she was qualified to provide valuable feedback for the main study. The other

participant had lymphoedema in both her arm and her chest wall i.e., she fitted the eligibility criteria for the main study.

Of note is the very strong negative feedback that I received from my first pilot participant on the poster invitation for the study (Figure 4). She revealed that she found the idea of using photographs in her interview "deeply condescending" as she felt that she was able to articulate her feelings without using photographs.

Nevertheless, she suggested that she could imagine that it could be useful for others, including children or people for whom English was not their first language.

Additionally, she felt that the poster conveyed a sense of how miserable life must be to live with lymphoedema. I assumed that these comments were in response to her interpretation of the poster images rather than the text, as I felt that the language and tone of the written content was neutral; certainly, this was my intention. In Appendix 17 I have offered some thoughts about why I selected these and other photographs which were included in a set offered to participants to consider selecting from for their interview. In relation to the photograph in the top half of the poster, for example, I have noted that there could be more than one potential focus for the image. While I acknowledge that the image could suggest sadness or reflection, I also believed that the barrier on which the woman is sitting could have been used as a metaphor to discuss barriers more widely. That is, it could have provided an opening to explore some of the silences which were anticipated to be a feature of women's experiences.


My first pilot participant also challenged the reference in the PIS (Appendix 17) to the possibility of finding it upsetting to talk about experiences of BTL. Despite this reaction, I was aware of my ethical obligations as a researcher to bring to the attention of potential participants any risks to participation and so this section of the PIS could not be removed. Meanwhile the reaction to the poster invitation served as a reminder of the numerous different interpretations that individuals create in response to visual images (Rose 2014). Given that the advisory group had deemed the poster acceptable, no changes were made to it for the main study.

Figure 4: Recruitment poster for the study

Sheffield Hallam University | Faculty of Health and Wellbeing


Are you a woman who has had treatment for breast cancer?

Have you developed breast or trunk lymphoedema after your treatment?



A research study at Sheffield Hallam University would like to find out about women's experiences of developing and living with breast or trunk lymphoedema.

- There will be an opportunity to ask questions about the study and learn more about it by talking with the researcher on a one-to-one basis (either face-to-face or on the telephone).
- Women who participate will be invited to take or select photographs which represent or convey aspects of their experience of lymphoedema, although this is not essential for taking part in the study.
- Participants will take part in one audio-taped interview with the researcher. Any photographs selected will be used as a springboard for discussion during this interview. Other studies have used photographs in this way to encourage different ways of thinking about issues.



If you would like to discuss taking part in research or learn more about the study, contact [REDACTED] on [REDACTED]. For further information, or If you think you might be interested in taking part, please contact Janet Ulman on 07593 554560 or at janet.ulman@shu.ac.uk

IRAS project ID 225878 Version 1.0 27.03.18

Recruitment information

There were 18 women who expressed an interest in joining the main study, 13 of whom were recruited. Reasons why the remaining five did not participate include:

- Withdrew (n = 1). The potential participant felt that her hand and arm lymphoedema would prevent her talking meaningfully about her trunk lymphoedema, which she perceived to be less severe;
- No further response (n = 3);
- Did not match the study criteria (n = 1): the potential participant had arm lymphoedema but not BTL

Recruitment sources included the following:

- A lymphoedema service acting as the participant identification site (n = 8)
- A cancer support centre (n = 1)
- Word-of-mouth (n = 3)
- Social media (n = 2)

Participant demographics

This section provides demographic information about the 14 participants whose interview data was included in the analysis.

Participant age

Participants were aged between 41 and 83 years old at the time of recruitment; this range reflects the age groups with the highest incidence of breast cancer. Most women were between 65 and 69 years old (n = 5). Participants' ages are represented in Figure 5.

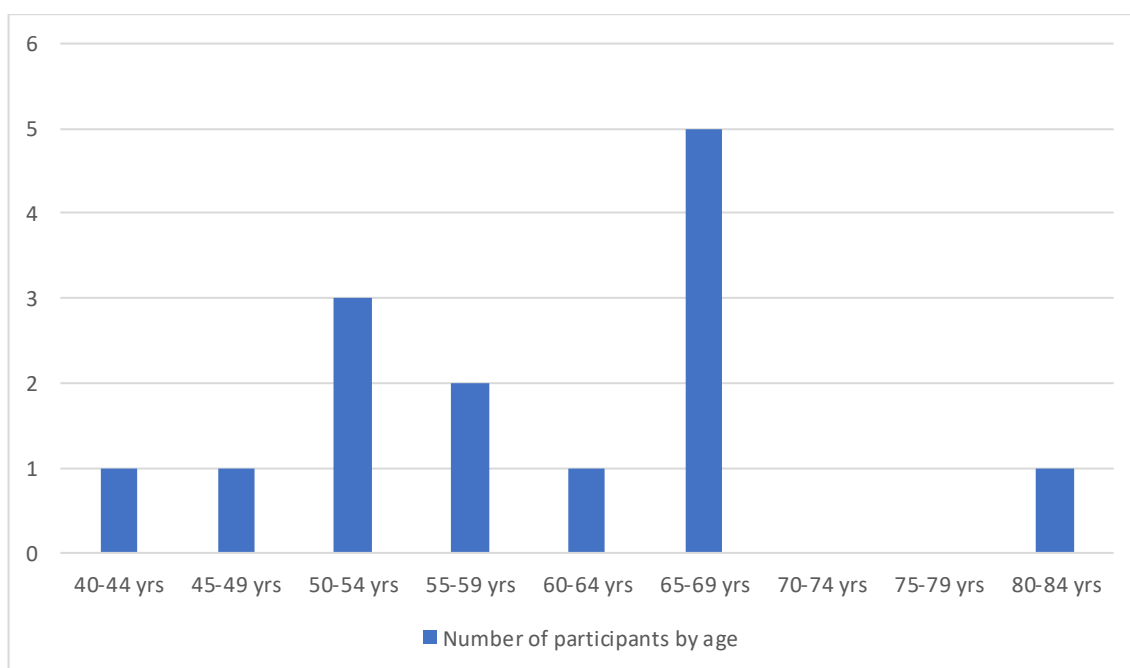


Figure 5: Participant numbers by age

Ethnicity

Despite efforts to recruit women belonging to minority ethnic groups through local and national organisations, including liaising with a local community engagement worker, there was no response; all the participants were White. Figure 6 shows participants' ethnicity according to how they self-identified.

Work status

I did not formally collect participants' working status and type of work, although while preparing for and undertaking interviews with participants this information was often disclosed. Participants were involved in a range of roles including teacher, academic, nurse, midwife, supermarket employee, undergraduate student and retired.

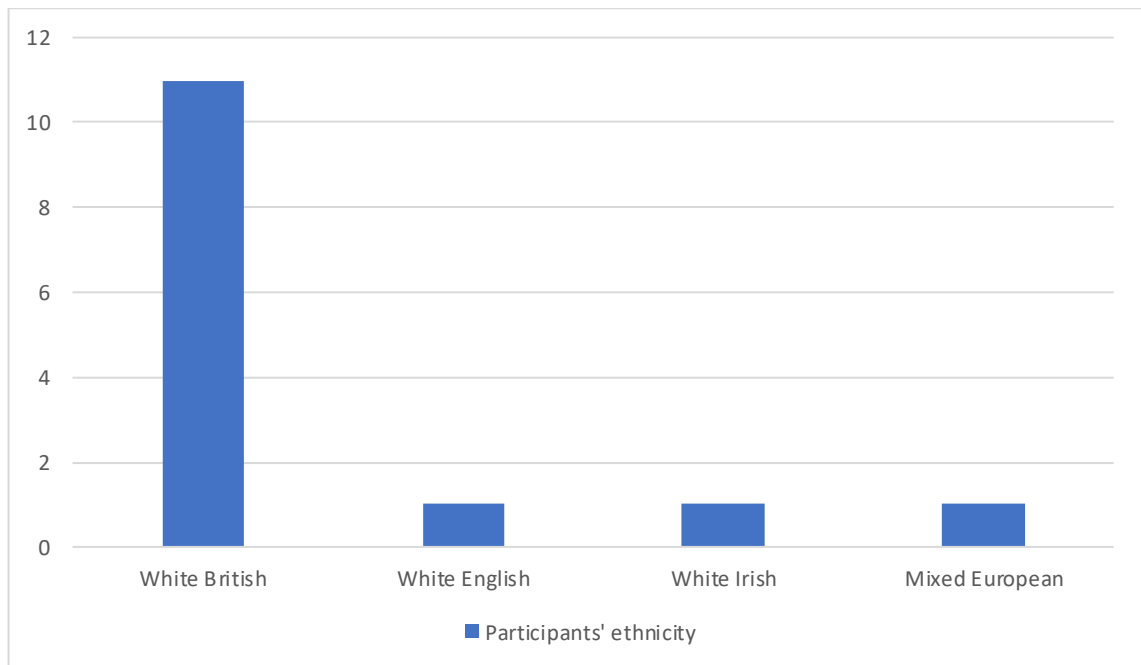


Figure 6: Self-identified ethnicity of participants

Type of treatment for breast cancer

Of the participants, 12 had undergone breast-conserving surgery and two had had a mastectomy. All 14 participants underwent radiotherapy. There was no uniform treatment pathway: for instance, Joanna underwent breast-conserving surgery three times following her diagnosis of breast cancer; while Sandra was operated on four times for breast cancer which was diagnosed on three occasions. Eight participants reported undergoing chemotherapy.

Time elapsed since treatment ended

Time since treatment until study participation ranged from several years (treatment ending December 2011) to several months (treatment ending in April 2018).

Details of lymphoedema diagnosis

The medical details provided by participants were accepted as accurate; I was not aware of any participant who did not have a formal diagnosis of lymphoedema as they all described using the services of lymphoedema specialists.

Anatomical location of lymphoedema

Seven women reported having lymphoedema solely in their breast; five women reported having lymphoedema either in their breast and armpit (n= 1); breast, armpit, arm, back and hand (n= 1); breast, trunk, and arm (n= 2); or trunk and arm (n = 1). Of the two participants who had had a mastectomy, one reported having lymphoedema in her chest wall and arm (n =1) and one at the site of her mastectomy scar, in her armpit and in her arm (n = 1).

Breakdown of demographic information by participant

The following women participated in the study. Names are pseudonyms or real names (with consent); participant ages are at the time of recruitment to the study; time since end of treatment for breast cancer is calculated until the time of the interview.

Tilly (aged 69): time since treatment = five months. She reported that she had lymphoedema in her breast and under her armpit.

Zoe (aged 69): time since treatment = one year and four months. She reported having breast lymphoedema.

Catherine (aged 54): time since treatment = two years and six months. She reported having breast lymphoedema.

Helen (aged 69): time since treatment = two years and ten months. She described having breast lymphoedema.

Jackie (aged 64): time since treatment = one year. She reported developing breast lymphoedema followed by lymphoedema in her arm, hand and beneath her arm/in her back.

Sharon (aged 59): time since treatment = six years and ten months. She described developing breast and trunk lymphoedema, followed by arm lymphoedema.

Samantha (aged 45): time since treatment = eight months. She described having breast lymphoedema.

Alice (aged 41): time since treatment = one year. She reported developing breast lymphoedema and lymphoedema down the side of her trunk; since her interview, she had also developed arm lymphoedema.

Joanna (aged 51): time since treatment = one year and three months. She described having breast lymphoedema.

Leah (aged 68): time since treatment = three years and four months. She described having breast lymphoedema.

Sandra (aged 69): time since treatment = five years and six months. She reported having breast lymphoedema.

Charlotte (aged 83): time since treatment = three years and two months (estimated). She reported having trunk and arm lymphoedema.

Sarah (aged 53): time since treatment = one year and six months. She reported having lymphoedema across her mastectomy scar (chest wall), in her armpit and in her arm.

Lisa (aged 59): time since treatment = two years and ten months. She reported having lymphoedema in her chest wall (particularly at the site of her mastectomy scar) and arm lymphoedema.

Hearing silences: Data collection process

Interviews – timeframe, location, and length

This is a qualitative study in which each participant was interviewed on one occasion. The pilot interviews (n=2) took place in September and October 2017 and the interviews for the main study (n=13) between September 2018 and August 2019.

Participants opted for a range of venues for their interview, but in their own home was the most popular choice (n = 6). Alternative options selected were venues known to participants including a lymphoedema clinic (n = 2); a support centre (n = 3); and a participant's workplace (n = 2). Two participants who were recruited via social media lived several hundred miles away and for logistical reasons were offered a video call or a phone call instead. They were both interviewed by phone, although for one participant this was due to technical difficulties in setting up a video call which was her preferred choice. While a telephone interview may have limited the opportunity to gain a rapport, it did also reduce the potential burden for participants associated with attending an interview at another location or hosting an interview in their own home. Interviews lasted between just over 19 minutes and one hour 22 minutes.

Managing the interviews

All women who took part in the study were considered capable of providing consent to participate. Written consent was obtained prior to each interview. My intention was to invite participants to choose the interview location so that they felt as comfortable as possible. In practice, however, I proactively suggested somewhere which was already familiar to them: that is, either the recruiting lymphoedema clinic, the local cancer support centre, or their own home. At the interview, an effort was made to put participants at ease and to further develop a rapport prior to proceeding with the formal audio-recorded interview. This was achieved using small talk, offering to answer any questions, and providing reassurance where necessary. Interviews lasted between 19 and 82 minutes.

Participants using photographs were encouraged to create or source their images over a period of two to four weeks. One participant opted to be sent a disposable camera which was returned to me in a stamped, addressed envelope. The concept of ownership in relation to participant-produced images was explored in a methodological paper by Guillemin and Drew (2010). They described how, in two studies exploring aspects of chronic illness in young people, two sets of participant-produced images were created: one for the participant to keep and one for the

researcher. By explaining this at the recruitment stage, it was argued that this promoted a sense of “shared ownership” (Guillemin and Drew 2010, p. 180). Hence in my study, two sets of photographs (one for the participant to keep) were developed from the disposable camera prior to interview.

The remaining participants who used photographs took them using their own devices, such as a mobile phone; or they sourced existing images from elsewhere. One participant opted to create drawings for her interview as well as using some existing personal photographs. Attribution of images is documented alongside the presentation of the findings in Chapter 7.

Participants who chose not to use images were simply invited to talk about their experiences of developing and living with BTL; otherwise, participants were generally prompted to talk about their images as the starting point for their interview. Any images used in the interviews were “a reference point to be used in conversation rather than an objective representation of reality that has meaning independent of these conversations” (Frith and Harcourt 2007, p. 1342).

Hearing silences: data analysis process

As the methods for data collection did not alter between the pilot and the main study, a decision was made to include the data from one pilot participant (whose characteristics met the eligibility criteria) with the data from the main study. Thus, the data from interviews with fourteen women was included in the analysis. This provided 11 hours and 51 minutes of interview talk and 72 images. The detail contained was sufficiently rich to allow some insight and understanding of women’s experiences of BTL.

I transcribed the audio files from the pilot study interviews myself. During this process I chose to retain aspects of speech such as false starts, pauses and unfinished sentences. In part this was to allow some flexibility should I later decide that these elements were important in the analysis. While it may be argued that transcribing the interview recordings enables the researcher to be fully immersed in the interview data

(Lathlean 2010), in fact I found the act of repeatedly replaying sections of the audio file to accurately capture elements such as the 'ums', 'ahs' and repetitions had the effect of desensitising me to the content and therefore acted as a barrier to understanding. This was compounded by the reduced readability of the completed transcript, particularly as the naturally occurring overlap in speech between the participant and I resulted in parts of the transcript being rather jarring to read.

For these reasons, I opted to use a professional transcription service for the main study interview transcripts; I had financial support through the budget attached to my Vice-Chancellor scholarship. It transpired, however, that the cost of having the transcriptions prepared according to 'strict verbatim' - which would include stutters, pauses and repetitions, for example - was prohibitive. I made a pragmatic decision to select 'intelligent verbatim' which would exclude the aforementioned details. Instead, I listened to the audio files alongside each professional transcription and added in those pauses, emotional responses, hesitations, and any other aspects that seemed potentially relevant to the analysis. I do realise, however, that this approach has interpretative implications which as a novice researcher I may not fully appreciate yet (Bird 2016). MacLean et al. (2004) address the issue of sections of the recording which are inaudible: however, this was not often a problem as frequently I found that I was able to detect the words missed by the professional transcriber due to my knowledge of the subject area or my understanding of the participant's dialect. I believe that taking the opportunity to independently verify, correct and embellish the transcripts allowed me to be immersed in the data while simultaneously manage the volume of material produced by the interviews.

All the interview transcripts, as well as the images used in the interviews, were uploaded into qualitative data analysis computer software ATLAS.ti, Version 8.4.20 (ATLAS.ti 2019). The software was downloaded onto my password-protected University laptop and the project within the software was stored in a password-protected folder. However, I began the analysis itself using Word documents for each of the four steps of the LG (see below). I then used adhesive notes to write out the themes created from the analysis for each participant and grouped the notes into tentative overarching themes which I arranged on a large piece of paper. It was after

this that I began to use ATLAS.ti software to advance the analysis. All the themes and tentative overarching themes were uploaded into the software. The software was employed for analytical tasks including writing memos to document the development of themes, drawing out supporting quotations, and creating visual networks to explore connections between themes. A memo documenting the timeline of events in the process of creating and developing themes was included.

i) TSF analysis phase 1: researcher review

As I explained earlier, the Listening Guide (LG) involves a series of 'listenings', the term denoting how the researcher "passes through the data" (Gilligan 2015). 'Listening' is therefore a form of carefully attending to what is being said while reading the interview transcript, although of course it can be supported by literally listening to the audio recording as well. Different researchers have adapted the third and fourth steps of LG to fit the needs of their own research. Hence in this study, my choices were based upon my theoretical stance reflecting sensitivity to those silences revealed in Stage 2 of TSF (Serrant-Green 2011), thereby being attuned to voices and experiences which had been silenced (Brown and Gilligan 1992; 1993). In the following section, I provide an explanation of the steps and how I operationalised them in this study. The entire process represents *phase 1* of TSF's cyclical analysis process (see Figure 1, Chapter 3).

LG Step 1: Listening for the plot

In step 1, the researcher reads the transcript and attends to the story told by the participant. This step has several purposes. First, listening to the participant's story (either by listening to the audio-recording, or 'listening' through careful reading of the transcript) establishes the participant's narrative as a form of knowledge (Mauthner and Doucet 2003). Second, this step establishes the researcher's emotional and intellectual responses to the story, which may be influenced by their own background and experiences (Mauthner and Doucet 1998; 2003). These reactions are documented, so that this process makes transparent where the researcher's views or assumptions

may influence the subsequent interpretation. The purpose of this step is also “to be descriptive, to be specific, to stay close to what she says and to use her words wherever possible” (Gilligan and Eddy 2017, p.78) to avoid interpreting and incorporating the researcher’s prior knowledge and assumptions.

This first step has been described as offering “a practical guide for ‘doing reflexivity’” (Doucet and Mauthner 2008, p. 405). In my study, my task was to listen for elements of the storyline told by the participant with reference to their photographs (if this option had been selected). In practical terms, this step can be achieved by creating a document with two columns, positioning the interview transcript in the left-hand column, and adding researcher comments and reactions in the right-hand column. Initially I listened for elements of the storyline as told by the participant, noting down particular words or phrases used. This included attending to recurring words or metaphors which were either verbalised by the participant or created using images. Thus, any photographs or drawings used during the interviews were revisited at this step to establish their meaning to the participant. I also considered my own responses to what was said, both at the time of the interview and on reading the transcript, noting my reactions in the right-hand column across from the corresponding section of the transcript.

LG Step 2: Creating the 'I-poem'

The intention of this step is to give priority to the participant’s voice over that of the researcher: it reveals how the participant “speaks of herself before we speak of her” (Brown and Gilligan 1992, pp. 27-28). Hence in this step the researcher ‘listens’ to the transcript again, focussing upon phrases beginning with the first person ‘I’. For practical purposes, these phrases are copied in the order they appear in the transcript and pasted into a new document; I used Microsoft word for this task. Using my own judgment, I then grouped the phrases into stanzas in the form of a poem.

As this step contains a method which is likely to be novel to many researchers, an example is provided at this stage to provide some clarity for the reader. The following

example is an edited version of the I-Poem created for Samantha, beginning after she finally receives her diagnosis of breast lymphoedema. It is presented to demonstrate elements of her story and to provide a sense of the impact of breast lymphoedema, as well as her relationships with HCPs and her family. It also appears to provide an impression of her agency and her powerlessness at different time points.

I just kind of thought, come on, you missed this

I'm not going to ... put in a complaint

I'm not angry at you, but

I would have expected you to apologise ... just say ... I'm sorry I missed that

I wasn't going to go on about my chest anymore

I don't expect doctors to get it right all the time

I'm very grateful my breast cancer has been found early

I'm not a person in the eyes of so many of the professionals

I'm just a problem ... to be fixed medically

I'm like ... it's good, but ... as a system you have no idea how to deal with me

I am damaged by it

I see other people where the treatment ... such a downward spiral

I kind of think, yes, my whole life is, from the moment

I wake up, it's just different, isn't it?

I have to adapt

I kind of can find ways around

I'm not making up these symptoms

I wouldn't choose to come to an appointment and tell you

I can't do this and I can't do that

I'm really tired

I know that every appointment is so pressured

I don't have the solution

I ... have to do my exercises

I've got such a busy life

I'm grateful for that

I've got kids

I work

I have less time for other stuff

I spend 40 minutes a day

I'm very thorough at my exercises

I think the impact on my family

I can't control the impact on them

I can't change it

I kind of feel like

I'm constantly trying to minimise the impact on them

I'm hoping I don't have to live with cancer all my life

I don't know

I'm hoping I don't

I do have to live with lymphoedema

I just feel lucky that I saw that doctor at that time

I only got that early mammogram because

I pushed and

I pushed and

I pushed

Creating the 'I-poem' is argued to encourage the researcher to listen more carefully to the participant's multiple voices or ways of speaking (Mauthner and Doucet 1998). For example, I became more aware of some participants' contradictory feelings within the same narrative, moving between expressions of power and vulnerability. The method has the potential to illuminate participants' associative logic rather than linear, rational, thought processes which are evident in the transcript. A further example can be seen in the I-poem extract in Appendix 18.

LG Step 3: Listening for contrapuntal 'voices'

During this step, the researcher reads through the transcript at least twice, each time attending to a particular 'voice' in which the participant is judged to be speaking. These contrasting 'voices' are evidence of the multiplicity of 'voices' which we are reasoned to use to express ourselves: the "different layers of a person's expressed experience" (Hutton and Lystor 2020, p. 10). Evoking musical references, the

contrapuntal or contrasting 'voices' may be in harmony or dissonant. The researcher may choose them in advance of the analysis or identify them inductively. In this study, the 'voices' were not pre-selected but were determined from the narratives to avoid imposing any preconceived assumptions. I selected those voices that I believed were most prevalent or the 'loudest' (Balan 2005). Nevertheless, I did bring to the task an expectation that some of the 'voices' were likely to reflect the silences that were anticipated to be a feature of participants' experiences, acknowledging that the research question "becomes the rudder in steering the researcher toward the voices in the text that speak to his or her inquiry" (Gilligan 2015, p. 72).

Remaining with Samantha as an example, I selected a *knowledgeable* and a *suppressed* voice. Her *knowledgeable* voice encompasses a range of features including her bodily knowledge; her critical evaluation of issues as a form of knowledge; and her clinical knowledge derived from her professional training and experience. Similarly, I have adopted a broad interpretation of her *suppressed* voice. It includes the suppression of her reported symptoms which were repeatedly ignored or dismissed by HCPs, as well as her wanting to shout about breast lymphoedema as having a significant impact upon people's lives. In addition, it includes her requirement to suppress aspects of her identity by withdrawing from preferred activities because of her breast lymphoedema.

Other examples from the present study include attending to an *ignored* 'voice', a *capable* 'voice' and an *ambivalent* 'voice,' representing the tone or feeling that I understood to drive or underpin the content of what was being said by the participant. The researcher uses a colour to highlight or underline each phrase or section of text in which the participant uses the identified 'voice'. This step enabled me to develop a deeper sense of the participants' stories, resulting in themes that were informed by more than merely the content of each narrative.

The proposition of 'voice' is distinct from that of 'theme' and is "a more textured, nuanced and embodied articulation of a lived experience" (Coghlan and Brydon-Miller 2014 p. 3). In this study I have used 'voice' as a feature not necessarily spoken aloud but nevertheless 'speaking' to me. I used the concept to encapsulate aspects of attitude, tone, or emotion that I detected, such as an *anxious*, *coping*, or *speculative* 'voice'. 'Voice' has been described as "polyphonic expressions of being, experience

and representation” (Hutton and Lystor 2020, p. 4). This step of the analysis can thus reveal contradictory or silenced features and so retain the complexity of the participant’s account which could be lost if the analysis were just reduced to a series of themes.

I appreciate the term ‘voice’ as used in this step of the analysis differs from the study’s intention to *give voice* to participants, the latter defined as enabling participants to express themselves while recognising there is no single authentic voice. To avoid confusion, ‘voices’ referring to the contrapuntal voices developed in step 3 of the LG analysis will hereafter be in inverted commas.

It should be noted that the analysis shared with participants and the wider network was only at the level of themes; it did not include any earlier analytical steps such as the ‘voices’ identified during Step 3. To the extent that the themes reflect the analytical work of the previous steps, however, the ‘voices’ are in fact incorporated into the themes, albeit not explicitly. I also felt that presenting the analysis in the form of themes was congruent with participants’ expectations.

LG Step 4: Composing an analysis

At this step, the researcher draws upon the evidence from all the previous ‘listenings’, bringing back in the researcher’s voice by showing how the evidence leads to the interpretation, i.e., the themes. In this study, the analysis is sensitive to the silences which were ‘heard’ in Stage 2 of TSF. In practice, I created a written account for each participant with elements of a case study-style of presentation; Appendix 19 shows an example. Examples of the final analytical step, alongside the associated interview transcript, were shared with supervisory team members as part of an ongoing peer debriefing process with the team throughout the analysis.

Each account begins with some introductory context to make transparent any factors which may have been influential in the analysis, such as details of my interaction with the participant prior to the interview. This is followed by the participant’s story

developed from the transcript – aspects of which may be supported by excerpts from the I-poem - together with the naming of and commentary upon the 'voices' which I identified in listening to the story. The account ends with a description of the themes that were developed from my interpretation of the participant's story, the I-poem and the 'voices' combined. Thus, this step enabled me to identify themes for each participant before drawing out themes across the dataset to ensure that the uniqueness of each participant's experiences was retained. Moreover, the entire process of the LG encouraged me to postpone identifying common themes across all the narratives and consider instead "the complete and unique story of the narrator, focussing on how her particular story is different to all others" (Byrne et al. 2009, p. 75). Recognising the uniqueness of each participant, a condition of the themes generated in this study is that they cannot be assumed to have universal representation; rather they are presented as examples of women's diverse experiences. Ultimately, however, there is value in generating themes to demonstrate the potentially wider applicability of the findings and as a means for HCPs to access participants' accounts (Montgomery et al. 2015).

A focus upon silences

My primary intent was to listen to all aspects of participants' experiences. Paradoxically, I felt that if I had only listened for silences in their stories during the analysis then I was in danger of silencing other features of the narratives. For this reason, after following the phases of the analysis according to the LG, I felt that it was important to undertake an additional reading specifically for silences. While some silences may have been easy to identify on initial readings of the transcripts, others were more subtle in how they manifested themselves. This process has allowed for a clearer understanding of them, and I was able to identify silences as either imposed upon participants by others – that is, either outside of the interview, or by me as the researcher inside the interview; or those that participants had imposed upon themselves, either outside or inside the interview. The silences also helped to illuminate where power lies in participants' relationships with others.

ii) *TSF analysis phase 2: first participant review*

As I discussed in Chapters 3 and 5, I have employed a two-stage (rather than one) participant review process and therefore an additional researcher review. This is an alteration to TSF as it was originally conceived and creates a six-phase analytical cycle. Others, including Janes (2016) and Nyashanu (2017), remain faithful to TSF's guidance and share with participants the themes which have emerged from across the dataset rather than the individual themes. In view of the varied stories told by participants, however, I was conscious that participants' individual themes could be obscured in the process of creating themes across the dataset early in the analysis. To avoid the risk of silencing participants further, I chose to remain at the level of participants' individual themes in the first instance.

For the first participant review, participants were therefore invited to comment upon the individual themes developed from their own interview transcript (Appendix 20). This was achieved by creating two Microsoft Word documents for each participant, one containing the themes (each with a supporting description) and the other containing the interview transcript itself. Even though the interview transcripts had been anonymised, for additional protection the documents were password-protected and e-mailed to each participant; participants were informed of their individual password via a telephone call.

None of the proposed themes were challenged or amended which gave me confidence that the subsequent overall themes carried some authenticity (Appendix 21). Nevertheless, it was important to have this verified by participant feedback on the draft final analysis: hence the requirement for a second participant review.

The individual themes which were sanctioned by participants in the first participant review became the *silence dialogue* which was then used to generate themes across the entire dataset. These overall themes became the *draft one findings* in TSF's analytic cycle.

iii) TSF analysis phase 3: wider network review

The *draft one findings*¹² were then presented to the wider network which included individuals with experience of breast cancer-related lymphoedema and organisations providing support or treatment to women with BTL. To recap, they included members of participants' social networks whose perspective was likely to acknowledge rather than further silence participants' experiences of BTL:

- Members of the study advisory group
- Two lymphoedema specialists at the recruiting lymphoedema service
- The chief executive of the Lymphoedema Support Network (LSN)
- A pilot study participant.

The LSN was selected after one lymphoedema service which had originally agreed to provide feedback was no longer able to contribute. The pilot study participant did not respond to two invitations to provide feedback.

The purpose of inviting the wider network – the *collective voices* - to review the *draft one findings* was to determine the extent to which the findings resonated with stakeholders beyond the research setting. By capturing feedback from members of the network, it also provided an opportunity for additional comments and perspectives to inform the findings.

Members of the wider network were sent two documents by e-mail: a visual network, i.e., the interrelationship of the themes, subthemes, and individual themes informing them (an earlier version of Appendix 22); and a text document containing the themes and subthemes, each with a supporting explanation – these are shown with feedback in Appendix 23.

Janes et al. (2019) recommended being clear at the outset of a study the potential sources of the wider network to avoid delays in obtaining additional ethical approval. The researchers also warned that the process of gathering this feedback can be misinterpreted as a part of the data collection stage rather than that of data analysis.

¹² That is, the overall themes across the dataset generated after participant feedback was obtained on their individual themes

This is an important feature to emphasise in articulating the research process using TSF.

The *collective voices* of the wider network and reflection upon the *silence dialogue* generated in phase 2 become the *draft two findings*. Any additional comments from members of the network are highlighted in red in the findings reported in Chapter 7.

iv) TSF analysis phase 4: researcher reflection

For this stage, I reflected upon the findings of the analytical process to date: that is, participants' individual themes and their feedback on them; the overall themes subsequently generated; and the feedback from the wider network on the overall themes. Several comments were generated from the wider network which were incorporated into the findings; however, the overall content in the themes presented to participants for their second review remained the same.

v) TSF analysis phase 5: second participant review

Participants were invited at this stage to provide feedback on the draft overall themes which already included feedback from the wider network. A text document was sent by e-mail to participants containing these draft themes, each with a supporting explanation. No password protection was deemed necessary for this document. Participants were asked the following questions:

- Do you still recognise yourself in the findings?
- Thinking about the set of themes from your personal interview that I originally shared with you, do you feel that anything has been lost or is now absent from the findings?

This stage provided an opportunity for participants to provide feedback which may support or refute the proposed themes. That is, women could comment on those aspects of the findings that related to their own experiences as well as highlight those features which did not relate to them personally (see Appendix 24). Participant comments are highlighted in red in the study findings in Chapter 7. This additional

stage was a change to the protocol submitted in the original IRAS application; hence approval for a non-substantial amendment was obtained prior to implementation (see appendix 11).

vi) TSF analysis phase 6: second researcher reflection

In this final stage, I reflected upon participants' responses to the draft final analysis, integrating their comments in support of themes into the findings and reflecting them in future recommendations. The outcome of this stage is the final study outputs.

An illustration of the analysis process

I have adopted one of the overarching themes '**you meet a wall**' to demonstrate the process of analysis which I used.

i) Data extraction

At the time of the interviews, a minority of participants (n=5) had developed arm or hand as well as breast or trunk lymphoedema. As it is acknowledged that some comments may not relate solely to BTL, to provide context the body area for participants' lymphoedema status is provided next to their quotations. The following are examples of data extracts relating to the theme '**you meet a wall**' which I developed in **phase 1** of the analysis.

"It's sort of almost one of those, it's sort of a bit cloaked you know, and we hope people don't get it and if they do ... put you into a little corner somewhere" (Lisa¹³, *chest wall and arm*)

"you meet a wall of you've got lymphoedema you've got to live with it" (Lisa, *chest wall and arm*)

¹³ Note: The names used in this chapter and the subsequent one are pseudonyms, other than in one instance where the participant opted for her real first name to be used.

"fobbed it off ... they don't know, they didn't look, they didn't anything." (Jackie, *breast then armpit, back and hand*)

" ... it's like they tell you so much. They don't tell you side effects ... Nobody tells you." (Jackie, *breast then armpit, back and hand*)

" ... it was just sort of brushed aside ..." (Sharon, *trunk and breast then arm*)

" ... at that time there was nobody there to actually talk to about it until I went to the clinic ..." (Sharon, *trunk and breast then arm*)

" ... the doctors not listening and not acknowledging. That just made, I guess, all my appointments stressful ... I'd been preparing for them thinking, well, how can I really try and get them to listen to this?" (Samantha, *breast*)

" ... made me feel like I was making it up and it's all psychological." (Samantha, *breast*)

"I think what would be helpful would maybe when you're finishing your treatment ... that somebody should say you know how is the size of your breast, are there any differences, you know because it's quite easy to get referred when you're in the system but then when you're sort of out of it and you've got to kind of get back in it ..."

(Leah, *breast*)

ii) Development of individual themes

I developed a set of themes for each participant as a part of the final analytical step of the LG. Each participant was then presented with their themes alongside a description of each one and invited to feed back any comments, additions, or contradictions (Appendix 21). This constituted **phase 2** of my adaptation of the TSF analysis process.

What follows are some examples of the individual themes developed from participants' interaction with health services in relation to their developing BTL.

you meet a wall

on being silenced

being ignored

difficulty accessing information and support

being unheard

it's all psychological

could do better

you're not listening to me

missed by so many healthcare professionals

ignored by others

healthcare professional withholding information

they said I was just too fat

iii) Refinement of themes

I used the function in ATLAS.ti software that enabled me to create a visual network of my proposed themes. Initially I drew upon those themes that I felt constituted *forms of silence* to obtain a sense of the degree to which silence appeared to be a feature of the data. I added to this by drawing out those 'voices' that appeared to relate to silence, identified at step 3 of the LG analysis. It was evident that there were many themes which were related to forms of silence. Nevertheless, I also attended to other themes emerging from the data that did not necessarily relate to women's experiences of silence, to remain faithful to their overall accounts.

The large number of themes early in the analysis made the task of refinement rather difficult and unwieldy. For this reason, I attempted to group the individual themes according to categories. The process allowed for clearer thinking and for me to appreciate the distinction between types of themes. For instance, to begin with I had two distinct themes 'suggestions for service improvements' and 'could do better'. At face value, they both relate to participants' negative opinions about services. However, on closer examination, the former theme lends itself to a list of items supporting it (what Braun and Clarke (2013) call 'a feature of the data'), while the

latter seems to have a more dynamic nature in reflecting participants' opinion about the subject. Consequently, I merged the themes under 'could do better' as more reflective of participants' active voice. Other individual themes were merged if they were felt to represent similar experiences. For example, 'being ignored' was merged with 'ignored by others'; 'getting round the problem' with 'managing breast lymphoedema'; 'head in the sand' with 'ignoring the swelling'; and 'what is this?' merged with 'wondering about all my symptoms.'

iv) Identification of the overarching theme

I have found it useful to consider Braun and Clarke's (2013) notion of a theme as having a 'central organising concept': that is, it reflects some content of the data which is meaningful in connection with the research question. I elevated the individual theme *you meet a wall* to the status of overarching theme as I felt that the image of a wall captured how many participants experience silence in relation to BTL. The theme represents a variety of ways in which the 'wall' is portrayed, and which maintain the silences surrounding BTL, including: being ignored or unheard; a lack of understanding from or a withholding of information by HCPs; a lack of access to information and resources; and issues with service pathways.

Methods to enhance the credibility and trustworthiness of the findings

Several methods were employed to enhance the credibility and trustworthiness of the study findings. Such criteria are widely accepted among qualitative researchers as indicators of quality; they are alternatives to the terms 'validity' and 'reliability' used within quantitative research. Of central importance to the methodology for this study was the researcher-participant relationship, so that in developing a rapport with participants it was hoped that they would feel comfortable disclosing their experiences, lending authenticity to the data. I also sought to ensure that the data was accurate by personally checking the interview transcripts (prepared by a professional transcription company) against the audio recordings of each interview. Other methods

to promote the trustworthiness of the findings included maintaining an audit trail of theme development - demonstrated in the section above - to make the process transparent. Moreover, the use of direct quotations from participants in support of each theme is demonstrated both in the audit trail and in the presentation of the findings in Chapter 7.

Integral to the application of TSF is engagement with participants and the wider network in the developing analysis. Their feedback enables the researcher to revise the interpretation until the findings resonate with these key stakeholders. In addition, TSF's emphasis upon researcher reflexivity encourages a transparent approach, as evidenced in the declaration of the researcher identity at stage 2. Throughout the research process I also kept a research diary and made some reflective notes (in PebblePad). The notes from the research diary relating to the interview planning and process are reflected in Step 1 of the LG as a part of the analysis. Other reflective notes are related to my development as a researcher and the research process for this study, and where relevant are incorporated within this thesis.

Confidentiality of data

i) Managing correspondence with participants

All the women who participated in the study used e-mail accounts to correspond with me during the research. Therefore, it was essential to identify good practice for storing and saving participants' e-mails and e-mail addresses to prevent them remaining visible in my University's Microsoft Outlook e-mail system. Following guidance from the University IT team, I established a process of saving the content of each e-mail into a document allocated for each participant which was uploaded and saved on the University's secure network for sensitive data. In addition, I manually deleted participants' e-mail addresses from my e-mail account immediately after corresponding with them so that they did not remain stored on the system.

ii) Managing participant data (personal data and interview data)

As detailed in the participant consent form (Appendix 13), information collected during interviews remained confidential unless I perceived that the participant (or someone they mentioned) could be at risk of harm. Participants were informed that in such circumstances, I was obliged to breach confidentiality and contact an appropriate professional (such as a lymphoedema specialist known to the participant or the participant's GP). This explanation was repeated at the time of each interview, prior to the interview commencing.

Audio recordings of the interviews were made on a digital recorder and a back-up recording was made using a second device. The back-up recording was deleted immediately after it was verified that the first recording had been successful. The audio files were uploaded to the University's secure drive as soon after the interview as was practically possible and deleted from the audio recording device. Until that time, the digital recorder was stored securely on University premises or in a fire-proof safe in my own home. A professional transcription service was used for which the interview audio files were transferred using encryption. After PhD completion the audio files will be destroyed from the University network due to the possibility of participants being identified through voice recognition.

During the research process other confidential data pertaining to participants, including personal details and the interview transcripts (in the form of Microsoft Word documents), have also been stored on the University secure network. Data analysis files, including anonymised interview transcripts, photographs, theme development documents and memos have been created in a password-protected project within ATLAS.ti software to support the data analysis. They have been stored during the study on the University's secure network.

My field notes and diary entries do not contain any identifiable participant details: any reference to participants has made use of a code number. No confidential information was revealed during the process of sharing provisional themes with participants and the wider network to obtain feedback.

Further information about dissemination and storage is provided at the end of this chapter.

iii) Managing the photographic data

I had intended to give participants prior guidance about taking photographs in which other people appear and advice to ensure that those people could not be identified. However, the Research Ethics Committee (REC) requested that photographs used in the study did not contain images of other people at all. Participants were advised accordingly and reminded about possible sanctions against taking photographs in certain settings, such as within hospitals (see 'Prompts and guidelines for images' document in Appendix 14). In fact, one participant did include an existing family photograph in the selection that she brought to her interview which in any case she wished to remain confidential. This image (a copy of the original photograph which was retained by the participant) has not been used in my thesis; it will be destroyed rather than stored in the archive or used in public dissemination outputs. Two other participants can each be seen in one of their own photographs: one has her back to the camera and is some distance away (and therefore is not identifiable from this image alone); however, the other participant is clearly visible in the photograph of herself. The agreed research protocol stipulates that any identifying features will be obscured in dissemination materials if the image is used and the participant wishes to remain anonymous.

Digital images have been stored electronically on the University's secure network. Any physical images – that is, drawings, photographs developed from the disposable camera or pictures from magazines – were themselves photographed using the researcher's digital camera and uploaded directly onto the secure network. The digital camera's memory card will be destroyed at the end of the study. All original physical images are stored in a locked cabinet in a locked room on University premises and will remain so until after the study has ended. On the occasions when the researcher returned directly home after an interview at the end of the day, any images were stored temporarily in a fireproof, locked box safe in the researcher's home until access to the University was possible.

Additional details of data management can be found in Appendix 25.

Ethical considerations

i) Informed consent

Women who participated in this study were all considered capable of consenting to take part by the nature of their having contacted me and their ability to discuss participation. They were provided with written information about the study (Appendix 13) and had opportunities to ask questions before consenting to take part. In addition, their ongoing consent to participate in the interview was monitored verbally and non-verbally throughout.

For those participants who used images within the study, further written consent was obtained after data analysis. Prior to interview, participants consented to participate in the study on the understanding that their data would be kept confidential while the study was ongoing. However, the participatory nature of the study means that women who took part were invited to make their own, informed decision about whether they wished to relinquish their anonymity and be identified in study outputs. That is, whether they wanted a pseudonym or their real first name attached to interview quotes and any images associated with them. Digital alterations were an option for any identifying features in photographs. Therefore, written consent of a different nature was obtained from participants following data analysis and before dissemination activities, as described in the next section.

ii) Participant confidentiality in dissemination outputs

Study outputs are anticipated to include exhibitions, academic and public presentations, academic journals, and teaching materials. Participants' written consent reflecting their decision whether any images that they created for their interview (or any personal, pre-existing images used) could be used in such outputs were documented in an additional consent form (see Photograph Reproduction Consent Form in Appendix 26). In addition, participants had the option to specify whether they consented to all, some, or none of their study photographs to be used in the outputs that they specified. Due to restrictions resulting from the COVID-19 pandemic, consent was sought via e-mail. This meant that participants were invited to print off

(or be sent a copy of) the consent form, take a photograph of it once it was completed and signed, and e-mail me the photograph.

In the spirit of promoting participants' empowerment, women who participated retain the copyright to any images that they created for the study, i.e., I did not seek to transfer the copyright to me. The approach is designed to give women the opportunity to make visible their experiences and to make those experiences accessible to others outside of the academic community.

Additional guidance from the Intellectual Property team at Sheffield Hallam University was gained relating to copyright in preparation for dissemination activity, to ensure that all legal matters were addressed (see appendix 27). It is also acknowledged that unanticipated risks to confidentiality may arise during dissemination of the findings. These will need to be addressed at the time, either through discussion with participants or by removing the material altogether (Chapman et al. 2017).

iii) Interview location

I wanted participants to feel comfortable in their environment during their interview with me so as not to silence them further. While it was important to enable them to decide on the location of their interview with me, I did enter the research with some clear opinions about the suitability of certain environments. Saarelainen (2015) conducted her research interviews with young people diagnosed with cancer in restaurants and cafes. I found this a surprising choice given the young and potentially vulnerable nature of her participants. As an early career researcher intending to embed sound ethical principles into my practice, my impression of these locations is as public and therefore potentially exposing. In fact, the author pointed out that participants were able to choose the location of their interview; so perhaps my initial response reflects my uninformed assumptions about what might constitute a safe space for this younger group of participants. The participant information sheet for my study invited potential participants to meet with me either in a familiar clinical setting, their own home, or "at another location of your choice where we will be undisturbed" (p. 2). Ultimately, guidance from the REC steered me towards taking a more proactive approach for participants who were later recruited through word-of-mouth. As these

participants were not known to my gatekeeping organisations, the needs of both the participant and my own personal safety needs were deemed to be best met for face-to-face interviews by suggesting a local cancer organisation already known to participants. Clearly this removed some participant choice and is arguably counter to my intention to foster a more equal and participatory relationship. However, my impression was that this was an acceptable option and did not stifle participants' ability to express themselves.

iv) Participant safety and wellbeing

Due to the sensitive nature of the topic under discussion, I recognised that participants may become distressed during their interview. Ensuring participant well-being was achieved by acknowledging any emotional distress and checking whether participants wanted to continue with the interview. It is acknowledged that using visual methods to explore sensitive subjects may cause harm to participants by evoking unpleasant feelings (Guillemin and Drew 2010) and an unanticipated emotional response.

Papaloukas et al. (2017) noted how in creating an image, the stark reality of participants' difficult circumstances may be captured, and this can diminish their ability to cope. Although it could be argued that the personal and specific nature of any images that participants produced for the study would be likely to elicit more powerful emotions than images from other sources, this is not necessarily the case: existing images could trigger an equally strong response. I will demonstrate in the findings how this was borne out in my study in relation to a participant for whom a photograph I provided appeared to accurately capture her painful feelings.

In the present study, the potential for distress was mitigated to some extent as the areas discussed during the interview were steered by participants. Nevertheless, I did ask unplanned supplementary questions to clarify or expand upon issues raised by participants and recognise that this would have had the potential to prompt an emotional response. Similarly, Dickson-Swift et al. (2007) noted that generating a trusting and open relationship can have the effect of encouraging participants to open up and divulge information that afterwards they regret. It is hoped that the involvement of participants in the analysis has mitigated against some feelings of

exposure as participants could comment upon and therefore influence the analysis emerging from their own interview transcript.

v) *Benefits to participants*

I anticipated that women who took part in the study would find it potentially rewarding and beneficial to have an uninterrupted opportunity to talk about their experiences to someone who was listening carefully. Indeed, a sense of feeling listened to is reported in the literature (Guillemin and Drew 2010). It is also possible that the opportunity to share feelings associated with difficult experiences - with or without images - was perceived as valuable by participants, rather than harmful. It may have been the first opportunity for some women to express their thoughts and emotions about the topic. Furthermore, participants could perceive it as valuable to give voice to their story if the findings from the research may help raise awareness among other women and HCPs, potentially improving the experience for other women in the future (Colbourne and Sque 2005).

Hence efforts to protect participants from sharing difficult experiences need to be considered against the potential benefits and in the context of a piece of research which was designed to empower participants to share their stories on their own terms. At the same time, as the researcher I had a clear obligation to be aware of the possibility of causing distress and so measures were put in place to support participants. These included an explicit plan to enable participants to access support if they required it. In most cases this was negotiated with the clinical staff at the recruiting lymphoedema service and at the local cancer support service where most recruitment and interviews took place. Participants were provided with written contact details of this support and the (then) *Breast Cancer Care* organisation. Details of support from *Breast Cancer Care* were also provided to those participants who were interviewed either in their own home or over the telephone. Participants could either make contact themselves, or if they preferred, I could make contact on their behalf. In addition, I was equipped with details of emergency contact numbers for the NHS if no details of professionals associated with the participant's care were known to me. In fact, to the best of my knowledge no participant availed themselves of specialist support.

vi) Participant involvement in the analysis

All data shared with participants and the wider network was anonymous. Nevertheless, although involving participants in the analysis of study data is assumed to be an empowering experience, there are ethical implications associated with the process. Forbat and Henderson (2005) reflected upon the sharing of interview transcripts with participants and the experience of seeing their narrative written down. Issues included the veracity of the written record of the original interview and participants' "experience of viewing a typed, solidified version of their constructions at a later time and in a different context" (Forbat and Henderson 2005, p. 1118). Indeed, the notion of 'freezing' participants' narratives in the transcript could be construed as antagonistic to the view of the multiple and changing nature of people's accounts, according to social constructionist beliefs. This issue is addressed in stage 3 of TSF during which participants are provided with an opportunity to review and offer feedback on the proposed themes. In using TSF, therefore, an opportunity emerged for each participant to confirm or challenge their transcript according to their perspective at a later moment in time. I report on participants' reactions in Chapter 8 during discussion of the findings.

In the process of obtaining participant feedback in this study, it occurred to me that I had not prepared participants for the potential impact of receiving their proposed themes alongside the transcript from their interview. From my knowledge of each participant and their responses, I identified a small number of women who may have been distressed by the activity. However, on returning to them and enquiring about this, none of these participants admitted to being distressed. Nevertheless, it became evident that I had not addressed the possibility that participants could be harmed by reading their transcripts or themes, with one participant suggesting that in future it could be useful to prepare participants for the potential impact of reading the transcript. Similarly in a phone conversation with another participant, she shared that she had felt uneasy about revisiting her interview (by reading the transcript) since the interview had been beneficial in enabling her to close the door on her experiences and

she was afraid that the feedback exercise could potentially undo this good work. We found a compromise by my reading to her a summary of her proposed themes, to which she provided a verbal response. This seemed to have the effect of providing some distance which could not have been achieved if she had been required to read the documents and provide written feedback herself.

vii) Researcher safety and wellbeing

For those participants who were recruited through organisations via a gatekeeper and were therefore already known, it was deemed that there would be minimal risk to researcher safety. However, visiting participants at home carried a degree of unknown risk for me as the researcher; hence a strategy was implemented to minimise this. The strategy was based upon local and national guidance for lone working and included ensuring that I carried a charged mobile phone. In addition, for each interview with safety concerns a university colleague was provided with the interviewee's name and the location of the interview contained in an e-mail attachment. This attachment remained unopened, and the e-mail was later deleted once I confirmed that the interview had been safely completed. Some women who were recruited directly via a social media invitation lived some considerable distance away and so video or telephone interviews were offered, which automatically minimised any risk to me as the researcher. Balancing participant choice and researcher safety, for the remaining participants recruited via word-of-mouth a cancer organisation known to them was suggested as a location for their interview. My sense was that this was an acceptable location where participants felt comfortable.

In terms of the interview content, I was able to debrief with a university colleague if I found any of it upsetting.

Dissemination and storage

Participants will be offered a written summary of the study findings. As described earlier, it is anticipated that study outputs could include exhibitions, presentations, academic journal articles, and teaching materials. The written consent process relating

to the dissemination of any images for which participants hold the copyright was also previously described. However, permission was not sought by me as the researcher to use any pre-published images selected by participants for their interviews, such as images of published leaflets or photographs from magazines, in recognition that they are copyrighted materials; a written description is provided instead.

To date, *Breast Cancer Now* has been provided with a report of the draft findings (which is not for distribution at this stage). This organisation is well placed to ensure that the findings reach targeted audiences, including breast cancer patients and HCPs, and has offered its support to do this once the findings are finalised. The *Lymphoedema Support Network* charity, lymphoedema clinics and cancer support centres will also be invited to be informed about the study findings, such as via poster and/or oral presentations, in which participants will be invited to be involved. In view of the pandemic at the time of writing, however, it is likely that some of these outputs will be delivered online in the first instance. Articles will also be submitted for publication in peer-reviewed journals such as the *Journal of Psychosocial Oncology*.

This thesis and any subsequent publications arising from the research will be deposited in Sheffield Hallam University's open access research archive (SHURA). It is also intended that on completion of the study, underpinning research data will be registered in the Sheffield Hallam University Research Data Archive (SHURDA), in line with the University's guidelines. This way, the data may be called upon for verification or for future research. In relation to storing the anonymised interview transcripts in the archive, a team check will be made to establish whether any details would be likely to reveal the identity of any participant and if so, the transcripts will be redacted. The transcripts will also contain written descriptions of the images used; the images themselves will not be included in the archive. Data will be stored in SHURDA for a minimum of ten years. Guidance was sought from the Intellectual Property team at Sheffield Hallam University regarding the copyright of participant images within the thesis (see Appendix 27).

Finally, since participants may choose to be involved in dissemination activities after the end of the study, participants' personal details will be kept securely for up to 12 months after the end of the study on the University's secure drive.

Reflections upon the data collection and analysis process

Participant responses to the option of using photographs

Reflecting the speculation of members of the advisory group that not all participants would be interested in using photographs, one of the two participants in the pilot study declined to use photographs at all. There were 10 participants in the main study who used images during their interview. Those participants who opted not to use photographs were simply invited at the beginning of their interview to tell me about their experiences of BTL.

The sources of photographs used in the study included personal (family) photographs, photographs produced by participants for their interview, images from the set of photographs provided by me, and images from the internet or magazines selected by participants. One participant chose to create some drawings. Some interviews drew upon a combination of these sources. Those participants who created images specifically for the study tended to use their own devices such as smartphones or tablets; the time of the interview was usually the first time that I had seen the images, although on occasion participants had e-mailed them to me in advance. Tilly had not selected any images prior to her interview with me; however, during her interview she invited me to take some photographs of some options for bras available to manage her breast lymphoedema.

Sharon chose to use a disposable camera which was an option to participants. She was provided with one of two sets of prints made from the photographs that she took (one set for each of us) to use during her interview and to keep afterwards. Besides a cursory glance to ensure that the photographs had developed properly, the interview was the first time that I too had seen the photographs, to prevent a power imbalance in my favour.

There was one exception to the use of photographs as images. As Samantha was concerned that images sourced from the internet could have copyright restrictions,

she chose to go beyond the proposed remit of the task and produced some drawings. These also appeared to give her the freedom to convey more precisely what she wanted to articulate. During her interview she used her drawings alongside some pre-existing photographs.

In the telling of their story, participants using images led the interview either with their verbal account or with their images, at times doing this inter-changeably. I too varied my introduction to the interviews, sometimes specifically inviting participants to talk about their photographs and at other times simply asking them to tell me about their experiences of BTL and later prompting them to discuss their photographs if they had not already done so independently.

Participant responses to the format for obtaining feedback on the proposed themes

After phase one of the analysis, participants were provided, via e-mail, with their interview transcript alongside the *initial findings*: that is, the proposed themes, each with an accompanying explanation, from their individual interview. While this was unsolicited information and not a feature of the analysis itself, some participants provided feedback on their transcript as well as on the themes. This feedback included comments about how much they seemed to have talked or shared their feelings during their interview. A sense of the transcript representing a moment in time was reflected in the comments from Leah who suggested that “even though it was our conversation I felt I was reading it about someone else.” At other times, participants reflected further on their lymphoedema or more widely upon lymphoedema management in the UK.

An example of the documents provided to participants containing their individual themes, together with the feedback received, is provided in Appendix 21; together they constitute the *silences dialogue*. Overall, participant feedback took the form of additions or corrections to their story as it was reflected in the description supporting each theme. No participant refuted the proposed themes, although one participant admitted that she did not recognise herself in them; this appeared to be at least in part due to the time that had elapsed since her interview.

Appendix 22 shows the diagrammatic relationship between the overall themes and the individual themes that informed them. A document containing the *draft 1 findings* – the proposed overall themes - which was shared with the wider network can be found at Appendix 23. To recap, the wider network included: specialists from one lymphoedema service; the Lymphoedema Support Network; and members of the study advisory group. Appendix 23 also contains the feedback from the wider network - the *collective voices* - which was collected in the form of e-mail responses or notes taken from recordings of video meetings. Although members of the wider network raised some additional issues and offered perspectives on some different experiences, all the themes were recognisable to the wider network and remained unchanged.

The overall themes were presented to participants to ensure that their voices were heard last and hence above all others. That is, the *draft 2 findings* - the proposed final themes informed by both the *silences dialogue* and the *collective voices* – were presented to participants for their final feedback and are presented in Appendix 24, alongside the feedback received from them. Once again, some additional reflections were offered but no comments were made that ran contrary to the proposed themes, even though – unsurprisingly - not every theme resonated for every participant.

Feedback from participants and the wider network is represented in red in the description of the themes provided later in this chapter. Some feedback has also been used to inform the implications for practice presented in the next chapter.

Researcher relationship with participants

The importance of researcher positionality in TSF, and in the VCRM of analysis chosen for the study, leads me to describe my relationship with participants. Perhaps unsurprisingly, I gained different levels of rapport with individual participants. There were several potential reasons for this. One influence was the degree of participant involvement in the interview process; it became apparent that those participants who embraced the photographic aspect of the study most enthusiastically were among the most engaged. It is for the reader to judge the extent to which this may have influenced the analysis: Appendix 28 offers some evidence of my attempt to remain transparent in my thinking during the analysis, offered at step 1 of the LG. However,

below I present some reflective extracts derived from my research diary to demonstrate my reactions and potential biases:

I'm not certain whether it's due to the number of previous e-mails and phone calls we have had together, or whether because I sense that she has made such an effort to produce photographs for her interview, but I noted that I was looking forward to interviewing her and told her so when I arrived. I felt that we had a good rapport. (participant: Sharon)

Leah's photos, received today, are wonderful, they moved me to tears ... They manage to capture aspects that I have already heard from other women, combined with creativity and artistic flair. Already she is preparing for my exhibition as she has some high-resolution copies available.

Meanwhile, my early focus upon photographs as a medium to use during the interviews led to a challenging situation prior to the first pilot interview:

My diary entry for this interview indicates surprise at how positive the experience was. I had described an earlier phone call with Lisa as 'challenging'. It was over a year earlier since her friend signposted me to her and I had since lived with the fantasy that she would be eager to share her experiences. So the fact that she had reacted so negatively to my suggested use of photographs within the interview had been hard to bear.

In fact, I described Lisa at the interview as very warm and willing to share information with me.

In one instance, I already had a relationship with the participant and her response to the participant tasks resulted in a rich, in-depth interview:

I already had a previous academic and professional relationship with Samantha ... More recently, Samantha and I had become friends. Hence this was an unusual research relationship: in relation to confidentiality, for instance, my personal mobile phone already held Samantha's contact details.

In fact, the interview did not feel awkward. This may have been because Samantha presents as confident and assertive. After the interview, Samantha

did ask me whether the research encounter had felt strange in view of the discussion around breasts. It seemed that it had not felt awkward for her; and I acknowledged that I had become accustomed to hearing participants talk openly about their breasts, so that it did not feel awkward for me either.

I was excited by the fact that Samantha had the confidence to go outside the strict remit of the study 'task' and opted to create some drawings rather than using just photographs. It became evident that this enabled her to tell her story about her breast lymphoedema, not just because of her reported concern that images sourced on the internet may have copyright restrictions, but that she could create just what she wanted to show.

My most limited rapport was gained with Helen which is perhaps evidenced by the short interview length (just over 19 minutes) and this diary extract:

Initially Helen struck me as potentially vulnerable as she had come to the venue for the interview with some family members who stayed and waited for her while her interview took place. Soon after we had sat down together, she returned to me the envelope I had sent her containing the researcher-found set of photographs, since she had concluded that they were not helpful for her interview. As this was the first participant who had elected to use no photographs at all during her interview, I am conscious that I felt that this closed some potential avenues for expression and researcher-participant discussion. I think that this hinted at the limited rapport I managed to gain with Helen. Furthermore ... as her family were waiting for her it felt as though the conditions were set for a fairly perfunctory and time-limited interview. As a consequence, I notice that I take opportunities during the interview to assert any knowledge I have of the topic of breast lymphoedema, in an attempt to validate my reason for being there and to give her some confidence in me.

Chapter summary

In this chapter I reported on the execution of the data collection and analysis methods. I restated the research question before describing the outcome of the pilot study. Details of recruitment and patient demographics were then provided. I explained the timeframe, location and length of interviews and the process for conducting them, including details of the use of photographs for participants choosing this option. Next, I described the preparation of the transcripts for analysis and how I employed the steps of the Listening Guide (LG) in the development of the findings as the first phase of the analytical cycle of TSF. I went on to show how the subsequent phases were implemented, and how I adapted the cycle to allow for a further phase of both participant feedback and researcher reflection. I also provided an example of how I undertook the analysis to arrive at an overall theme. Methods used to enhance the credibility and trustworthiness of the findings were reported, as well as data confidentiality, ethical considerations, and dissemination and storage issues. This was followed by a reflection on the data collection and analysis process including participant engagement in research tasks (using images and providing feedback on the analysis) and my relationship with participants.

The next chapter (Chapter 7) reports on the second part of stage 3 of TSF: *voicing silences* by presenting the study findings in the form of themes.

Chapter 7

Findings

[TSF Stage 3 - Voicing silences, continued]

Chapter outline

The findings from this study are presented in this chapter in the form of themes, each accompanied by an explanation, images used by participants, and supporting quotations. There were two key themes: *mysterious breast or trunk lymphoedema* and *you meet a wall*. These key themes provide the context for the additional themes of *the silent consequences* and *adapting to breast or trunk lymphoedema*.

Introduction

In Chapter 5 I set out aspects of my personal and professional background to indicate the influences that motivated me to undertake this research at this time. The process also enabled me to consider the ways in which I might contribute to the silences surrounding women's experiences of developing and living with BTL, either in the design of the study or during data collection and analysis. I declared myself as having outsider status as I have not had breast cancer myself or worked clinically delivering breast cancer treatment. In the process of data collection, I recognise that this could have resulted in my inattention to cues from participants, such that through my inexperience I failed to explore some avenues in the stories told to me. Similarly, my lack of first-hand experience of BTL could have inhibited some participants from sharing aspects of their own experiences. I acknowledge, however, that some of my personal losses may have resonated with study participants, if our conversations led me to share this detail with them; and my status as a more mature PhD student places me in a similar age group to women who experience breast cancer. I also considered the power relations between myself and participants and argued that my position as

an outsider in relation to experiences of BTL placed participants as experts and able to assert power within the researcher-researched relationship.

Further silences were identified beyond the immediate research setting. In working with silences at stage 1 of TSF, a literature review of the research topic demonstrated that women's experiences of BTL are absent from the academic landscape. Meanwhile in the wider cultural context, the female breast is strongly associated with sexuality and with motherhood as well as femininity (Ehlers and Krupar 2012). It is influenced by perceived social norms in terms of shape and appearance and the conditions for public display: that is, within Western culture it is viewed as an intimate body part and is generally hidden by clothing in everyday life. This representation of breasts in Western society as private and intimate has the potential to inhibit women from talking about their experiences of BTL, fostering the silence surrounding their experiences. Against this backdrop, the body's inextricable link to personal identity helps to explain the myriad of negative emotions which women can experience following changes to their breasts from treatment for breast cancer (Kang et al. 2018).

This study was also driven by the expectation that there were silences located within the previously unheard experiences of the women who were interviewed. Both anecdotal evidence and comments on the patient forums of breast cancer patient support organisations reveal women's sadness and disappointment at the lack of receptiveness and support from HCPs for women's BTL. The biomedical model largely operating within healthcare contexts suggests that lymphoedema in the breast or trunk or can be assumed to be blanketed in the same layer of dismissiveness by some HCPs that is often accorded to arm lymphoedema (Maree and Beckmann 2016; Greenslade and House 2006; Ridner, Bonner et al. 2012). This response has the potential to silence any alternative responses from women other than one of gratitude for surviving cancer.

Themes

The key themes, themes, and sub-themes are presented in Table 4. *Mysterious breast or trunk lymphoedema* and *you meet a wall* are the key overarching themes which

provide the conditions for the themes *the silent consequences* and *adapting to breast or trunk lymphoedema*. Appendix 22 provides a diagrammatic representation of the themes and their relative importance, reflected in their position and size, with the two key themes located at the top of the network. The network also shows the association between the themes and the individual participant themes which support them.

The themes have a chronological element, beginning with women's experiences during the period when they develop symptoms, represented by the theme *mysterious breast or trunk lymphoedema*. The response of HCPs is captured in the theme *you meet a wall*. The third theme, *the silent consequences*, describes the physical, psychological, and social impact upon women of developing and living with BTL. Finally, *adapting to breast or trunk lymphoedema* describes how women gradually develop expertise and an ability to accommodate their lymphoedema both practically and psychologically.

Key theme: *Mysterious breast or trunk lymphoedema*

"it was a surprise, and it was the unknown ..." (Sandra, breast lymphoedema)

"I mean I hadn't heard of it you see ..." (Charlotte, trunk lymphoedema)

"when the breast care cancer nurse had rung up to tell me about lymphoedema, it was about looking after my arm ... There was no mention of it being something that could be in your chest – no." (Sarah, chest wall lymphoedema)

Many women spoke about their bafflement, unease, anxiety, or discomfort at developing breast or trunk symptoms. Their experiences were made worse if there was a delay in getting an accurate diagnosis. In general, participants could not recall being told about BTL as a possible side effect of their treatment for breast cancer. Furthermore, if lymphoedema was mentioned in patient leaflets, it was with reference

Table 4: Overarching themes and sub-themes

Key theme:	Mysterious breast or trunk lymphoedema
Key theme:	You meet a wall
Theme:	The silent consequences Sub-theme: The final straw
Theme:	Adapting to breast or trunk lymphoedema Sub-theme: The right bra Sub-theme: Renegotiating identity Sub-theme: Gaining expertise

to the arm rather than the breast or trunk; while ‘breast changes’ were acknowledged but not in relation to lymphoedema. In fact, the tone of the leaflets may be one of downplaying potential side-effects; or else lymphoedema information adopted the perspective of prevention rather than diagnosis and management. Accessibility was also an issue for some participants, Jackie noting that the Macmillan service containing patient information was “down the other end of the hospital ...”

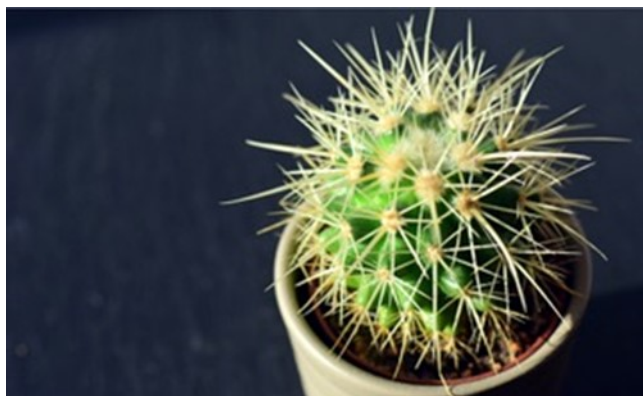
Physical symptoms

Symptoms of BTL developed soon after treatment for some women. For instance, Samantha developed some chest tightness after her surgery; while Sharon and Alice

recall already having breast lymphoedema symptoms during their radiotherapy. However, other participants experienced a delay before noticing symptoms, such as Charlotte who developed trunk lymphoedema approximately one year after her treatment: “I suddenly realised I couldn't get my bra to fasten.”

Participants described limited chest and shoulder movement and enduring breast symptoms such as sharp pains, ‘jabbing’ pains, redness, hardness, heaviness, heat, prickliness, soreness, and severe swelling for many months or more (see Images 1 and 2). Zoe commented that “my breast was feeling very hard and lumpy ... it just felt like there were stones in it” and “I felt like there was an insect crawling under my skin”; whereas for Leah “it was solid, absolutely solid down this side here. The inner breast, the inner area of the breast, it was solid ...” Sandra reported that her breast swelling fluctuated, leading her to take photographs as evidence for her clinical team to demonstrate how it appeared when the swelling was at its worst. For Sarah, chest wall lymphoedema was reported to feel “really, really tight ... it was uncomfortable ... It didn't hurt but it was very uncomfortable”; “I did have this awful, when I coughed, this awful pain in my side, which I think ... I didn't realise at the time but with hindsight

Image 1: The pain ... the prickly ... (Sharon)



Source: Pixabay

probably was the lymphoedema making it uncomfortable” (Sarah). Similarly, Lisa also described her chest wall lymphoedema as uncomfortable, attributing this to her bra tightening as the swelling grew: “and that can be quite painful you know if you try to imagine yourself wearing a bra that was actually two chest sizes too small it would cut in ...”

Image 2: Hard as marble

*"This is how my breast felt, it
felt like it was all hard inside."*
(Zoe)



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However, Leah described her symptoms thus:

*Stabbing pains, yes. They came in from this side here for some reason from the
outer area of the breast, not far from my armpit and then a weird feeling in my
nipples as well and then all this solid stuff which was on the inner area. Bizarre.*

These sensations had an impact during the night:

*it used to wake me up in the night ... It'd like, I'd go to bed quite comfortable
and everything would be okay and then there'd be – the jabbing pains I can only
describe as like an electric shock, like a zzzz, that kind of oh! –*

Moreover, the pain and discomfort of breast lymphoedema had been a potential driving hazard for both Tilly and Leah: "it started and I had to pull in ... rub it a bit to try and distract myself from the pain really ..." (Leah).

Jackie created the photograph in Image 3 to accompany her explanation of how her breast looked – in relation to its orange peel appearance - and felt. Other women also

described discomfort rather than pain, alongside a feeling of uncertainty: “is it going to keep getting bigger or what's going to happen with it?” (Joanna).

Image 3: Orange boob

“I could only explain it to them as if I desperately needed to feed a baby... I mean they literally were different sizes, and it was massive, it was hard.”
(Jackie)



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Emotional responses

Because of these bodily changes alongside feelings of pain and discomfort, Leah admitted that “it was getting me down a bit ...” (Image 4).

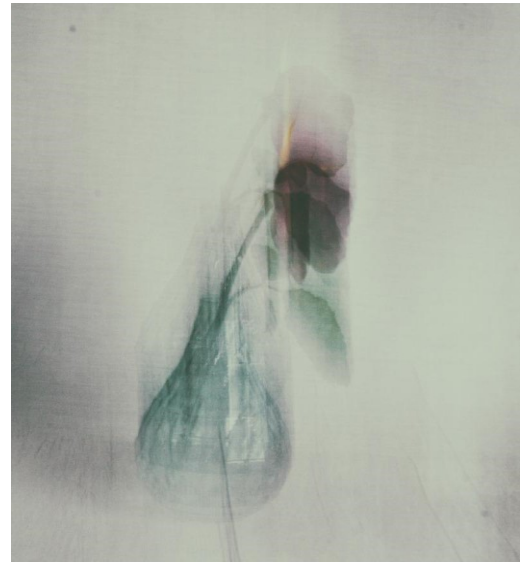
Several women speculated that their symptoms were a sign of cancer recurrence; Sharon reported that “I said something doesn’t feel right and of course you immediately think that it’s something that’s come back ...” and “I was on the internet daily looking at what was wrong and I thought I’d got Inflammatory Breast Disease”.

Sandra’s experience was very similar:

I Googled ‘red, sore, heavy breast’ and came up with this horrible thing that (it) sounded like Inflammatory Breast Cancer ... I was very, very worried that I’d got it again, really desperately worried ... And that was the scary bit, that’s the bit that, I mean I did I broke down ... thinking that this is what I’ve got.

Image 4: Some days I feel this droopy

*"it's blurry, it's droopy, there's no definition and sometimes there's no definition to how I feel ... and it did sort of harp back to when this was at its worst."
(Leah)*



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Helen was eager to know what her symptoms were: "when I noticed ... I got in touch with them straight away because I thought, 'has it come back or is there something else?', which is worrying, isn't it?"

At times women had difficulty acknowledging their symptoms. Joanna admitted that "I suppose it was partly as well not wanting to accept what was going on ..." when she allowed her arm to be measured for lymphoedema even though she had lymphoedema in her breast. Although a teacher and accustomed to asserting herself, at the time she felt so disempowered that she said nothing. While she wondered whether there had been "a miscommunication" with the clinic in the first instance about her type of lymphoedema, she noted that "when I was ill, I became very, very passive and I sort of couldn't make any decisions ... what I should have done is said oh no it's nothing to do with my arm it's my breast ..." Similarly for Sarah, her situation was compounded by her own inability to face looking at her mastectomy scar which was affected by lymphoedema: "I was doing my head in the sand trick of not looking at it"; and she acknowledged that:

when I actually sort of had a proper look at it I thought, hmm, I should have perhaps spotted that a bit sooner ... I knew it felt uncomfortable and I knew it

was probably slightly swollen ... But it was more swollen than slightly swollen and it clearly wasn't normal.

This attitude was echoed by Jackie who acknowledged that "... I can understand because I don't think I wanted to know," suggesting that some women may choose to remain silent about their symptoms as a form of self-protection.

Understanding of symptoms among healthcare professionals

There was evidence that some HCPs were not knowledgeable about the symptoms of BTL: "... I remember, like I said, seeing that doctor in that room and he just didn't cotton on at all what it was, but it was starting to pit, like orange peel" (Sharon). In some instances, professionals shared participants' concerns that their symptoms may be a recurrence of cancer. Joanna's GP was reported to have been "quite alarmed" at the orange peel effect on the skin of her breast, thinking that it was a sign of cancer recurrence and referring her back to the hospital. Meanwhile, Samantha's story indicates an element of chance in whether patients' breast lymphoedema will be detected by knowledgeable healthcare staff. When she was referred for a mammogram to investigate her breast which had become 'really lumpy around the scar area' - at this stage, lymphoedema was 'never mentioned' - it transpired that the doctor immediately recognised her condition, without any examination or history-taking.

The lack of awareness of BTL among some HCPs simply worsened some women's distress. There were many examples of the anxiety experienced by participants while they remained uncertain about their symptoms. Even sympathetic clinicians could not alleviate participants' concerns in the face of their lack of knowledge about BTL: "I had the same oncologist that I'd had seven years previously, he was ever so good and the surgeon but they just didn't know, you know, what it was" (Sandra).

For some, the period of anxiety was prolonged because they did not have access to a prompt assessment. In addition, a misdiagnosis could result in inappropriate treatment and lengthy delays in an accurate diagnosis. For example, Sandra

‘eventually’ had a biopsy to rule out cancer, even though her surgeon had been reluctant as she had already undergone repeated surgery to her breast. A negative result led to speculation that it was cellulitis, for which she “had lots and lots of antibiotics, penicillin ... which ... didn’t make any difference ... it was just this very hot, red breast.”

The sense of mystery around BTL even after diagnosis was compounded for some women by HCPs’ inability to offer clearer information: “... I said to the nurse, I said, ‘is it something I’ve done or not done?’, she says, ‘no, we don’t know why some people get it, why some people don’t’ ...” (Helen). Sandra similarly described the uncertainty surrounding the causes of her breast lymphoedema among clinicians:

Well eventually they sent me to this lymphoedema therapist. So obviously, they knew it was an ‘oedema’ of some sort ... They just called it ‘oedema’ ... I mean they were all ever so good but they weren’t sure whether it had come from ... the radiotherapy or what.

Compounding her unwillingness to acknowledge her symptoms, for Sarah a lack of physical examination following her mastectomy gave health professionals no opportunity to establish that she had developed chest wall lymphoedema: “before I realised it was in my arm, and it obviously was in my chest, I hadn’t actually been examined by anybody at that point, so nobody could actually look at me and say you’ve got lymphoedema ...”

Nevertheless, this was not everyone’s experience and on occasion breast lymphoedema was correctly diagnosed immediately, such as for Helen who was diagnosed at her hospital follow-up appointment six weeks after her radiotherapy ended; and Alice whose surgeon referred her “straight away” to the lymphoedema clinic when he saw her after the completion of her radiotherapy.

Seeking an explanation for symptoms

Once diagnosed, some women speculated on the possible triggers of their BTL, recognising that it is a condition which is still not well understood. For example, Jackie noted: “I think now, well if I had that much fluid straight after surgery, was that the point at which it all started or was I more liable to get lymphoedema at that point ...?” Likewise, Sandra reflected: “whether it had started with an infection or inflammation from the inside ...” and Joanna believed that radiotherapy and lifting small weights may have been responsible for the development of her breast lymphoedema. It was not until her breast lymphoedema was finally diagnosed and Samantha began treatment that her limited range of movement in her shoulder area began to disappear: “that was a real moment of, like, oh my god, this is so different now I'm treating it.”

Sadly, sometimes participants were led to believe by HCPs that they were to blame for developing BTL. Lisa, who initially developed lymphoedema in her arm and later in her chest wall, reported being told that it was her own fault as she must not have followed the prescribed exercises properly. The following quotation includes her resistance to this charge:

it's quite a strong blame feeling that you know you did something wrong to get it. And I think this is because some people get it and some people don't so if you get it it's obviously your fault ... you think hey, you know, come on, some people develop it and some people don't.

She impressed the importance of women being reassured that “it's nothing to do with you ... I think that probably would be my biggest thing that ... health professionals need to get over that people who develop it, it's their own fault. Because I don't think it is.”

Feedback from the Lymphoedema Support Network supported this experience, with patients reporting a sense that they may have caused their lymphoedema to develop by not complying with advice, for example. The notion of blame will be returned to in the next theme, *you meet a wall*.

Theme summary

Participants encountered a range of physical symptoms including discomfort and pain, often leading to feelings of anxiety and uncertainty and a fear that their cancer had recurred. Some women had difficulty acknowledging their symptoms of BTL and the situation was made worse by the limited opportunities for a physical examination which would have identified symptoms. Women's feelings were often compounded by a dismissive response from HCPs. Although on occasion participants had received a swift and accurate diagnosis, the majority had not. Moreover, many HCPs seemed to lack awareness of BTL, sometimes misdiagnosing the symptoms, and inappropriately providing treatment for cellulitis. Their misunderstanding sometimes extended to blaming patients for developing lymphoedema, with negative consequences for women who were already feeling vulnerable following treatment for breast cancer.

Key theme: You meet a wall

The title for this theme was selected to capture the attitude of some HCPs towards women presenting with symptoms of BTL in terms of the indifference and dismissive attitude experienced by many participants. In fact, the phrase is an extract from a quotation about a particular aspect of lymphoedema care: that is, it is specifically about the unwillingness of the health service to consider possible treatments for lymphoedema: "you meet a wall of you've got lymphoedema you've got to live with it ... "(Lisa). Her comment "it's sort of a bit cloaked you know, and we hope people don't get it and if they do ... put you into a little corner somewhere ..." reinforces a sense of silence around the topic. This was reflected by Samantha's comment: "... it's like they don't know about lymphoedema, breast lymphoedema, but they do. It's there, isn't it? It's known about." Speaking about a course for younger women who have had breast cancer, Alice commented that it involved "a whole day on lymphoedema and people coming in and talk about the arm the whole time and no-one talked about breasts ..."

Some women felt that once their treatment for breast cancer had ended there were limited or no opportunities to discuss these unfamiliar symptoms with anyone from the healthcare team. The perception of a barrier was also reflected in the feeling of

having “fallen off a cliff” (Jackie) which was echoed by feedback from a member of the advisory group who reported being unable to access advice from her specialist beyond a year after her treatment, and another who commented on feeling forgotten once she was given the all-clear from cancer. Joanna remarked that “... suddenly you're like oh I've got something, and I don't know who can I talk to about it.” Meanwhile, Samantha suggested a sense of effort in trying – and failing - to get HCPs to listen to her concerns about her symptoms, leading her to conclude that she would not be helped:

... the doctors not listening and not acknowledging. That just made, I guess, all my appointments stressful because I'd come out of them, I'd been preparing for them thinking, well, how can I really try and get them to listen to this? ... just to get knocked back every time ... right, well, I've got to figure out for myself what this is.

For other women, the scene was set for them in the healthcare setting to remain quiet about lymphoedema by staff reducing its significance: “I think they play it down, they say oh well it's very, very rare ... she said oh we don't get many cases of lymphoedema” (Zoe). Thus, her efforts to get her lymphoedema recognised appear to have been dismissed: “I had this hardness but every time I spoke to anybody, they said it would be the radiotherapy.”

Not on the checklist

“... three times where it got sort of missed or held up ...” (Joanna)

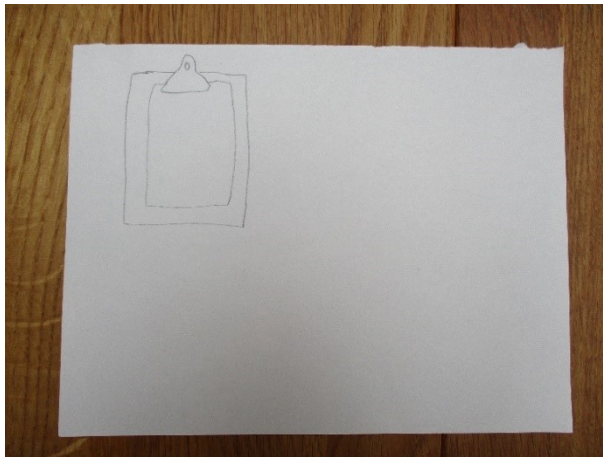
Sadly, even if they were seen by HCPs, having their concerns ignored, dismissed, or misdiagnosed was a common experience among participants. One participant commented that she was made to feel “like I was making it up and it's all psychological” (Samantha); while another spoke of her concerns being “brushed aside” (Sharon). This was reflected by an advisory group member in her feedback, who had felt that she was “imagining things” at the point when her symptoms did not appear to be understood by anyone. Patients not being believed was also reported by the

Lymphoedema Support Network as a familiar experience. For Samantha, her breast lymphoedema was “missed by so many health professionals” including four doctors, her breast cancer nurse, specialist nurses and the therapeutic radiographers treating her during her radiotherapy: “I had lymphoedema at that point and my breasts were being seen every day by all these health professionals ... and nobody even mentioned lymphoedema.” Her personal explanation of why this occurs is captured in her drawing of a clipboard (Image 5), signifying that breast lymphoedema was simply “not there on the checklist”. That is, each HCP had a specific focus and remit which led them to ignore or not notice anything outside of this: “everyone is so focused on their little bit ...” For example, she had repeatedly told her radiotherapy consultant that her breast had changed, yet she was told that this was ‘normal’. As a health professional herself, she understood the context in which others were working and stressed that she was not seeking to blame anyone; in fact, she appeared to accept some of the responsibility when she admitted that she herself had missed it. Meanwhile other participants also referred to a sense that their healthcare was compartmentalised, with specific staff and departments only dealing with one aspect of their care. For example, Catherine’s experience was silenced because the breast care doctors at follow-up appeared unable to recognise her breast lymphoedema; rather they “just deal with the lumps and bumps.”

The consequence for women, however, was that “nobody ever sat down and told me the whole picture” (Jackie), which was also reflected in Joanna’s comments:

I just think with the lymphoedema thing I think they could really mention it at any stage. They could talk about it. They could discuss it with you ... you just assume that everything is just going to go according to plan ... at least if it does happen you feel like you sort of knew a little bit more ...

Image 5: Clipboard



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“... the clipboard to me represents the fact that I'm not a person in the eyes of so many of the professionals, I'm just a problem and a problem to be fixed medically and anything else that gets in the way of that - me having a personality, me wanting to ... - it gets in the way.”

(Samantha)

While some women felt unable or unwilling to assimilate information during treatment, there was a sense of there being a point in the pathway at which participants may have had the capacity to take in the information: “now it would have been nice to have had something. You know, like a road map” (Jackie). Meanwhile, in relation to the responsibilities of the healthcare system, Samantha suggested that there should be ‘time and space’ to consider patient need beyond treatment for breast cancer, with her sense of relative powerlessness evident in the following comment:

we're people and, yes, I want them to save my life and I don't care how badly they treat me, on the one hand, if they can save my life. But really, there should be time and space to go beyond that.

This adherence to a specific circle of knowledge and expertise was demonstrated in the response of Samantha's consultant to her diagnosis of breast lymphoedema, reflected in the extract from her I-Poem earlier in this chapter. But she admitted that while “the NHS has done amazing things ... it could still do better” (Samantha). Conversely, Catherine's experience of the staff at the lymphoedema clinic demonstrated the positive impact of good care, making her feel that “because you were given that expertise for that length of time, they were taking you seriously ... which is a big thing ...”

Indeed, a sense of gratitude and an appreciation of the NHS in successfully treating their breast cancer meant that often participants were willing to accept its inadequacies in detecting and treating BTL. An example of the clinical challenges of diagnosing trunk lymphoedema is provided in the story of Charlotte, an older woman with co-morbidities. While her lymphoedema specialist's assessment was that her trunk swelling "seemed to be water rather than fat", this was contrary to her experience with the medical team: "the doctors sort of look at it and say oh you're just too fat." However, she recognised the additional diagnostic challenges of trunk lymphoedema in comparison to arm lymphoedema: "it's easier to diagnose an arm, isn't it? ... When it's sort of twice as big as the other one." Similarly, both the relatively hidden nature of BTL and the potential for a differential diagnosis was felt to play a part in its being ignored: "if you've something like a leg that's swelling, you can see that, and you'll treat it but something like this, it's very easy to say oh you've had surgery, you've had radiotherapy, it's all to do with that." (Zoe).

Likewise, Sarah, who developed lymphoedema around her mastectomy scar, expressed uncertainty about how much to expect of HCPs:

I don't know because I'm not a health professional and I don't know whether the fact that the scar didn't look right would make somebody think, oh, that's more at risk of getting lymphoedema; I don't know if it is.

A silent subject

"It's a hidden problem and both publicly and medically nobody wants to know." (Jackie)

Often there was silence around the topic of breast lymphoedema which appeared to be related to its sensitivity. This was alluded to by some participants, such as Joanna:

I think it's just that it's something that is not talked about ... So somebody's not going to say oh and how big are your breasts at the moment? (laughs) ...

because it's breasts then some people find it a bit, you know like a ... dodgy territory

This attitude had implications for the thoroughness of Joanna's assessments with her GP. For example, she indicated that she was not physically examined as often as she might have wanted, suggesting that "they don't want to ... trouble you ..." because her health concerns related to her breasts. In Tilly's experience, if she had not directly asked her oncologist to look at her breast, she felt as if she would not have received a diagnosis: "Nobody ever asked me how it was feeling".

Patients themselves may be reluctant to raise the subject **and this is supported by the lymphoedema nurse specialists who provided feedback on the findings who observed that as an intimate area of the body, the topic is personal for women to broach with others**. The subject's sensitivity also made it difficult for some participants to talk to friends or family about it: "it's not something that's very easy to talk to people about. I suppose people at the support group, I'd sort of talked to people there ..." (Joanna). Nevertheless, some participants reported that it was now easier to share experiences with others and that the topic of breast cancer itself no longer carried quite the same degree of sensitivity:

nowadays I'm talking to you about (laughs) my breasts and what have you. I mean when I was first diagnosed in 2006 I couldn't even mention it to my mother ... I just told her I was going in for an op on my knee (laughs) (Sandra)

For Joanna, the attitude of staff at her follow-up appointment had a silencing effect: "I felt very rushed, and I don't think I asked one question ..." This effect was compounded by the lack of written information: "even these leaflets that they give you on lymphoedema, it doesn't say much about the breast, it's all the arm, you know" (Helen). Meanwhile an impression of busyness deterred some women from seeking advice about potential side effects in general: "such a busy place and yes, they are all professionals, but the question might not be something you want to bother..." (Jackie). A similar sense of feeling unable to seek reassurance for any emerging symptoms was

exemplified by Catherine who wished to “have a drop-in service just to say yes, that’s fine ...” but admitted “I know we are all busy ...”

These comments appear to be evidence of a power imbalance such that participants seemed compelled to put the perceived needs of HCPs before their own. In fact, remaining silent for the protection of the health service is evident in other stories. For example, the complexities of breaking silence are demonstrated in the following comment from Zoe who had complained about the poor handling of a referral for her lymphoedema. In the following quotation, she explains her response to the GP practice which had said that

we can take it further if you want and I was just so stressed about the whole thing and I said no. So I’ve just kind of left it because, to be honest, GP surgeries are closing aren’t they by the minute and I’d hate to make a huge fuss and it closed down.

This was against a background for Zoe of earlier experiences of silence and resistance from the health service: “I complained about the health service in the past and it’s just caused me a lot of stress and (I) got no answers.” Similarly, she had left a patient group aimed at improving the patient experience as she felt that they avoided true consultation, whereas “I as a patient could have told them quite a lot if they'd wanted to listen ...”

Meanwhile Samantha described her ambivalence about alerting her local hospital trust to her difficult experiences, even though she was well-positioned to do so, for fear of misusing her formal role in patient experience:

... so I can't really do anything with all my- It feels quite awkward. Because on the one place- I'm really well placed to actually have this message go straight to the people who can maybe ... But that feels kind of wrong and awkward.

Using a drawing of a loudspeaker (Image 6), Samantha expressed her desire for HCPs to wake up to the significance of breast lymphoedema:

Image 6: “Just wanting to shout about breast lymphoedema”



“... it’s just that wanting to shout so, okay, so breast lymphoedema is a big thing, it has a massive impact on people’s lives. Do you all know about it? Are you thinking about it? Because I think they’re not. I don’t think they know much about it.”
(Samantha)

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Delays and their consequences

Delays in diagnosis and in accessing lymphoedema services had clear consequences for some participants, including a worsening of their BTL. Jackie reported that the lymphoedema nurses were “horrified” at her breast lymphoedema; while Catherine endured breast symptoms for two years before she was treated. In the knowledge that her breast lymphoedema could worsen without treatment, Samantha took the initiative to ring up the local lymphoedema specialist and was given “a one-minute over-the-phone tutorial” which she found very beneficial. In fact, it was not until she began treatment for her breast lymphoedema that her chest pains, tightness, and stiffness disappeared, and she made the association between these symptoms and her lymphoedema. Nevertheless, this was not Joanna’s experience as she received quite a different response when she rang her local lymphoedema clinic: “I said well the GP suggested that I ask you how to do it over the phone and they just sort of laughed at me ...” **Feeding back on the findings, the lymphoedema nurse specialists noted the significant additional impact of the COVID 19 pandemic upon patients’ ability to obtain a referral to and access the lymphoedema service, with implications for the severity of their lymphoedema at the point of initial treatment. The lack of face-to-face**

consultation at the service had also meant that when patients did get referred, they had been obliged to undertake instructed self-care as the only option available to manage their lymphoedema when normally they would have received treatment from a therapist initially.

The impact of poor understanding and awareness of BTL among healthcare professionals

Frequently participants suggested that there was a need for increased awareness among HCPs. For example, it was not unusual for participants to describe GPs' lack of BTL awareness: "none of my GPs picked up on it at all" (Sharon); "I'd been to see my GP ... and she gave me sort of the wrong advice, what you would do if you hadn't had your lymph taken out" (Joanna). Other GPs appeared pessimistic about the possibility of treatment and failed to inspire confidence: "I can remember him saying, oh well I can refer you, but I don't know what they'll do for you. Typical man, fobbed it off" (Jackie). Although educational courses may be available for GPs, they were not necessarily well attended. Some participants were clearly surprised and disappointed at the lack of knowledge among HCPs, Sharon commenting "the doctors not knowing, I mean how bad is that?" She was also surprised that none of the radiotherapy staff had recognised her breast lymphoedema. Moreover for Sharon, a lack of understanding about BTL had painful consequences when she was given a back massage by a physiotherapist:

... she massaged round this side here and I was in agony because obviously I didn't know what it was, she didn't know what it was, but she said it's knots. It's knots that need to come out, so she was kneading my knots and it wasn't knots it was lymphoedema.

For some, there was a sense of luck that their BTL was picked up at a follow-up mammogram or highlighted on a *Moving Forward* course that is offered by *Breast Cancer Now* to women after their treatment for breast cancer. Samantha's disappointment in the NHS' performance can be seen in the following comment:

They saved my life so, yes, the fact that they've maybe been dismissive of me and missed stuff doesn't matter. But if we're trying to make things better or supposed to be. Western world, you know, first nations, you know, and all that stuff, but you kind of think, hmm.

The emotional consequences of a dismissive attitude were also apparent for Samantha: "I feel it really almost has damaged my relationship with my consultant because I kept saying that this is my priority and she's saying you're anxious ..." and for Charlotte, who also offered a hypothesis for this attitude from staff:

.. telling me it's fat was a bit you know depressing. I didn't really believe them, and you feel a bit helpless, don't you?... even if they don't have a cure for it, at least if they agree what it is you feel a bit happier about it ... I'd been to the breast nurse, and she just dismissed it. I don't think she knew what to do about it ... So she wasn't going to acknowledge it.

An acknowledgement of the condition, however, had potential negative consequences, too, if HCPs deployed misinformation to undermine some women. Lisa described "quite a strong blame feeling" that she had somehow caused her lymphoedema. Patient blame as a form of power over patients was perceived to be considerably disempowering:

I think some people could actually retreat completely ... you're at quite a vulnerable point ... I think for some people it could actually be enough to make them give up ... I think you putting blame onto somebody who's already vulnerable is actually unkind really ... and it's not truthful because you don't actually know. (Lisa)

Patient vulnerability was raised by other women as having a silencing or suppressing effect. Sharon described her relative powerlessness in her relationship with the lymphoedema specialist who had noted her weight gain, which prevented her from

retaliating: "... I felt a bit judged and a bit told off. I ought to have said, you know, what are you saying, do you think I've put weight on then but you feel a bit – you're vulnerable aren't you?"

She also felt judged by the lymphoedema specialists about the type of bra that she was wearing: "because they always look at your bra that you wear, you're never wearing the right bra either ... I'm in the bad books again ..." At the same time, she felt unable to position herself in a place where she was allowed to be vulnerable; as a nurse, Sharon had a sense that others felt that "you should know better because you're a professional" even though she wanted to be treated like everyone else: "I'm a patient this time ... treat me as a patient not as a nurse."

Sharon's powerlessness against a paternalistic healthcare system – and lack of confidence in the healthcare professional delivering the treatment - was shown again during the back massage mentioned earlier, when her lymphoedema was not recognised and her resultant pain was dismissed: "... I said that's really hurting, she goes yes, yes it will hurt, these knots need to come out." Furthermore, her sense of being ignored was compounded when her feedback on the massage (solicited by the cancer centre which provided the service) went unacknowledged.

This relative powerlessness of participants was evident in other narratives. In this noteworthy example, Sandra described her encounter with her GP when she approached her for antibiotics to take on holiday abroad, which is the recommended precaution against infection for people with lymphoedema:

she was most horrible (laughs) ... I was telling her that I needed them, to go on holiday... And she was really, really put out that I was now, you know like diagnosing myself, but I wanted them and I said 'but no, it's in the form' ... so I've got the leaflet and I didn't take it with me so I couldn't show her, you know, what is the recommendation. So she was really horrible. I never went back to her after that... Because she was the most, she was the most (laughs), really, it really made me feel so small, so awful. In the end she gave me them because I

was going on holiday, but it was as if you know I was asking for heroin or something (laughs).

Fortunately, this was not the experience of all women; in fact, **one advisory group member commenting on the findings noted that her GP had accepted her expertise and therefore was willing to prescribe her antibiotics.**

Other examples of the more powerful status of the HCP relative to the patient include this interview exchange with Helen:

Helen: Well, he said... I didn't really question him on it. He just said something about, 'don't be taking these tablets, just take Paracetamol'.

Me: Which tablets?

Helen: I don't know, I didn't ask. I ought to have asked really.

Likewise, Joanna commented that "sometimes when you go to the doctor's you feel like you're making a fuss ... and you're, you know and maybe you've got it wrong ..."

Other women revealed that even though they had been assertive in their encounters with HCPs they had been met with some resistance. For example, for Alice her breast lymphoedema had compounded her issues with her breast shape which was distorted in the first instance by surgery. Her ability to challenge medical authority was demonstrated during negotiations with the surgical team about whether her breast shape could be improved, as she joked that "I've sent it back to the MDT, with a telling off (*laughs*) ..." although she admitted that "... he actually really told me off, he kind of shouted at me ... we did have a bit of a fallout (*laughs*)..."

Both Alice and Samantha commented on the potential for poorer outcomes for patients who were not as assertive as themselves: "... I just kind of think for other people who aren't as assertive as me, yes, they wouldn't have got the diagnosis and things could have got even worse." (Samantha).

Occasionally the silencing of patients by the healthcare system was more explicit. When Zoe formally complained about the delay in her referral to the lymphoedema

service, she finally received a letter “which was called 'final answer', there was no opportunity for me to argue with it ...” Furthermore, inaccurate information was used in defence of the response: “... three times you see it says, ‘as I stated at the outset, this condition would not have been made worse ... you will suffer no adverse effects.’ Conversely, the lymphoedema nurse specialists can be seen to be patient advocates in the face of surgeries “not really taking this seriously”; Zoe described her specialist as “a bit of a warrior for people with lymphoedema ...”

Poor understanding about BTL extended to a lack of awareness among GPs and other HCPs about the development of treatments such as kinesiology taping. Although her comments stem from her experience of arm as well as chest wall lymphoedema, Lisa feared that there was no impetus to develop knowledge and understanding:

nobody does any research very much on lymphoedema and I think probably because there's not going to be a drug at the end of it, so nobody's really bothered about doing it. I suspect there's a great deal more that could be done if people would research what techniques really work.

On some occasions, a lack of understanding was revealed to extend into the workplace. Like other women, Tilly experienced fatigue which she believed may have been linked to her breast lymphoedema. At work, however, there was ‘no communication’ about her need for breaks, resulting in a ‘battle’ to relay the agreement reached with her workplace human resources department to the staff on the shop floor.

Patient awareness of BTL

Patient information and awareness of BTL was also discussed by participants. Frequently participants were unable to recall that lymphoedema had been mentioned during the consent process for treatment. Jackie offered a reason for this: “when I went to the lymphoedema clinic, they said oh, they mentioned lymphoedema on your consent form for surgery and I am thinking they also said I might die, but that never entered my head.” That is, it could be that not absorbing some of the detail –

including being alerted to lymphoedema as a possible side effect of treatment – was a coping mechanism for some participants. Similarly, Sarah admitted during the feedback exercise that the chance of survival had trumped the risk of any potential side effects, such that on revisiting her consent form for surgery she now sees that lymphoedema is listed although she does not recall it. These comments are reflected by feedback from the lymphoedema nurse specialists who acknowledged the difficulty for patients in registering information given to them around the time of their diagnosis of cancer.

Joanna remarked that “you get a lot of leaflets ...which is not quite the same as information really because a lot of it is very dumbed down, I think”, with implications for how information can be effectively conveyed to patients. Jackie suggested that after six months you are mentally and physically prepared to take on further information about adjusting after treatment for breast cancer, reflected in *Breast Cancer Now’s Moving Forward* course, including information about possible side effects. In fact, Sandra alluded to the fact that some women may not get important information such as the precautions against infection on holiday, unless they had heard it from a lymphoedema nurse at one of these sessions. In the absence of support, prior to diagnosis some participants had sought information from the internet. Jackie was able to work out how to manage her lymphoedema through her nurse training; however, YouTube had been an unhelpful source of information – “rubbish”.

There were several examples of silences imposed by participants themselves as a way of coping with the symptoms of BTL, such as this remark from Joanna:

... when you've got so many different things that are going on with your body, you sort of tend to zone in on one thing and then you kind of get that fixed and then you go off and find another thing and unfortunately the lymphoedema was quite low down on the list

Meanwhile, although Sarah noticed that she had developed lymphoedema in her arm she admits that:

if I'd paid attention, it was actually on my chest ...And I think my experience of being able to deal with the mastectomy and the fact that the scar is ugly – it can't be described any other way – is to actually not pay much attention to it.

Lymphoedema services: a different experience

In contrast to the 'wall' frequently encountered by participants in relation to obtaining an accurate diagnosis and referral for BTL, participants frequently complimented the care and support that they received from HCPs, particularly at the lymphoedema clinics. Once they were able to access the service, participants tended to speak very favourably about the expertise and success of the lymphoedema staff in treating them, as the following quotations demonstrate:

they're brilliant, absolutely brilliant and ... I suppose they're doing this all day every day and you never feel like you're a condition, you are you and they're ... really good with you and ... I haven't got high enough praise for them ... (Lisa)

"... since being involved with the lymphoedema nurses ... it's been nothing but positive" (Leah)

"when I eventually went to (name of lymphoedema clinic) and she started doing the massage I could feel the relief straight away..." (Sharon)

"it feels like a great service now I'm in it." (Samantha)

"I felt well supported by this lovely team of people, yes." (Leah)

Likewise, although Alice waited six months for her first appointment at the lymphoedema service she commented: "... that dedication and showing me how to do the whole process and the technique of how to do manual drainage myself was really good and the follow up appointments were really good ..." Reflecting on her referral delay, Joanna commented "... the lymphoedema exercises were fantastic and I just wish that I'd started with them the year before ..."

Overall, it was felt that lymphoedema services did not appear to be accorded high priority and this was reflected in Sandra's belief that they can be "a bit of a battle" to access. Difficulties accessing local lymphoedema services were due variously to misunderstandings about the referral pathway, long waiting lists or the reorganisation of services. While Samantha argued that "... it's not incompetence, is it? ... It's a system issue ...," she felt that HCPs should have knowledge of BTL to facilitate an early diagnosis and timely treatment. But the situation was compounded by limited access to services: "... a four-month wait for a condition that gets worse ... is just wrong." Her joint location as a healthcare professional and as a patient allowed her to develop some strategies for beginning to address the barriers, which she has been proactive in discussing with the lymphoedema clinic:

... get everyone in early and give them something, I would say, and then ... still get the one to one ... It's the bigger picture to me. Get rid of austerity, invest in the NHS and get the NHS listening to people ... and being better at putting changes into practice. So it is the fact that, yes, breast lymphoedema and trunk lymphoedema is more common, in my understanding now. It's more common because of changes to surgery. But the practice around that hasn't changed ... and awareness hasn't changed...

Theme summary

There are many features to the 'wall' encountered by most participants. Some women were able to adopt the perspective of the HCPs and noted that BTL was simply not on their checklist as a side effect which ought to be considered. In addition, some women acknowledged the diagnostic difficulties compared to lymphoedema of the arm. Several participants also accepted that services were busy and resources were stretched, such that at times women seemed to prioritise the needs of the HCPs over their own needs. This sense of a power imbalance was evident in many of the subthemes. For example, some women expressed gratitude that their lives had been saved and consequently were prepared to accept an inferior service when it came to

managing side effects. Their vulnerability was evident in the face of some attitudes which appeared less than compassionate, including apportioning blame to patients for their lymphoedema. There was a complex relationship between a lack of understanding and knowledge among HCPs, and women's preparedness and ability to take in information about side effects or to acknowledge their BTL symptoms. The patient-centred approach of the lymphoedema specialists tended to sit in stark contrast to the dismissive attitude of many HCPs encountered by participants when they had undiagnosed symptoms of BTL.

Theme: The silent consequences

Participants expressed strong feelings and views about their experiences which are shown in the following examples, some of which reflect the lack of knowledge and understanding of others. Samantha admitted that:

my lymphoedema has had a massive impact on my life and always will. You know? It's lifelong—isn't it? - and, you know, now, 40 minutes a day I have to spend massaging. And if they'd caught it earlier, I'm led to believe it would still have a massive impact, but it maybe wouldn't have got as bad.

During the feedback exercise, these sentiments were echoed by Lisa who commented that

the life-long nature of lymphoedema is overwhelming at first as you have just dealt with a life-threatening condition, only to have it followed by a life-long one which is poorly understood and makes a massive difference to the way you can live your post-cancer life.

Samantha reflected that "just being listened to" would improve patient relationships with HCPs. A sense of isolation was also expressed by Tilly: "you do feel as though

you're very much on your own sometimes" and this contrasted with the relief she experienced at the attention she was provided with by a bra-fitting service. Similarly, for Alice, the time spent with her to find a well-fitting bra was significant: "actually having somebody who's ... willing to listen to you and understand what your issues are."

Sharon drew upon a long-standing abhorrence for pipes to describe graphically how she now felt about herself (Image 7).

*"... how I felt about myself ...
what you look like and just yes,
just an ugly, horrible feeling,
you know, that people don't
really realise ... I know it's there
..."*
(Sharon)

Image 7: Ugly, horrible feeling



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Keeping silent

The silence surrounding women's experiences of BTL in the wider context of their lives after treatment for breast cancer is demonstrated in this quotation from Alice:

*... people don't see there being any lasting effects of breast cancer. I think
people see I had a shit year, I'm over it, move on ... one of my other friends ...*

she said it's the end of the story ... So I think people just don't realise and see that there is that issue there.

The circumstances within which women were managing following treatment for breast cancer was summed up by Jackie who indicated the absence of someone to listen:

... it's worse after because you've got nobody, nobody to talk to and say this or that. Very much on your own even though everybody's there going how are you? How are you? ... So you say yes, I'm fine and carry on regardless of whatever's happening under my tee-shirt.

This is an example of the way in which many women chose to remain silent as a way of coping, since they felt unable to try and explain their BTL to others. Charlotte, who has trunk lymphoedema, admitted that:

I haven't really sort of told anybody much about it ... I mean it doesn't show you see because I sort of wear loose clothes anyway ... I mean everybody sees my arm and sympathises ... but a trunk you know, you don't go into it, it's just too involved.

Similarly of breast lymphoedema, Tilly remarked of her friends "... they don't know what it is and I don't feel like going into detail ..." Both Tilly and Jackie framed their approach as a way of coping:

I'm the kind of person that doesn't talk a lot about my own illnesses to people because I've got a few friends that do and they're on and on all night, it's like you've come out to have a laugh not to talk about ... (Tilly)

... you don't want to talk. I got fed of people saying oh, how are you and I got fed up of telling people, so in the end you just say oh, I am fine, you know and carry on. (Jackie)

Some participants demonstrated how they were also selective in the information that they shared with family and friends, for fear of being misunderstood or of being perceived as tiresome or a burden, as these quotations show: "My daughter had got a bit of an idea, you know, but it's not something you talk about because it feels a bit of a – oh God what now? Something else wrong with her now." (Sharon); "I wouldn't say this to anybody else, any of my friends or my family because they'd think well, you're alive Mum, you know ..." (Tilly)

In contrast to other participants, Samantha clearly felt that it was important to share her experiences for the sake of her children: "I don't want to worry them but equally I don't want to not talk about stuff ... because I think that's not good for their mental health ..."

Alice, who at 41 years old was the youngest participant, appeared highly assertive with her medical team, but was much more subdued with her friends in the face of their insensitive behaviour towards her:

... I've got a group of friends who are all going out having breast enlargements and enhancements and things at the moment and I'm like, a little bit of me feels like you're being really insensitive to me ... I see that we live in a consumerist society and you know everyone's keeping up with the Jones's ... putting foreign bodies in your body can't ever be a good thing ... they all know how I feel about it and then they know that I've had the breast cancer ... and then they're all like asking me for advice and stuff.

At times there was a sense of downplaying emotions around developing BTL from some participants. For instance, Catherine made repeated reference to her mother who had reportedly developed lymphoedema in her arm 25 years after surgery for

breast cancer. Although Catherine commented that this was 'a bummer,' potentially making light of the situation, during her interview she displayed some apprehension that her breast lymphoedema may be a precursor to lymphoedema in her arm. In fact, she used her mother's arm lymphoedema as a benchmark against which she measured her own breast lymphoedema in an apparent effort to downplay it: 'it wasn't a major thing because it wasn't like a big you know, deformity like my Mum's hand ...' even though she goes on to describe physical discomfort and anxiety relating to the lymphoedema in her breast. She endured two years with breast lymphoedema before it was diagnosed, yet she reflected upon it in an extremely understated way when she remarked that: "you shouldn't really be upset by it because it (lymphoedema)'s only a little add-on to potentially the treatment, so you know, you have got rid of the cancer, that's the main thing" thereby allowing no space for the impact of any side-effects. As the interview progressed, however, she was able to admit that "lots of people feel oh, well it's only a little bit of lymphoedema, but it's a lot more. It can be a lot more both physically and mentally ..."

Her instinct to downplay or silence her experience of breast lymphoedema was reflected in her comments in which she appeared grateful that the lymphoedema specialists did not discriminate based upon the degree of lymphoedema: "They didn't say oh, well, you know, yours is not bad enough ..." Using an image of two faces (Image 8), she reflected that it symbolised herself before and after treatment: "to other people I probably look the exact same" although it became clear in her interview that she was required to wear a sports bra for compression and deal with her emotions, including fear of developing arm lymphoedema. Reflecting on suppressing her feelings, she commented that "you feel different, but you try to put it to the back of your mind because you are thinking get on with life ..."

Fear of arm lymphoedema

Several participants openly expressed anxiety that they would go on to develop lymphoedema in their arm as well as their breast; and indeed, this fear has been realised for Alice since her interview. On getting her diagnosis of breast lymphoedema, Helen noted: "it scared me a bit because I thought, is it going to go into

my arm?” Leah also admitted that she knew about arm lymphoedema due to her own mother’s condition: “it was huge, and I was really terrified that it would end up going down my arm I was scared of that ... it was on my mind all the time.” Similarly, Alice expressed her fears - “I’m so scared of that happening” - although her GP had warned her that ‘because you’ve had so many nodes taken out for you it’s a case of when it happens, not if it happens’” and Joanna admitted that “I was paranoid about getting (it) in my arm. I really didn’t want that ...” Interestingly, this was not the experience of the lymphoedema specialists: in their experience, lymphoedema in the breast had greater consequences as it was more painful and difficult to manage, alongside its effect on women’s sexuality.

Image 8: Two masks



*“to other people I probably look
the exact same”
(Catherine)*

Source: Pixabay

Even if there was a feeling that regular massage techniques were controlling breast lymphoedema, participants felt uncertainty about whether lymphoedema would develop in their arm: “I mean I don’t know, I think there’s always a possibility ... you know, I think after two years that it’s less likely that I’m going to suddenly get it in my arm or something ...” (Joanna).

An additional consequence of the focus upon the risks of arm lymphoedema in patient literature was the unexpected nature of BTL:

I was worried for my arm ... but I was not aware of the breast ... I just don't think anybody had mentioned that you could get it ... I did not know about the breast, and that's why it was you know a shock. (Sandra)

Impact on self

For some women, the requirement to carry out daily simple lymphatic drainage (a form of self-massage) acted as a constant reminder of breast cancer, something that other people may not appreciate: "It takes you back all the time and I think probably people don't realise that ..." (Sharon); "you try to put it at the back of your head, really, but it is a daily reminder" (Catherine).

The emotional impact of breast lymphoedema being recognised was demonstrated at a *Moving Forward* course session led by a lymphoedema nurse, such that:

by the time she'd finished several of us were in tears thinking yes, this is me ... she's going oh, you could have skin changes - yes - it could get an orange peel effect - yes - it could get heavy - yes - and I'm thinking, this is me (Jackie).

Towards the end of her interview, Sharon made a startling revelation which reveals the significant impact of her breast lymphoedema upon her physical and mental wellbeing:

something I didn't tell you actually, I've just remembered, I went back to see my breast surgeon and asked him if I could have a mastectomy because the lymphoedema was being such a pain ... he said he wouldn't and I'm glad now but at that time I think I was so despairing about it all ... I couldn't see the way out of it that I would never get rid of the pain ...

A sense of being excluded was conveyed in Catherine's comment about a skimpy top - "you are conscious like oh, I can't wear that" - and Sharon reflecting on being unable to wear the same pretty bras as other people: "because you see pictures in magazines

don't you and they're just like perfect and there's a fantastic bra and you're thinking oh that's lovely, I can't wear them." Additionally, Sharon reflected that:

it's all about body image isn't it ... and I think there's like the ageing process as well all comes into it doesn't it and about how you handle that and when there's something else going off as well it sort of is a bit of a double whammy.

Some of these sentiments were reflected by Charlotte who, as an older woman of 83, noted difficulties carrying out some of the exercises prescribed by the lymphoedema specialist due to her other health difficulties: "I'm dropping to pieces (*laughs*)."

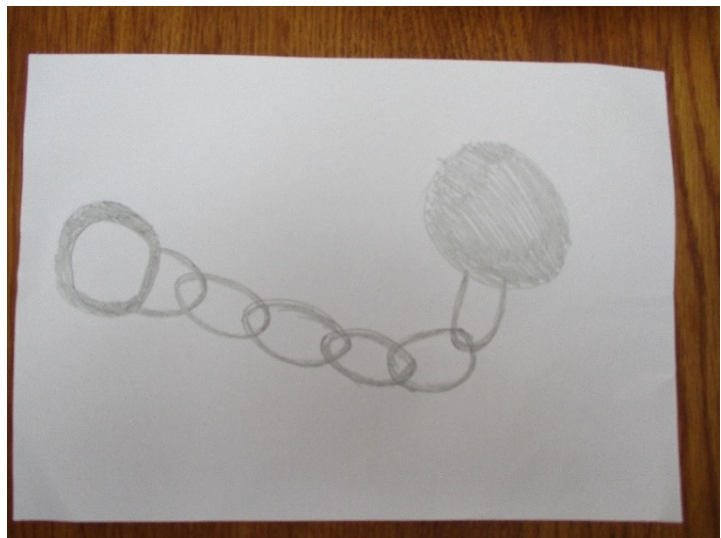
Similarly, both Lisa and Sharon voiced fears about how they would manage their lymphoedema self-care as they grew older, fears which Sharon expressed to her lymphoedema specialist but went unanswered.

BTL was acknowledged to be a life-long condition, with the potential to be made worse by any delay in diagnosis. Sharon recalled a conversation at the lymphoedema clinic: "they teach you how to do the massaging and she said it will never leave you, it will never leave you and that's a big thing to actually tell somebody ..." Similarly for Samantha, the impact of breast cancer and subsequently of breast lymphoedema was "massive ... my whole life ... from the moment I wake up, it's just different." This was reflected by her drawing of a ball and chain (Image 9) which represented the weight of living with breast lymphoedema that she was "dragging around." It referred to her need to incorporate daily self-massage exercises into her busy family life, as well as manage the risk of developing cellulitis. Like other participants, she also lived with the fear of developing lymphoedema in her arm. Anxiety and stress surrounding the need to take life-long preventative measures to avoid worsening their breast lymphoedema was evident in women's accounts. Several commented on having to take extra care to avoid infection from a scratch or an insect bite - "I carry antiseptic wipes everywhere ..." (Samantha), by judicious use of sun cream and clothing to avoid burning - "I go on holiday now and this arm is absolutely caked in insect repellent ... sun cream ..." (Alice) - and by ensuring a supply of antibiotics when going abroad. Jackie admitted that "you're still uncertain what's going to happen. You know, you've got to carry antibiotics around with you all the time. I've got antiseptic cream if I get a cut or

anything.” However antibiotic use was problematic for one participant for whom it was thought it may cause liver damage if used long-term. Foreign travel was also impacted by the perceived potential for swelling to be exacerbated. Sarah, who has lymphoedema in her chest wall and arm, commented: “I was quite anxious as to whether it would make my chest and my arm swell up, because I knew flying was one of the things.”

Image 9: Ball and chain

“my whole life ... from the moment I wake up, it’s just different”
(Samantha)



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Thus, BTL was perceived as life-changing and in some ways “as much as ... if not more than the cancer” (Samantha). It was perceived as “always there, you can always feel this sort of tightness that gets worse and then you massage it and it eases. It doesn’t go away, but it eases.” (Jackie). A sense of feeling trapped on a constant round of hospital and clinic appointments from which there was no escape was echoed by Sarah. Images of being on a conveyor belt or being unable to step off a carousel were described (Image 10) as lymphoedema was experienced as yet another part of the breast cancer journey, heightening a sense of women’s lives as always being dictated by appointments and treatment.

Image 10: On a carousel



“you can't get off ... that's how it still feels”

“I think with the lymphoedema coming, you realise that it's now never going to end”

(Sarah)

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Impact of fatigue

Alice argued that the silent effects of lymphoedema, such as fatigue, needed to be acknowledged as long-term conditions. Several participants described experiencing fatigue which they believed to be associated with their BTL. For instance, Samantha reflected that although she could never know how much of her own tiredness was caused by lymphoedema, her energy levels increased significantly once she began to treat it. She speculated that “... the last year would have been so different because I would have been much more able to do stuff, much less tired ...” had she received an earlier diagnosis. During her interview, Samantha drew upon a picture representing ‘family’ to describe the toll of breast lymphoedema upon her own family life (Image 11).

The impact of fatigue on family relationships was also described by Sharon:

I think there's nothing worse is there when you live with somebody that's not well or not a hundred percent and every time you see them, you know, like things like how are you today? Oh I feel rubbish. Do you know what I mean? You want that day where they turn round and say oh I feel great, you know.

Image 11: Family



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“... I’m constantly trying to minimise the impact on them, but it’s really hard to do that without more impact on me, which then has more impact on them ... So it’s like tough, really, isn’t it? ... It’s changed all their lives, I guess. And obviously the cancer was doing that but I kind of feel the lymphoedema has done that as well ...

I kind of feel my kids are going to grow up seeing me as someone who’s tired and probably anxious about stuff I wouldn’t have been ...”

(Samantha)

Fatigue was also shown to impact some participants’ ability to work. For example, Sharon attempted a phased return to work and discovered that she could not work two days in a row: “... I was just floored ...— and that’s not the cancer, that’s the lymphoedema that did that ...”

Acknowledgment of BTL by others

For Alice, a close circle of friends and family were aware of her breast lymphoedema and that it “bothers me.” Conversely, in wider circles breast lymphoedema was perceived by Jackie as “an unseen thing ... an unseen ailment” which was therefore “totally ignored.” A sense of being ignored was viewed as extending into clinical research into lymphoedema, Lisa commenting that she felt:

a bit irked that nothing gets changed for lymphoedema because it's one of those sort of things that there's very little research done ... in terms of curative research ... they're all quite happy to accept it can't be cured therefore you've got to put up with it.

Subtheme: The final straw

"The lymphoedema, I think, felt a bit like the final straw. The final what else can I get thrown at me?" (Sarah)

Earlier examples have shown that the emotional consequences for some women of developing BTL were considerable. They included feelings of despair, feeling misunderstood, miserable (Image 12), judged, and disconnected from friends and family. Jackie summed up the impact of developing breast lymphoedema:

the lymphoedema upset me more than anything else. I think at that point I was on the verge of going to the doctor for antidepressants (she is upset). I coped with the cancer ... I coped with the treatment ... It was the final kick.

Image 12: I felt miserable



"well that's it, as if I'd not been through enough, I've now got this for life ... I felt miserable and I felt like crying ..."
(Sarah)

Source: Pixabay

Commenting on the development of her breast lymphoedema, Sharon remarked: “I think you lose your identity a bit, not just with the breast cancer but because once you’ve had that you think well that’s it now, you’ve been through your treatment and then suddenly something else comes along.”

The compression garments provided to women were often uncomfortable and they affected participants’ feelings of femininity. Sharon described her appearance as “totally flat chested ... as though I'd been bound.” Meanwhile Tilly’s comments (Image 13) reveal how unfeminine she was made to feel (Image 13). **Nevertheless, the lymphoedema nurse specialists who provided feedback on the findings spoke of their intention to develop a patient’s treatment plan in participation with them, and of striving to understand patient barriers to adherence to advice.**

Image 13: Compression vest

*“what’s it come to, I’ve got
through cancer, radiotherapy
and now I’m reduced to looking
like a man”
(Tilly)*



Copyright: J Ulman

The attitude of HCPs could significantly worsen women’s experiences. **Lisa commented in her feedback that her “experience of being told it was my fault, which would be hurtful if it was, but when it wasn’t it was very difficult to stand up to. You are quite vulnerable at this stage ...”**

Theme summary

The silent consequences for women were considerable and encompassed many aspects of their lives. There were many examples of participants choosing to remain silent or downplay their BTL for the protection of themselves or others. Uncertainty and surprise were features of women's stories. Several feared that they would go on to develop lymphoedema in their arm; and the relatively high profile of arm lymphoedema in existing patient information contributed to the sense of shock at the development of BTL. Some participants expressed a sense of feeling excluded from wearing feminine clothing. Many women realised that BTL was a life-long condition, requiring regular management and precautions against infection. For some, this entailed time-consuming daily massage routines to drain the lymph fluid from the affected area. Concerns about managing these routines as they grew older were expressed by some participants. Fatigue appeared to be related to some women's experiences of BTL, with consequences for home and work life and their relationships with others. There tended to be few people who knew about their lymphoedema beyond close family and friends; and in the wider context of clinical research, an impression of disinterest in finding effective treatments. The sub-theme *the final straw* captured some women's despair at having coped with breast cancer and its treatment but now being required to meet the challenge of an unexpected and burdensome condition.

Theme: Adapting to breast or trunk lymphoedema

The title of this theme is descriptive in name and perhaps belies the fact that many of the individual themes which make up this overarching one relate to those experiences which may go unacknowledged in women's lives and therefore remain silent or hidden.

All participants had been required to adapt their lives to manage their BTL to a greater or lesser degree. For some, the most challenging time was prior to receiving a diagnosis and treatment. Zoe reported that although her breast lymphoedema now

had a minimal impact: “It doesn’t really affect me very much now, I can’t say that’s it’s a big change to my life,” she had a challenging experience in getting the correct diagnosis in the first instance. Meanwhile for Jackie her breast lymphoedema was so uncomfortable prior to receiving treatment that it had severely impacted her sleep: “I don’t think I’d slept a night for months ...”

Subtheme: The right bra

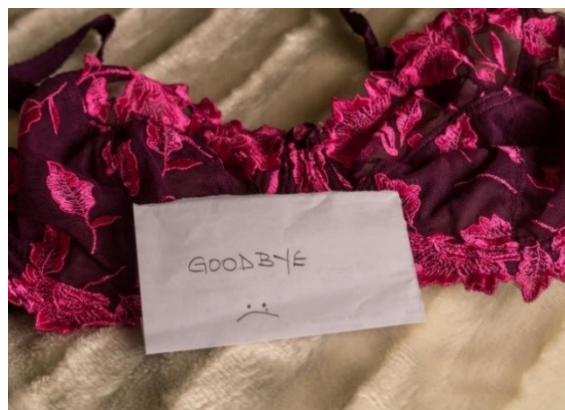
Participants all spoke about difficulties wearing bras, with bras being too tight (particularly for women with trunk and chest wall lymphoedema) or unsupportive (for those with breast lymphoedema). Prior to receiving treatment from the lymphoedema service, participants chose clothing which allowed them some comfort, including “baggy clothes and big bras” (Jackie). However, choice of clothing was made more challenging by the skin effects of treatment: “you’ve had surgery and I’d had radiotherapy and it had all broken down underneath to the point it was dripping and slimy and yuk” (Jackie).

A major issue for many women with BTL was the trial-and-error process of finding a comfortable and supportive bra that met the needs of their lymphoedema but also met other needs, such as enabling them to regain their breast shape and a sense of femininity or take part in physical activity. Often this resulted in repeated purchases of bras because the items quickly became unsuitable due to breast size changes; or they were discovered to be contrary to the advice of the lymphoedema specialists. In feeding back, Alice reported that this problem had worsened during the COVID-19 pandemic due to her need to buy bras online, which was inadequate since she required fitting to purchase bras of the correct size. The consequence was that she was required to purchase many options (up to 30 bras), yet only one might be suitable; and she would discover that even this bra would be a poor fit after only three or four days.

Images shared by participants included before-and-after photographs displaying a beautiful item of lingerie that Leah had previously enjoyed wearing (Image 14) next to

a rather beige and clinical-looking supportive bra that she was now required to wear (Image 15); and Joanna's large pile of redundant bras (Image 16).

Image 14: Goodbye beauty



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Image 15: Beige and colourless



Reproduced with permission

*".. this horrible thing ... this like whitey beigey thing with no seams in."
(Leah)*

Several participants expressed their dismay at being presented with a compression vest at the lymphoedema clinic: "this bra thing that I've got to wear is horrible. It's like grandma's" (Jackie); "... really was a bit of a sight to behold" (Leah). In creating the photograph in Image 3 (page 171) Jackie noted the contrast between the compression bra and the type of bras she would prefer to wear: "I was just thinking you know a nice pretty bra ... with this great big, horrible thing and you almost feel cheated that you can't wear nice things."

Other participants described a similar negative reaction:

so I went back and she got it out the box and I looked at it and I thought what the hell's that? ... and I went there's no cups in it. She goes no it's just a support. No it's squashing my tits to my chest basically, it is not – what is that supposed to be supporting? ... and I just thought wearing it for work with my uniform over the top, what the hell would that look like? ... I could not understand why this had been made for women with lymphoedema. (Sharon)

From the perspective of a younger woman, Alice reasoned that the compressions bras were “not pretty ... they're mega- supportive ... I couldn't wear them, couldn't go out on a weekend and wear them ... with a nice dress or something.”

Catherine raised the importance of being able to access the expertise of staff at the lymphoedema clinic, or else “you don't know what you are buying.” This is reflected by Joanna's experiences:

quite often I would buy one and then like the lymphoedema nurse would be like no, that one's not doing you any good. But there's nobody I mean even like bra fitting services whatever. They just don't know ... you'd think it would be something that people would know about ...

Image 16: ... there isn't very much that is suitable



*“that's just what life is like when your breasts are continually changing sizes and you're forever buying different bras”
(Joanna)*

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Being told that participants' usual feminine bras were not advisable clothing was distressing to some women:

I know at first I was a bit upset because she told me, I always wear bras with wires because I feel, because I've got a big bust, it feels more comfy, so she told me not to wear them, to get more of a support bra, and I felt so uncomfortable and, they're not very nice (laughs), they're not very pretty, should I say. And, so for a long time I just used to use those although I didn't feel feminine really ...

(Helen)

Many participants commented that the main type of bra worn when they were symptomatic was a sports bra, with some women needing to wear it at night as well, although they were not always particularly comfortable. The impetus to seek more suitable bras was reflected by Alice who noted that "I can't live in sports bras all the time." Indeed, there were stories of women's success in obtaining well-fitting, supportive, and attractive bras when they were provided with individual attention and support from retail staff, both in chain stores and in specialist shops. Lisa described how she was able to buy bras which catered for her fluctuating chest wall lymphoedema: "they'll talk to you about what to do if you've got a lot of swelling there you know they make sure that you've got ones that you've got enough room." However, this was not the experience of Alice who, as a younger woman, felt that bras and swimming costumes were not designed for her. Similarly, she felt that underwear companies - and VAT exemption rules - were more responsive to the needs of women who had undergone a mastectomy rather than breast-conserving surgery, finding a well-known department store with a specialist service "absolutely useless."

Subtheme: Renegotiating identity

Women shared descriptions of their changing breast size, shape, and texture. Zoe provided an image representing the stark contrast in her breasts (Image 17); while

humour was used by several participants during their accounts: “When I’m on holiday and I’m wearing a bikini and I go to the beach, and I’ve got one that looks like a beach ball and one that looks like a deflated beach ball.” (Alice). In providing feedback on her themes, Alice adopted a critical stance as she considered whether her use of humour was an attempt to normalise her situation or a form of “resistance to the challenge.” She also offered a critical perspective on her motivation to seek further treatment for her breasts, wondering whether her wish for breast symmetry was driven by social expectations about the female body and the breast’s associations with male sexual desire. Additionally, in describing her surgeon’s judgement about her breasts as conflicting with her own, she alluded to a sense of being silenced given that his judgement as the clinician viewing her body appeared to be prioritised over her own. Alice’s experiences also suggested that women who have a mastectomy were offered more reconstructive options than women who may feel disfigured following breast-conserving surgery.

Image 17: Altered breasts



*“.. this picture is trying to show you where the scar was and how, I was trying to get a big droopy (laughing) because I am F cup and this one is now quite smaller, a lot smaller and pert and this one is still as it was ...”
(Zoe)*

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Maintaining a sense of self

Although some participants spoke of losing their identity, often women had adapted to “just being you but differently” (Lisa). Adaptations included incorporating treatments into everyday life and finding a compromise with clothing. Accounts from participants demonstrated how they had tackled problems such as finding garments which provided suitable compression and support to prevent pain and discomfort but also gave them a feminine shape or enabled them to pursue enjoyed activities. For instance, Alice had found a suitable compromise for clothing to wear in the gym, involving a combination of tight, supportive underwear and a baggy outer top to disguise the “bulge out of the bra.”

Meanwhile, Helen, who had been upset at being unable to wear her usual underwired bras, took the initiative to wear them for special occasions on an incremental basis and deal with the build-up of lymph fluid afterwards:

But, then I thought, I'm going to try using the bras again. And ... if we were going out at night and it was only for a couple of hours, I'd use them and it seemed to be alright. And, then I started, if I was going somewhere special in the day I'd use them. Sometimes, after I have had them on all day, it does get a little bit hard under here, but once I've done the lymphatic drainage it goes back soft again.

Other participants had adopted similar strategies, with Jackie explaining: “So occasionally if we were going out somewhere I might put a nice bra on, but because it swells up and if I've got an ordinary bra on, I end up with a line and it like overflows.” Similarly, Leah reported: “Occasionally for an evening out I will wear something nice under my outfit to give me a better shape really but for the most part it's, you know, having to embrace the non-glamorous stuff.”

The importance of ‘a nice bra’ for some women contrasted with the way in which compression vests had the potential to undermine their sense of self. Initially Tilly

silenced her own dismay at the compression vest: “when I got home and I was stood looking in the mirror and I thought well I mustn’t complain it’s for my own good, I’ve got to wear it, I’ve got to wear it”, although she quickly asserted her sense of identity and sought an alternative, shop-bought bra. Tilly spoke strongly about the inappropriateness of the compression vest in undermining her femininity: “I looked in the mirror and I could have cried because I just looked like a man.” Similarly, some garments suggested by the lymphoedema service were perceived as a threat to participants’ sexuality, as can be seen in these comments from Catherine: “...wearing a sports bra at night, it’s just not very sexual ... you’re strung up there and it’s like, it doesn’t lead to spontaneity as such (*laughs*).” Likewise, Zoe remarked:

*when I first went to the hospice [site of the lymphoedema clinic], they said you could sleep in something like this and it was this huge bra thing and I said no (*laughs*). It was just awful, (I said) there’s no way I’m doing that ... I took one look at it and I thought no, it’s very hard to buy a pretty bra anyway, I thought that’s a real passion-killer isn’t it?*

Meanwhile, in relation to wearing sports bras in the daytime, Catherine remarked that “you can’t have lovely see-through things because it’s just like ‘oh’.” Although appearance was not a major concern to all participants, the responses of many women indicated a lack of understanding from retailers about the need for acceptable garments. That is, clothing that met both women’s physical needs for compression and their desire for comfortable and aesthetically pleasing clothing.

It was not unusual for participants’ treated breast to change from being larger than the untreated one (due to swelling) to becoming smaller once the swelling had subsided because areas of the breast had been surgically removed. This was summed up by Alice: “... well if the swelling’s not there and I’ve not really got half of this boob am I actually going to have any shape there at all or, would I look like I’ve got half a breast ...?” and echoed the experience of other women. For some women, however, the oedematous breast remained larger, with options to address this tending to be limited. For instance, reconstruction or liposuction were not always advised due to previous episodes of breast cancer.

Women also had to learn to deal with anxieties associated with once-loved activities, such as going on holiday abroad: “we do like our holidays, and I was a bit worried about flying ... and about getting bitten because if there’s mosquito around it will find me” (Zoe). Learning to live with lymphoedema involved additional items to pack: “whenever I go on holiday now, I have my little, my little bag with all my new things in there” (Sandra). However, for Samantha this prospect was too overwhelming:

For now it just all feels like, oh, too much. Still learning to go away with all the medicines and now with my stress ball I have to use for my lymphoedema massage ... and my, you know, my antibiotics

In addition, at airport security Jackie had learned to warn the staff that she had had breast cancer, following an experience where her underclothes had been searched: “she literally put her finger inside my blouse and had a poke around ...”

Having reduced energy levels due to fatigue meant that some women needed to offset their own needs with the demands of work and family life. For instance, Samantha recognised that she could not join her children in shared activities as she once did, because she needed to “balance my own health for their health”: “I guess I would quite like to do more and be more involved and I just kind of think, well, I just can't.” Meanwhile Joanna noted that “... you just don't have the energy levels, so it's like if I go to work then I can't do exercise as well.”

Acceptance of BTL

Closely linked to participants’ maintaining a sense of self was evidence of an attempt to come to terms with BTL. Leah reflected a sense of acceptance: “there’s no cure for it. It will never actually go away as such. I shall always have to live with it, but it is manageable and I’m happy in my mind now that it’s – I know it’s manageable.”

Sandra positioned herself in relation to other women who have breast lymphoedema: “it can be worse for other people, you know, I've been able to manage mine which is really good.” She was also careful to distinguish between ‘living with’ and managing breast lymphoedema, firmly placing herself in the managing category, using strategies

which included precautions against infection, the need for supportive and seam-free bras and ensuring that the shower water was not so hot as to induce redness in her breast. In relation to her different breast sizes, Sandra demonstrated a degree of acceptance: “I’m just used to now having one large and one small (*laughs*).”

Nevertheless, she considered how her uneven breasts might appear to others through her clothing - “it’s always a case of can you tell?” – even though she claimed that “I’ve just got so used to it and I don’t even think what other people think.” Similarly, Samantha was less concerned with the appearance of her breasts than some other participants: “The breast didn’t really bother me; I just kind of accepted, oh, well, you know, one’s bigger than the other.” Nor was she too concerned that her need to wear a sports bra for support meant that it showed under most of her existing clothing: “... it’s just, again, another thing.”

Some participants cited examples of drawing on alternative support, thereby countering the silence surrounding their BTL which they met within healthcare settings, to adjust to living with the condition. Of her friends who had had breast cancer, Catherine remarked that: “it’s really good you know, talking to them and it’s really good you know, sharing, just sharing ... so you can say, oh, it’s a bit of a bummer, you know, blouses won’t fit kind of thing.”

During feedback, Lisa explicitly spoke about the significance of becoming “knowledgeable about what works for you and what doesn’t, which is a huge step on the path to acceptance.”

Subtheme: Gaining expertise

“... health professionals know that actually they often don’t... it’s the person who’s dealing with it that knows.” (Lisa)

In a change in the balance of power, the quotation from Lisa above implies that the patient is the expert, rather than the healthcare professional. Universally, women became proficient in managing their BTL, in part due to the skilful, detailed and hands-on way that they were taught by the lymphoedema specialists: “when I was doing it she said no you’ve got to press harder there and into your armpit” (Joanna). Sarah

commended the lymphoedema specialists for the way that they explained to her the lymph system and self-massage, in particular:

for the way that they impart their knowledge to you ... a way of imparting that knowledge to you so that you retain it ... She tries to put things in different ways so that- to make sure that you've understood them ...

For Samantha, the effectiveness of self-massage became obvious even prior to education at the lymphoedema clinic:

I hadn't even had the specialist treatment at this point; it was just me fumbling around with what the consultant who diagnosed me told me to do. Just, you know, great, massage away, and the impact of that was just enormous.

Nevertheless, with specialist support participants often developed an understanding of when they needed to employ techniques to drain lymph fluid from their breast or chest wall: "... I can tell that my breast has got larger again and I've got pain and I had it down the side, that's always been painful round there because that's where it sort of spread round the back ..." (Sharon). Similarly, Sandra reported: "... if I forget and I can't be bothered then it will start getting heavy, the breast will get heavy. And then I know ah okay, it's time (*laughs*)."

Meanwhile Jackie commented that "it's the build-up under my arm and around the back that I have to get rid of ... Just to be comfy to get to sleep," albeit she needed to be "a bit of a contortionist" to reach it.

Lisa was one of a small number of women who spoke about kinesiology taping¹⁴ as a method for reducing swelling, in her case in her chest wall:

at that point that's when I think kinesy tape ... get that on and I do that ... it's not there all the time it's only sometimes. And if it gets bad ... I just put the tape on for a few days ...

¹⁴ This form of treatment was originally used for sports injuries and is designed to lift the skin to enable lymph fluid to move more freely (Finnerty et al 2010)

Some women had to learn ways to manage lymphoedema in their arm as well as their breast: “I didn’t know, I’d never been shown how to massage my arm and then I’m doing two things which way am I massaging this? Massaging that?” (Sharon); while Lisa noted that her daily massage was more effective in alleviating her chest wall than her arm lymphoedema.

The demands of self-massage varied between participants. Samantha had to dedicate up to 20 minutes twice daily. Meanwhile Alice, a younger, busy woman studying for a degree while bringing up young children, admitted that “I don’t do (it) as frequently as I should, I’d probably say I might do it twice a week when I should do it twice a day ... finding that time to do it is a bit of a nightmare.” **Having developed arm lymphoedema since her interview, however, meant that she had to substantially increase the time spent undertaking lymphatic drainage to half an hour three times a day.** For other participants, incorporating self-massage into a daily routine had become natural: “I can’t remember when I last didn’t do it because it’s just there” (Zoe). Likewise, Helen admitted that “at first I found it a bit hard... but I thought, ‘if that’s all I’ve got to put up with’, you don’t mind do you? So, now I just do it automatically, you know.”

Only one participant, Lisa, spoke about paying a private therapist for massage which she found “very beneficial.” The sense that her lymphoedema was well-managed meant that “it’s just a part of me now ...” Additionally, she found kinesiology taping effective for swelling around her mastectomy scar: “what I tend to do is if I’ve got a lot of swelling, or particularly my chest does tend to get painful, you can use kinesy tape ... I can’t tell you how, how relieving that is.”

Using image 18, Jackie described her progress in overcoming her difficulties:

Image 18: Light at the end of the tunnel



Source: Pixabay

“light at the end of the tunnel, that’s my hope, but I mean, yes, the lymphoedema is more under control than it was, it’s not gone away completely, so there is still little dark areas, but yes, I’ve come out of it still sane, just about.”
(Jackie)

Lisa reflected that knowledge and understanding increases “exponentially ... when you’re in the situation,” commenting on how much learning occurs through living with a condition. Speaking about its empowering nature, the following quotation indicates the silent nature of this experiential knowledge:

... there’s a depth to those people that there isn’t in everybody else so you know it may not be what you want and it’s not what society puts forward as being the thing to be, but actually, quietly in the background there are people who know that they know a lot more.

The lymphoedema specialists also appeared to have an empowering effect upon participants. For example, the specialists were realistic about women’s ability to fit the prescribed exercises into their lifestyle or to follow them accurately: “They’re like well don’t worry if you get it in the wrong order or, you know. And that’s good because it makes you feel relaxed about it and then you do it ...” (Joanna). The significance of the lymphoedema clinic was also spoken about in relation to a sense of feeling connected and having someone to talk to: “you’re not sort of, on your own and having to live with something and not be able to talk to anybody about it” (Helen).

On occasion, participants themselves had taught the lymphoedema specialists some original methods which appeared to be effective. For instance, Leah had developed a way of providing her breasts with suitable compression, commenting that “they’ve

seen this ... now and said 'hmm, well in that case we might just bear this in mind and mention it to other patients as well'." Similarly, Charlotte demonstrated confidence in seeking solutions for her trunk lymphoedema beyond the advice offered by the lymphoedema service:

she just told me to do these exercises, sort of putting my arms out horizontally and sort of lifting them up and down ... But I was wondering that perhaps I ought to have a look if there's some lymph nodes down there that I can stimulate.

During interviews, the wealth of experience described by participants and its potential value to others became apparent. Lisa noted that "until I'd spoken to you now, I hadn't thought about writing down what I've found works ... because I think that would really help people." Similarly, in the absence of precaution advice being routinely offered to patients about taking antibiotics abroad in case of infection, Sandra was positioned as the expert and able to provide information to a friend. Meanwhile, from an insider position – as a patient, a healthcare professional and an academic – Samantha was able to draw on her knowledge and experience to offer suggestions for improving the healthcare experiences of other patients:

... find someone else ... who's got more time on a lower band in the NHS who can take the time to listen to me and think through, oh, okay, what else could it be ...? ... But just to have a little think about it ... it must be cost-effective—mustn't it? - to get in early.

Given that lymphoedema requires maintenance treatment and that it worsens over time if left untreated, Samantha also suggested the following:

Why can't the British Lymphoedema Society have an approved YouTube video where they do say, okay, you still need to see a medical professional ... But also ... because there isn't such a thing ... I took notes and diagrams when I went to

my appointment, but it would still be great to have a video, to be able to go back to ...

Improving patient understanding, such as providing women with a leaflet which explains “that it’s not just in your arm” (Sarah), was recommended. Women who have had a mastectomy have specific information needs; reflecting on her lack of awareness of her developing chest wall lymphoedema, Sarah commented that:

I suppose in the same way I'd never looked at my scar and thought that's not right, it shouldn't be like that, I didn't know what it was meant to look like ... I'd never seen anybody else's. I never have seen anybody else's still.

... And maybe - maybe if I'd known what my scar should have looked like ... I might have known that it didn't look like that.

Theme summary

All the participants expressed ways in which they had adapted to BTL, balancing its demands alongside those of family and work. However, for many the trial-and-error process of identifying a suitable bra was long-lasting and costly. Women spoke of attempting to accommodate their fluctuating breast or chest wall swelling and some were disappointed at the lack of knowledge among bra-fitting services. Sometimes their purchases were contrary to the advice of the lymphoedema specialists in relation to suitable support and compression; however, many women reacted strongly against the idea of wearing a compression vest. Several participants described ways in which they had reached an acceptable compromise which enabled them to manage their lymphoedema while maintaining their feminine and sexual identity. There was a degree of acceptance among participants which was evidenced in their satisfaction at managing their BTL and with the expertise that they had developed, as well as an ability to contrast their own circumstances with others.

Participants' developing expertise, including education from lymphoedema specialists, was empowering. Moreover, participants were able to identify ways in which their knowledge and understanding could improve services and help other women.

Chapter summary

I began this chapter by acknowledging the silences that had been uncovered in Stages 1 and 2 of TSF. Silences were noted in the academic literature, where women's experiences of BTL were shown to be absent. I also highlighted the silences which exist in the form of 'blind spots' in relation to my outsider status to the research topic; and the topic of BTL was argued as sensitive due to its focus upon an intimate area of the body.

I then presented the key themes, themes, and the sub-themes, explaining that *mysterious breast or trunk lymphoedema* and *you meet a wall* were the key themes which provided the conditions for the themes *the silent consequences* and *adapting to breast or trunk lymphoedema*. *The final straw* was presented as a sub-theme of *the silent consequences*; and three sub-themes were associated with *adapting to breast or trunk lymphoedema*: *the right bra*; *renegotiating identity*; and *gaining expertise*.

In the following chapter, I address stage 4 of TSF: *working with silences*. I reflect upon methodological issues, including those associated with my adoption of TSF, the VCRM, and participant-selected photographs. I discuss the silences which were created around women's experiences of BTL during the study, as well as those existing silences which remain afterwards. I go on to consider the findings in relation to the wider literature and discuss their potential contribution to advancing healthcare practice and improving women's experiences of BTL. Some recommendations for follow-on research are also offered before I reflect upon the study's limitations. The chapter concludes by confirming the study's original contribution to knowledge and the implications for practice arising from the findings.

Chapter 8

Discussion

[TSF Stage 4 - Working with silences]

Chapter outline

In this chapter, I begin by offering a critique of the study methodology including my use of TSF, the Voice-Centred Relational Method (VCRM), and the use of photographs. I go on to reflect on the research process before considering the silences identified at TSF stages 1 and 2 in the light of the study's findings and the wider literature. In evaluating the study findings, I critically examine the forms of disempowerment experienced by women with BTL within the healthcare context and beyond. I highlight the study's original contribution to knowledge and explore the implications of the findings for healthcare practice and policy, making some recommendations for future research. This is followed by a discussion of the study's limitations. Finally, I conclude this thesis by confirming its contribution to knowledge.

Introduction

In Chapter 4, a review of the literature demonstrated a gap in knowledge about women's experiences of developing and living with breast or trunk lymphoedema (BTL) after surgery and radiotherapy for breast cancer. This study sought to address this gap and give women an opportunity to be heard. The study also had a pragmatic intent to generate findings with the potential to educate women with breast cancer, the healthcare practitioners who care for them, women's families and friends, and organisations that support women who have had breast cancer. The research question remained intentionally broad due to the study's exploratory nature; that is, the study sought to answer *what are women's experiences of developing and living with breast or trunk lymphoedema after surgery and radiotherapy for breast cancer?*

Under this wide enquiry, I sought to determine how women described these experiences and which aspects of their lives they spoke about. Using The Silences Framework (TSF), I was prompted to consider the evidence for silences that were anticipated to surround women's experiences. I also explored whether photographic images helped women to articulate their experiences of BTL.

In alignment with the methodological premise that women's accounts are a legitimate form of knowledge, in this chapter I refer to or use quotations from participants' narratives to support some of my assertions.

Critical reflection on the study methodology

In this section, I reflect upon the success of the study methodology and methods in providing participants with an opportunity to share their experiences of BTL and identifying silences surrounding those experiences. I also consider the extent to which women's voices were retained during the interpretation of the data.

Participant empowerment

If we accept that empowerment can refer to personal as well as political transformation (Proctor 2001), it may be said that the interview process was empowering for some of the women who took part in the study. For some, the act of having their story heard and being provided with a way of processing their experiences appears to have had personal benefits, including a sense of closure on some difficult experiences. Some also spoke of their desire to promote awareness of BTL, which may have been empowering (Burles and Thomas 2014).

While the research was designed to promote a more equal participant-researcher relationship, there were times when the participant appeared more powerful. This was most evident with Lisa. In our first conversation, she used strong language to convey her negative response to the recruitment material. Examples during her interview included demonstrations of her wealth in declaring an ability to consider private surgery for her lymphoedema; and assertions of her knowledge and experience borne

of a series of difficult life events. Another attempt to give some control to participants was the act of including them in the selection of a pseudonym. The fact that one participant used the opportunity presented by the options in the Photograph Consent Form (Appendix 26) to select her own real name rather than a pseudonym suggests that she had confidence in the dissemination process.

Critique of The Silences Framework (TSF)

This study adopted TSF to reveal the silences surrounding women's experiences of BTL after treatment for breast cancer. Framing the topic of BTL in the language of 'screaming silences' helped to maintain a focus upon the marginalised status of women's experiences and attend to power relations within and beyond the research context, promoting a critical approach to the inquiry. Like Janes et al. (2019), I also appreciated the structure that TSF offered to the research process.

A criticalist perspective recognises the fluid and changing nature of narrative which alters according to the relationship between the speaker and the listener (Bell 2002; Mauthner and Doucet 1998); while the stories themselves may contain "contradiction and reconstruction" (Bravo-Moreno 2003, p. 632). Narratives also change at every reading and subsequent interpretation. A transcript is therefore never 'neutral' (Mauthner and Doucet 2003). This was seen in this study in participants' responses to their own words when they read their interview transcript several months or more after the event. It may be that information is mis-remembered; and the fact that Leah did not feel as if it were herself speaking demonstrates how different her account could have been if she had been interviewed at another point in time.

In Birt et al.'s (2016) discussion of the ethical dimensions of obtaining participant feedback, they noted that the process has the potential to be detrimental to participants if, for instance, their physical health or emotional state has changed since the interview. Sharon's uncertainty about her emotional availability to take on the task required an alternative strategy which would allow her to provide feedback without causing harm and undoing the beneficial work that the interview had achieved. The experience demonstrates that while involving participants in the analysis in the way

that TSF allows may be welcomed by the women who took part, it cannot be assumed (Mauthner and Doucet 1998).

One of the objectives of this study was to promote an active style of participation, facilitating a more equal relationship with the researcher, of which involvement in the data analysis is one aspect. In this study, two additional phases were incorporated into the analytical cycle of TSF to allow participants more involvement in the analysis. As they were presented with their individual themes before being invited to consider the overall themes, this may have provided participants with some insight into the trail of theme development as well as providing an opportunity to revise or refute their individual themes. On this occasion, however, the fact that none of the women who took part disagreed with the themes I developed from their individual interviews could suggest a degree of acceptance by participants (Birt et al. 2016). This may be associated with their perception of me as more powerful in the research context; on the other hand, it could be that they are not more deeply invested in the feedback process for reasons of interest, time, or comprehension of the activity.

Waller et al. (2016) highlighted the potential difficulties for researchers operating within a criticalist paradigm in seeking participant feedback on the researcher's interpretation of their data. For example, if the interpretation does not align with the participant's own view of themselves, the process may be disempowering. In my own study, I was conscious of this possibility and acknowledge that I was selective in some of the detail that I shared with participants from my analysis. For example, in my original analysis I had described Helen's relative powerlessness in relation to me as the researcher. Not only could this have been disempowering to read, but the critical interpretation may not have made sense to her since the study was not presented to participants in this way. Certainly, my theoretical stance would not have been explicit to the women I interviewed unless they had asked about it. Hence, I chose to exclude this aspect when I sought her feedback as I felt that she may have felt misrepresented - and therefore unheard - if this interpretation did not resonate for her (Birt et al. 2016).

I anticipated sources for the 'collective voices' at the beginning of this study: that is, at TSF stage 1: *working in silences*, I identified those who I believed to be significant individuals or organisations related to the research topic. The women and

organisations who were selected were, I believe, those most likely to acknowledge rather than further silence participants' experiences of BTL, either through personal experience or witnessing the experiences of others. Hence, I opted not to seek feedback from groups of HCPs where silences around BTL appeared to be located. Wary of the risk of obscuring participants' voices by consulting with a broader selection of the wider network, some of whose members may have held conflicting views to participants, I acknowledge that I may have missed an opportunity to provide a fuller contextualisation of participants' experiences.

I also recognise that there are alternative approaches to identifying the wider network. In her study investigating the experiences of people under 60 years old who had experienced a fragility hip fracture, Janes (2016; Janes et al. 2019) drew upon participant interviews to establish who had played a role in their recovery.

Critique of the Voice-Centred Relational Method (VCRM)

An objective of this study was to employ an analytical method that positioned participants' voices and testimonies at the centre of the analysis. In Chapter 5, I discussed how using the Listening Guide (LG) permits the researcher to delay the development of themes by guiding the researcher through a series of steps to familiarise them with the participant's story and the 'voices' in which they speak. Together these steps inform the themes, enabling a more in-depth appreciation of each participant's experiences. For example, the 'voices' identified at step 3 contributed to an understanding of the silences surrounding women's experiences of BTL. In the case of Samantha, for instance, although in my research diary I noted that she presented as 'confident and assertive,' in fact one of the 'voices' I identified in reading her transcript was a suppressed voice. It transpired that many participant 'voices' were ones of silence, including unheard, ignored, and not knowing, which confirmed the role of silence in women's stories.

The I-poems created at step 2 offer a way "to emotionally engage the reader or audience, and to resist the urge to turn a participant's complex story into a single linear narrative" (Koelsch 2015, p. 96). Poetry has been used by other researchers in the social sciences to provoke an emotional reaction (Carr 2003; Koelsch 2015). This

has implications for their utility in educating HCPs by raising awareness about the patient experience in an effective way (Hutton and Lystor 2020). Nevertheless, in my own study I noticed that Catherine relied heavily on the pronoun 'you' when she was talking about herself, so that the resultant I-poem did not capture some elements of her voice. Edwards and Weller (2012) also noted that people's speech patterns vary, such that some individuals' limited use of 'I' may mean that the analysis misses some important dimension of the participant. They argued for alternative poems, such as "you-poems or me-poems, or indeed we-poems" (Edwards and Weller 2012, p. 207) as equally capable of reflecting an individual's authentic voice. Woodcock (2016) also commented upon the societal constraints that may steer participants to use the pronoun 'you' rather than 'I'. In using I-poems, therefore, aspects of expression can become silenced. Meanwhile, Balan (2005) combined the pronouns "me," "my," or "myself" within I-poems as they all denote ways in which the participant is referring to herself. While alternative forms of I-poem have not been used in the analysis for this study, they may be an illuminating method in any future secondary analysis of the data.

Critique of the use of photographs

This study intended to facilitate discussion and encourage alternative ways of thinking by providing participants with the option to use images in their interview with me. The purpose of creating a set of photographs from which participants could choose – the researcher-provided set - was to stimulate ideas, rather than prescribe what participants would be expected to talk about. In fact, those participants who did select some of the images from this set also produced some images of their own, indicating that they did not feel constrained by this option. Thus, participants responded to the task of producing photographs in a variety of ways, often using a combination of their own images created for the study, the researcher-provided set, and images from the internet. At times participants expressed interest in using photographs but had difficulty generating ideas for images. While I appreciate that the examples offered to them as encouragement could invite an element of bias, I believe that the images subsequently produced by participants reflected their own stories rather than my perspective. Guillemin and Drew (2010) similarly refer to providing participants with

“ongoing coaching and support from research staff to facilitate their reflection and decision-making” (p. 180) to facilitate ideas for photographs.

The option of a disposable camera, which was only taken up by Sharon, generated some unique issues which did not apply to the production of photographs on participants’ own digital devices. As Sharon returned the camera to me so that I could arrange for the photographs to be developed, there was a risk of my taking control away from her because I would have an opportunity to see the images before she did. This was avoided as I developed two sets of prints and chose only to glance through them to ensure that there were some clear images among them before sending her a set. Had the photographs not developed properly and I had returned a set to Sharon without looking at them, this would also risk disempowering her as she may have felt disappointed, foolish, or upset. Sharon had evidently invested a great deal of thought in choosing her images. So, while it could be argued that returning a set prior to the interview implies an expectation that she would prepare for the interview beforehand - which could be construed as an additional burden – in this instance, I believe that it acknowledged her personal investment in the study.

Catherine reported that she had ‘flicked through’ the researcher-found images and identified those which meant something to her. She appeared to be using the photographs in an associative way, describing an image of a stained-glass cathedral window as a breast with a nipple, “there’s all these pockets, you know, so when you are massaging it’s the pockets that are draining back out of the breast” (Image 19). It occurred to me that Catherine may have assumed that her responses to images in the researcher-found set of photographs would be interpreted by me, as might be expected of a psychoanalytic therapist, possibly bestowing upon me an unintended degree of power. Other participants drew upon images to express their thoughts and feelings. For example, Jackie drew upon an image of a woman walking on a road (Image 20) to describe her sense of being on “a long journey” and uncertainty for the future.

Of course, not all participants embraced the invitation to use photographs. Some appeared disinterested in a visual approach, although this may have been driven by a perceived lack of skill. Lisa found the idea of using photographs in her interview “deeply condescending,” explaining that she felt able to articulate her feelings without

photographs and viewing them as unnecessary props. Indeed Guillemin (2004) argued that our means of expressing our thoughts and feelings is generally word-based, so that it should come as no surprise that some participants chose not to engage in this aspect of the study.

Image 19: Breast



Copyright: J Ulman

*Image 20: "It's a long journey
and you just don't know what's
round the corner"*
Jackie



Source: Pixabay

Reflecting other research (Guillemin and Drew 2010), Samantha reported that she had found the interview process empowering as she was able to direct the conversation, highlighting the elements that were important to her and providing her with a voice. She recognised that the visual method suited her as she enjoys images, although her uncertainty about copyright restrictions on internet images led her to use drawings and some existing personal photographs. In fact, although none of the researcher-found images were 'quite right,' they enabled her to think about other images to create in drawings; moreover, she felt that it was easier to represent her experiences this way. Other studies have invited participants to create drawings, often during their interview with the researcher (Cross et al. 2006; Guillemin 2004; Kearney and Hyle 2004). However, there are different practical and methodological issues associated with drawings in research. For example, there is evidence that some participants lack confidence in producing drawings (Kearney and Hyle 2004; Mannay 2016). Indeed, during her interview Samantha adopted a slightly defensive attitude when she suggested that her drawings may not be perceived as particularly good, even if they were effective in enabling her to recount her experiences. Thus, although drawing had not been one of the methods envisaged for this study, it fulfilled the same purpose (Guillemin and Drew 2010); moreover, to deny Samantha this option would have been to silence her further. The process enabled her to consider the key issues relating to her experiences of breast lymphoedema, teasing out those experiences from the wider context of her breast cancer experience. Significantly, the process of being able to focus upon breast lymphoedema became a route to legitimising the condition: that is, her sense of "It's like, okay, no, this is a condition in its own right ..."

The degree of engagement with the study varied between participants, with this most evident between those who chose to use images and those who did not. As Guillemin and Drew (2010) pointed out, adopting a visual method requires a considered response to the researcher's inquiry; whereas those participants who attended an open interview with me would not be required to prepare in advance. For Sharon, the deep engagement with the photographic element of the research task resulted in a long and reflective interview which was beneficial to her. Arguably the images used by participants in this study provided access to aspects of their stories that might otherwise not have been available to them. Each participant was invited to explain

their chosen images, indicating that the images were more than a “quirky addition to the research” (Guillemin and Drew, p. 183). Originally, I had intended to place participants’ images in a central role in the analysis, employing an analytic strategy that considered text and images as having equal importance. Once I began data collection, however, the role of images became clearer as the range of ways in which participants used them emerged. Radley (2010) discussed the “kinds of important work” (p. 278) of photographs that may not be immediately obvious. Frith and Harcourt (2007) admitted to their early disappointment with “the apparent banality” (p. 1348) of some of their participants’ photographs. Nevertheless, they began to appreciate that these images symbolised a significant feature of participants’ experiences. It prepared me to approach the task of looking at participants’ photos with a curiosity for what they meant to the participant. For instance, Sharon’s image of a pair of trainers in a corner of a room provoked a detailed consideration of her thoughts and feelings about her current circumstances in contrast to the past; the meaning of the image lay in Sharon’s interpretation which could otherwise be misunderstood by me as the researcher (Mannay 2010). Hence an image may provoke talk about an aspect of experience which is not visible in the image itself, as in the case of Sharon’s photograph of her trainers (Rose 2014). Ultimately, although I no longer treated the images as separate data items for analysis, their presentation alongside women’s narratives allowed for a clearer understanding of the meaning of each image. This might be evident in instances where I have removed images for confidentiality or copyright reasons and have resorted instead to a description of the image, thereby possibly hampering a fuller understanding.

Guillemin and Drew (2010) argued that an important consideration is whether research images are created with an imagined audience in mind, as this influences how the images are produced. The recruitment material for this study made clear reference to the anticipated dissemination outputs, indicating from the outset an intended audience beyond the academic context to raise awareness about BTL (Pauwels 2013). Certainly, some participants acknowledged this intention, such as Leah who offered some high-resolution copies of her images for reproduction purposes. However, Samantha’s uncertainty about how a family photograph might be used in the research led to her omitting it from her interview, reinforcing the need for

the researcher to be as specific as possible about the intended audiences for research images.

Reflections on the research process

I had entered the field with a degree of confidence in my interview skills, based upon my clinical experience as an occupational therapist when I had worked with adults of all ages. Most recently, I had facilitated groups using elements of a cognitive behavioural approach for carers of people who have dementia. While a member of my supervisory team read one of my early interview transcripts to ensure that my interview style was broadly appropriate for the research question, I note that during interviews I tended to lapse into my therapeutic role, reflecting back phrases used by participants, for instance, or offering a brief interpretation of what was said. My responses also reflected how participants behaved with me. For instance, although Tilly mentioned that she does not talk to others about her experiences, my sense was of somebody who wanted to share her story - certainly at least within the confines of my interview with her. I felt that the interview had therapeutic value to her which may explain why I so frequently adopted a therapeutic attitude. Similarly, Joanna reported that her interview had been beneficial, explaining that it had felt positive to look back over her experiences.

One of the study objectives was to enable participants to share their stories of their experiences of BTL on their terms by undertaking individual, unstructured, audio-taped interviews with them at a location of their choice. The intention was to create an environment where participants would feel comfortable talking to me. In this study, stories of discomfort, distress and silencing by HCPs dominated because they represented the experiences of most of the women who came forward to participate at this time. Where this was not the case, I have highlighted this in the findings; indeed, warning against “the allure of the transgressive” (p. 69), Shapiro (2011) reminded academics to allow space for conventional stories alongside the counter-narratives of patients’ difficult experiences. Nevertheless, in underpinning this research with TSF, it remained sensitive to the silences around women’s experiences of BTL.

Similarly, I appreciate that the reader response to an interview transcript (documented in the first step of the LG) would be different for someone else; in fact, my own response would likely alter according to the context and over time. No doubt my analysis of the data was influenced by my own physical, emotional, and social circumstances on any day, such that I could question whether each transcript was analysed 'correctly' (Mauthner and Doucet 1998). Hence, I acknowledge that, rather than having 'captured' participants' experiences (Mauthner and Doucet 2003), the findings are one of many possible accounts; knowledge is therefore grounded in the context of its production.

A key ethical consideration was the potential to do harm to participants. Although the interview process may have been experienced as therapeutic for some participants, Sharon's ambivalence is a reminder of its complexity, as is demonstrated in this quotation from her interview:

... it is cathartic in a way to talk about it, but the upsetting thing is it reminds you of all the horrible things that happened that shouldn't have happened, so that doesn't make you feel very good does it and I don't always think sometimes talking about things – does talking about things actually help you because it – ... Revisits them and maybe if you've not put them to rest, by revisiting them it does still affect you doesn't it?

Weighing up issues of protection with those of empowerment was highlighted in relation to the use of participants' images in dissemination outputs. While images can promote participants' voices by making visible their experiences, other researchers have drawn attention to the uncertainty about how others might use them: "once material is put out into the world, it does have the potential to take on a life of its own" (Guillemin and Drew 2010, p. 181). Hence it felt important to reinforce to participants that my thesis would be published electronically and would therefore be globally available, ensuring that they understood the potential scope of the audience and reach of their images. I was also prompted to consider Sandra's invitation to send me her photographs of her lymphoedematous breasts which she had taken to show her clinician. My feeling was that this demonstrated her willingness to be vulnerable with me in offering to share such personal images. It could also have been an

indication of our rapport and her desire to promote the awareness-raising aspects of this research, which may be empowering.

Remaining and newly created silences

In reflecting on the extent to which I have managed to give voice to participants, in this section I will consider silences which remain, and which may have been created in the research process.

The voices of Black and Asian women who have BTL remain silent since the findings of this study only reflect the experiences of White women. This is also mirrored in the over-representation of young, White females in the set of photographs produced for participants to choose from, which is itself a feature of the images which were freely available on the internet.

The option to use photographs may have been off-putting to some women, thereby silencing those who may otherwise have participated. Although not a requirement for participation, the recruitment information could have led potential participants to believe that using photographs was the preferred option. Admittedly my investment in a visual approach is likely to have influenced the researcher-participant relationship. In the previous chapter, I shared a diary entry for my interview with Helen which indicated that I felt that her lack of engagement with the photographic option seemed to restrict our rapport and may have inhibited her in recounting her experiences.

During my interaction with participants, I sought to achieve a level of equal power with them - for instance by being willing to share personal information (Bravo-Moreno 2003) - to create an environment where women felt able to disclose their experiences. Power is not always balanced towards the researcher (Bravo-Moreno 2003), however: I noted some power play with some participants, such as Lisa, who asserted her power in a variety of ways. Although my more mature age and my healthcare professional status might have helped to provide some legitimacy to my research role, it is also conceivable that some participants may have been reluctant to make critical comments about some aspects of the healthcare system if they knew my background. I noticed that some women were keen to emphasise their appreciation of the health

service after they had disclosed their difficult experiences with BTL. Similarly, while I have strived to adopt an approach which enabled participants to feel comfortable in offering their feedback on the draft findings, some may have been inhibited in sharing their views if they felt that they conflicted with mine as the researcher.

I acknowledge that my relative inexperience as a researcher has influenced the research process. Thus, this research conducted at this time within my existing capabilities, drawing upon the skillset and support of my supervisory team, have combined to create specific outcomes. As I commented in Chapter 5 when I discussed my researcher identity as a part of TSF stage 2: *hearing silences*, undoubtedly there will be 'blind spots' which have influenced my ability to be reflexive (Mauthner and Doucet 2003) and caused silences to be maintained or created about which I may remain unaware. On occasion, my silencing of participants is quite explicit, albeit unintentional, such as when I have interrupted a participant in my eagerness to ask a question. Similarly, in asking three pre-set questions at the end of each interview, sometimes I note that I inhibited participants from adding anything more. For example, I prevented Samantha from adding anything to a topic when I commented that "I think we've covered that." Likewise, in *hearing silences* I noted that my outsider status risked preventing participants from sharing some of their experiences if I failed to appreciate the significance of something that was said by them and to follow up a potentially rich lead.

Although it could be argued that the degree of control I have exerted risks silencing aspects of participants' stories, my responsibilities to them as a researcher have guided me to uphold their confidentiality. For example, one participant provided me with a photograph showing her participating in an enjoyed activity, albeit it from a distance and with her back to the camera. It may seem, therefore, that this photograph would not reveal her identity. However, I believe that features of this photograph could provide sufficient information to identify her if they were combined with other aspects of her personal details provided in her interview.

I also concede that as the researcher I make the final decision about how to edit and curate the images. My decision to exclude some of the photographs provided by participants from dissemination outputs could be argued as a form of silencing. The ethical or legal implications of using some photographs led me not to include any

images of people (including themselves), nor any images sourced from the internet (unless they were known to be copyright-free) in dissemination outputs. In part this was for pragmatic reasons: for instance, I would have been required to gain permission from Warner Brothers to use an image provided by one participant - a potentially costly and lengthy process. I am conscious that this is a change from the explanation provided in the recruitment material in which I merely state that elements of images could be digitally altered to retain anonymity. Although I felt that I was still able to retain participants' voices in the findings, the consequence of my actions means that for one participant, none of her images are included in the dataset. Additionally, that none of the participants challenged this alteration could also be perceived as a display of my power over them. I am aware that in taking this stance, I have claimed my authority over some participants in a manner which could be construed as not participatory (Faurey 2017) and a form of silencing.

Finally, I note that I have altered the terminology to capture all the forms of lymphoedema which have been experienced by study participants - that is, breast and trunk (including back, chest wall and armpit) - as the study has progressed. This has resulted in some discontinuity when I presented the draft overall findings to participants, variously using *breast lymphoedema* or *breast, trunk, or chest wall lymphoedema* in the titles of different themes. Hence when the term *breast lymphoedema* was used, this may have inadvertently excluded and silenced participants who had other types of lymphoedema.

Evaluation of the study findings

The central aim of this study was to gain an understanding of women's experiences of BTL. This was achieved through individual interviews with 14 women, either face-to-face or on the telephone. The second aim, to create the conditions for change by generating findings which can be used for educational purposes, will be evaluated through feedback from the audiences and readership for presentations, peer-reviewed articles and educational materials which are intended to be developed from the findings. This study generated new understanding about women's experiences of developing and living with BTL which is distinct from the evidence for women's

experiences of arm lymphoedema, as well as areas of common experience (Table 5). This section will evaluate the findings, reflecting upon the silences which were identified in TSF stage 1.

Cultural norms as a form of disempowerment for women who develop BTL

In their discussion of the historical, political, social, and cultural context surrounding the term 'cancer survivor,' Bell and Ristovski -Slijepcevic (2013) noted that some people resist the term's focus upon the presence of life itself rather than upon the quality of life. Moreover, while the term 'cancer survivor' may provide an identity and a voice for many people with cancer, for some it acts to silence them. The language carries assumptions in which survival is seen as an achievement which has been worked for, denying a voice to those who do not fit the "sanitised image of breast cancer" (Koczwara and Ward 2015, p. 343). Breast cancer patient support forums provide a space not only for sharing distress and confusion about uncertain symptoms; they also provide a space for resistance where women can articulate thoughts and feelings that may be considered less publicly acceptable. The ability to express their relief if they have not developed lymphoedema, or to admit to being concerned about the appearance of their breast rather than simply being grateful to be cured of cancer, is an opportunity for women to counter societal expectations. However outside of this context, Jackie noted that there was no space to talk honestly about her experiences of developing breast lymphoedema after her treatment for breast cancer: "Very much on your own, even though everybody's there going, how are you? How are you? ... So you say yes, I'm fine, and carry on regardless of whatever's happening under my tee-shirt." Therefore, by inviting women to share their stories in this study, participants have been required to resist the cultural expectations of breast cancer survivorship associated with celebration and positivity.

Table 5: Study findings in relation to existing evidence from women's experiences of arm lymphoedema, highlighting this study's original contribution to knowledge

Findings from studies of women who have arm lymphoedema which are similar to the findings from this study	New findings from this study of women who have breast or trunk lymphoedema (BTL)
	<p>Cultural influences upon BTL:</p> <p>Breast and trunk area as culturally sensitive and intimate areas of the body; impact upon both patients' and HCPs' willingness to investigate BTL symptoms. Also impact upon self-care routines around family and friends.</p> <p>Theme: The Silent Consequences</p>
<p>Marginalisation: absence of information:</p> <p>Lack of patient information about the risk of arm lymphoedema from treatment for breast cancer.</p> <p>Acebedo et al. (2021); Dönmez et al. (2021); Hare 2000; Honnor (2009); Thomas-MacLean et al. (2005)</p>	<p>Marginalisation: absence of information:</p> <p>Lack of patient information about the risk specifically of BTL from treatment for breast cancer.</p> <p>Implications –</p> <p>Patient anxiety about unfamiliar symptoms and fear of cancer recurrence. Patients hindered from seeking appropriate and timely support. Patients unsupported along pathway to address readiness for and preferred degree of information about BTL.</p> <p>Key themes: Mysterious BTL; You meet a wall</p>
<p>Marginalisation of patients:</p> <p>Poor awareness among HCPs about lymphoedema as a chronic condition which impacts upon life. Inaccurate beliefs or a dismissive and minimising attitude, impacting upon quality of care.</p> <p>Greenslade and House (2006); Honnor (2009); Johansson et al. (2003); Maree and Beckmann (2016); Ridner, Bonner et al. (2012); Ridner et al. (2016); Thomas-MacLean et al. (2005)</p>	<p>Marginalisation of patients:</p> <p>Poor awareness of BTL among HCPs (hospital and community-based), impacting upon the quality of care including misdiagnoses; inaccurate HCP beliefs or a dismissive and minimising attitude; patient knowledge as not legitimate.</p> <p>Key theme: You meet a wall</p>

Findings from studies of women who have arm lymphoedema which are similar to the findings from this study <i>continued</i>	New findings from this study of women who have breast or trunk lymphoedema (BTL) <i>continued</i>
<p>Marginalisation of patients:</p> <p>Lack of understanding from others (friends, family, workplace).</p> <p>Johansson et al. (2003); Ridner, Bonner et al. (2012); Ridner et al. (2016); Sun et al. (2020)</p> <p>Dealing with fatigue</p> <p>Anbari et al. (2019); Heppner et al. (2009); Radina et al. (2014); Ridner, Sinclair et al. (2012)</p>	<p>Marginalisation of patients:</p> <p>No visible evidence of BTL to others – lack of understanding from others (friends, family, workplace).</p> <p>Dealing with fatigue related to an unseen condition.</p> <p>Theme: The silent consequences</p>
<p>Emotional, social, and physical impact:</p> <p>Negative influence upon sexual experiences.</p> <p>Radina et al. (2008); Radina et al. (2015) - (<i>note: participants in this study had arm, hand, breast and/or chest swelling</i>)</p> <p>Feelings including anxiety and isolation (Hare 2000) and uncertainty (Ridner, Bonner et al. 2012; Ridner, Sinclair et al. (2012).</p> <p>Challenges associated with accommodating regular self-massage into daily life.</p> <p>Jeffs et al. (2016); Radina et al. (2014); Ridner, Bonner et al. (2012)</p>	<p>Emotional, social, and physical impact:</p> <p>Negative influence upon feminine and sexual identity through requirement to wear compression garments on chest area.</p> <p>Linked to: Significant difficulty acquiring suitable bras to accommodate fluctuating breast or chest wall lymphoedema, with financial implications.</p> <p>Theme: The silent consequences</p> <p>Finding a compromise to meet lymphoedema management requirements and maintaining identity and roles</p> <p>Theme: Adapting to BTL</p>
<p>Lymphoedema as a daily reminder of breast cancer</p> <p>Ridner, Bonner et al. (2012); Whatley et al. (2018)</p>	

Ambivalence about how to position themselves in relation to having BTL was seen by women during the research process. Some potential participants were cautious about putting themselves forward for the study because they were unsure whether they qualified to participate on the grounds that they believed that their BTL was mild; invariably, however, they went on to describe details which suggested that they had been minimising their issues. This downplaying of their circumstances reflects the marginalised status of their experiences of BTL. In her interview, Alice displayed her struggle in trying to reconcile her desire for improved breast symmetry with her critical understanding of the potential of reconstructive work to conform to social expectations. Her critical standpoint is reflected in the theme *resisting appearance pressures* in Thornton and Lewis-Smith's (2021) qualitative study, in which women who had a positive body image after treatment for breast cancer were interviewed about their experiences. For Alice, her wishes to return her appearance to 'normal' have the effect of silencing her resistance (Else-Quest and Jackson 2014; Emilee et al. 2010).

As an intimate area of the body and therefore a sensitive topic, there are cultural influences which are unique to women who experience BTL. During TSF stage 2: *hearing silences* I commented upon the ways in which BTL could be construed as a sensitive topic for reasons such as the association of the breast area with a woman's sexuality. Most women in the present study admitted to being concerned about their appearance, concerns which are associated with cultural perceptions of femininity as well as motherhood and sexuality (Ehlers and Krupar 2012). Breast size is arguably a symbol of value in industrialised countries (Nash 2014), so that women's experiences of fluctuating and uneven breast size and shape may be experienced as a threat to this aspect of their identity. Under this study's theme of *the silent consequences*, these influences can be seen in several accounts of participants' dismay at being offered a compression vest which effectively flattens women's chests and thereby reduces their sense of being a woman. Several women who developed breast lymphoedema described their experiences of living with uneven breasts, with the oedematous breast initially larger than the other one but becoming the smaller one once the swelling reduced (because an area of breast tissue had been surgically removed). This was less important to some women than others, which is reflected in some evidence suggesting that there is no association between the extent of arm lymphoedema and levels of

quality of life (Devoogdt et al. 2011; Keeley et al. 2010; Viehoff et al. 2008).

Meanwhile, Kool et al.'s (2016) finding (n = 350) that participants rated the avoidance of severe breast symptoms such as pain and oedema higher than a two-year increase in disease-free survival (RI 18.30, 95% CI 17.38-19.22) supports the potential emotional significance of BTL.

The desire of some participants to retain their femininity is also reflected in the theme *adapting to BTL* in instances where women resisted the guidance about the features of appropriate bras so that they could reclaim a sense of their identity, adopting a compromise which met their emotional as well as their physical needs. Indeed, women's resistance to wearing garments recommended by their lymphoedema specialists could suggest a more empowering relationship which is not found with other HCPs who treat them; this was alluded to by the specialists who fed back on the study findings when they spoke of inviting patients to be a part of the treatment plan.

The cultural sensitivity of the breast area was borne out in the study findings when some participants speculated that HCPs' reluctance to assess their symptoms of BTL may have been due to the relatively intimate nature of the examination. Hence, the topic's sensitivity disabled HCP action. Yet during radiotherapy for breast cancer, women are required to be undressed above the waist, their bodies handled by therapeutic radiographers to ensure that accuracy is achieved in positioning the body for treatment. Thus the 'routine' nature of their breasts being under the clinical gaze meant that some participants in this study clearly had an expectation that HCPs would undertake a physical examination of their breasts as part of their monitoring role, despite their vulnerability at being undressed. In fact, the minimal examination of their breasts at follow-up had consequences for some women in identifying BTL. This study found that delays in addressing BTL symptoms were potentially exacerbated by this apparent unwillingness from HCPs to investigate women's concerns, or for women themselves to acknowledge changes in the chest. This is a key distinction between the findings of this study and the evidence for women's experiences of arm lymphoedema.

Several potential participants questioned their eligibility for inclusion in the study because they felt that their BTL was mild. On occasion, participants appeared to downplay their BTL: the examples of Jackie, Sarah and Joanna being unable to acknowledge their BTL hint at the complexity of women's experiences. Participants'

responses perhaps also highlight a medically driven perspective which focusses upon the severity of a condition, rather than the personal impact upon each person. This is reflected in feedback from the Lymphoedema Support Network which commented that the degree of swelling was not associated with its impact, such that mild swelling could be 'devastating' for some women and vice versa.

The role of health services in disempowering women who develop BTL

Many of this study's findings relate to forms of marginalisation which were experienced by women (Table 5). Participants reported a lack of information about BTL, and this is reflected in the experiences of women who develop arm lymphoedema (Burckhardt et al. 2014): however, there is an important distinction. While participants may not have been offered it in their healthcare setting, patient information about arm lymphoedema does exist; whereas an online search conducted most recently in October 2021 revealed that BTL does not appear to be routinely included in patient literature about BCRL provided by NHS Trusts in the UK. Consequently, as represented by the key theme *mysterious breast or trunk lymphoedema*, participants in this study were confronted with unfamiliar breast or trunk symptoms which created anxiety and, in some instances, a fear of cancer recurrence. Evidence that meeting the information needs of cancer patients influences QoL and levels of anxiety and depression (Faller et al. 2016; Husson et al. 2011) supports this finding.

The findings under the key theme *you meet a wall* demonstrate that the silence around information can have significant physical and psychological consequences for women. Participants often gave accounts of disempowering experiences related to developing and seeking support for their symptoms. These experiences manifested themselves in a variety of ways, including women being silenced, ignored, or dismissed by HCPs; a lack of access to information and advice; women opting to downplay their experiences; and women placing their own needs after the perceived greater needs of the health service. Sometimes HCPs were seen to actively assert their own power in relation to their patients. Women were hindered from seeking appropriate and timely support by a lack of knowledge and understanding from HCPs about BTL. The view that oedema in the breast area could be a temporary side effect from surgery or

radiotherapy contributed to delays in obtaining an accurate diagnosis. None of the participants could recall being told about the possibility of getting BTL prior to their treatment for breast cancer. While some women acknowledged that this could have been due to inattention as their focus was upon obtaining life-saving surgery, the absence of any reminder information – either basic or tailored to their own information needs – left them all unprepared for the development of BTL. In their feedback on the draft findings, the lymphoedema specialists also noted that patients do not retain all the information provided to them at the point of diagnosis. This sense of inattention - and therefore feeling personally to blame - is reported elsewhere (Acebedo et al. 2021). In this study, Sarah rationalised her lack of recall by explaining that she would have willingly signed the form for life-saving treatment irrespective of the potential side-effects, a phenomenon which relates to patients' readiness to receive information (Honnor 2009).

Barlow et al. (2014) and Conway (2016) also reported that HCPs' limited knowledge often left women who had treatment for breast cancer ill-prepared for the development of lymphoedema. While some participants in this study reported that their symptoms were mild or well managed, for others the impact was more severe. Several participants experienced a significant delay in obtaining an accurate diagnosis and accessing treatment, with the result that their symptoms became chronic and required lengthy, more complex treatment. Delays in accessing treatment led some participants in this study to seek out information online, although much of material was recognised as poor quality. In addition, the potential psychological impact of this delay is evidenced in the finding that a greater degree of breast lymphoedema has a negative impact upon body image (Adriaenssens, Verbelen et al. (2012) and distress (Degnim et al. 2012).

HCPs' lack of knowledge or inaccurate beliefs about lymphoedema has been reported elsewhere in Europe and beyond (Acebedo et al. 2021; Greenslade and House 2006; Hare 2000; Honnor 2009; Maree and Beckmann 2016; Ridner, Bonner et al. 2012; Thomas-MacLean et al. 2005). It was reflected in Greenslade and House's (2006) findings in the theme *abandonment* which denoted the absence of education about BCRL and an attitude of indifference from HCPs. Meanwhile, a Swedish qualitative study found that participants had been incorrectly told that lymphoedema would only

develop in the first months after treatment; and they had not been made aware of its chronic nature (Johansson et al. 2003). Joanna's incorrect massage advice from her GP is an example of the potentially damaging effects of misinformation from HCPs; similarly, Sandra experienced severe pain during a massage with a therapist who mistook her BTL for knots of muscle. The women in Ridner, Bonner et al.'s (2012) qualitative study and Paskett and Stark's (2000) small study of medical professionals reported conflicting beliefs and advice from HCPs about how to prevent or live with arm lymphoedema, with implications for its effective management. This poor understanding appears to continue today where patients may be blamed for the development of BTL, risking profound negative effects on patients who are already vulnerable.

The potential for further emotional harm is evident in patients not being believed by HCPs; a member of the study advisory group notably commented in her feedback that she had felt that she was 'imagining things' without an explanation for her symptoms of breast lymphoedema. Cheek's (1997) analysis of patient-HCP interaction illuminated the HCP's power to decide on what counts as legitimate knowledge, such that medical and scientific understanding is given priority over patient experience. For example, in Samantha's interview account, her consultants were shown to retain their authority by using their lack of knowledge about lymphoedema against her: having tested for and excluded several other differential diagnoses, she was treated as if "I was making it up and it's all psychological." However, Cheek (1997) suggested that the dominant discourses influencing healthcare practice also serve to disempower HCPs themselves because their scope of practice is firmly defined, placing limitations on their ability or willingness to seek new knowledge or alternative ways of understanding. Thus, women speaking out about signs and symptoms that are poorly understood by HCPs could be construed as a challenge to the knowledge and certainty in which healthcare aims to practice. From this perspective, HCPs' not-knowing is likely to be highly resisted to maintain the ideology that medical knowledge is superior to patient experience. Hence, to retain the power and stability of this discourse, challenges to knowing may be silenced among patients. This may explain why HCPs downplayed the significance of lymphoedema (Conway 2016; Ridner, Bonner et al. 2012), and why HCPs in South Africa adopted a form of denial by telling patients who

developed BCRL that they ought to just accept and live with lymphoedema (Maree and Beckmann 2016). In addition, a dismissive attitude may be argued to derive from the fact that troublesome side effects do not fit within the focus of the healthcare system upon life-saving treatments (Nielsen 2019). Lisa's perceived lack of incentive or political will to invest in and investigate treatments for lymphoedema is a further demonstration of the ways in which women experienced a sense of being misunderstood, ignored, or dismissed, contributing to women's sense of marginalisation (Ridner, Bonner et al. 2012).

Participant responses to the experience of BTL

Several women in this study expressed a fear that they would go on to develop lymphoedema in their arm, indicative of a sense of helplessness to prevent this occurring. Uncertainty surrounding the course of lymphoedema and its management may have a negative impact upon women who have BTL; an online survey of 166 women found that those who had lower expectations of control in managing BCRL (referring to the arm or chest wall) had significantly higher levels of distress (Alcorso and Sherman 2016).

Important aspects of patient readiness to receive and retain BTL information appear to include the timing and the need for a personalised approach. Consistency of information and signposting patients to appropriate information sources were recommended by the lymphoedema specialists and are reflected in Jackie's comments that she would have liked "a road map," even though at the time she realised that she was unwilling to receive the information. Conversely, a member of the advisory group commented that she had a need for as much information as possible to alleviate her anxiety. Hence this research revealed diverse opinions about the breadth and depth of information that women may want to receive. Indicating the threatening nature of being faced with unwelcome information, Jackie reported that participants at a lymphoedema session as part of a *Moving Forward* course had provided negative feedback. Meanwhile, generic patient information may be unhelpful for someone wishing to develop an understanding of their own circumstances (Leydon et al. 2000). The findings of Honnor's (2009) interviews with 16 women who had had breast cancer

suggested that there was not a one-size-fits-all to information provision. Most of the sample in Honnor's study perceived information as empowering and – had they received information - it would have supported them to cope, provided reassurance, and enabled them to seek earlier advice. At the same time, some women feared anxiety would have been provoked by too much information. One explanation to this negative reaction to information is provided from a study using in-depth interviews (n = 17) with women and men who had been diagnosed with cancer in the preceding six months (Leydon et al. 2000). The authors suggested a complex relationship between participants' feelings of hope and their information-seeking behaviour: while some actively sought out information, others avoided it, circumventing any threats to their hopefulness. The findings from this small study challenge the expectation that information is inevitably empowering.

Patients' psychological readiness is also a feature of their ability to comply with treatment. This is recognised by the lymphoedema specialists, who provide patients with the opportunity to return to the clinic if they currently feel unable to engage. In addition, noting that some patients attend the clinic on advice rather than because they have chosen to themselves, the specialists are alert to compliance issues. By inviting patients to discuss their barriers to compliance, a participatory approach is adopted. Patients are provided with the knowledge and skills with which they can make their own decisions; meanwhile the specialists offer compromises to fit in with patients' lifestyles. Despite this, it was acknowledged that patients may expect to be scolded for acting against advice, suggesting that a true patient-clinician partnership is difficult to achieve.

The influence of the COVID-19 pandemic on women's experiences of BTL

In the view of the lymphoedema specialists attached to the study, the effect of the COVID-19 pandemic would have heightened the findings relating to the extent of treatment delays. Patients had no face-to-face access to the lymphoedema service in the specialists' area of the United Kingdom, although the response varied in clinics across the country. Moreover, as women were unable to present with symptoms of BTL to their GP in the usual manner, referrals to the lymphoedema service were

delayed such that lymphoedema will be assessed at the later, more chronic stages when women finally do present at the clinic. The cumulative effect of the pandemic upon clinic waiting list times means that further delays are likely before women can be seen by a specialist. The consequence has been that patients have had to develop the skills to self-manage earlier than they would otherwise have done. Furthermore, patients may have had lower expectations of support at this time, reflected in the fact that demand for the specialists' online support was lower than anticipated by the lymphoedema specialist team.

Women's experiences of empowerment: developing expertise

Women's experiences of adapting to BTL and gaining expertise in their condition appeared to be empowering for them, although in their developing expert role they may receive either validation (such as from lymphoedema services) or resistance from HCPs, including GPs. The findings of this study show that the skills and experience of lymphoedema specialists and their ability to impart information to patients in an accessible way sit in stark contrast to the absence of information or support from HCPs which is often experienced prior to a diagnosis of BTL. With developing understanding, participants made their own self-care decisions. For example, several participants described how they accommodated the guidance they had received from the lymphoedema specialists about suitable types of bras to allow themselves occasions when they wore their own, preferred bras. While these bras may not have provided suitable support or inhibited swelling caused by lymphoedema, they allowed women to reclaim a sense of their own identity. This 'interruption' of self-care is reflected in the findings of Karlsson et al.'s (2015) qualitative study (n =16) with women who had had breast cancer. Meanwhile in the present study, Samantha expressed a clear conflict between the needs of her family and her own self-care needs. Although the complexity for women in attempting to address their multiple roles while adhering to self-care routines for their arm lymphoedema has been demonstrated by others (McGrath 2013; Radina et al. 2014), this study reveals this as a feature of self-care for women with BTL.

The superiority of the patient perspective over clinician assessment on many outcomes of breast cancer treatment has been acknowledged (Letellier and Mayo 2017). For instance, patients are clearly better placed to report upon physical symptoms such as pain or fatigue, sexual function, and mental well-being. Similarly, of note is the tendency for women in Leydon et al.'s (2000) study to value other patients' experiences and understanding over medical sources of information to support their treatment decisions. However, HCP resistance to patient attempts to deploy their superior knowledge is evident in this study. Sandra's account of being made to feel "so small" by her GP for requesting antibiotics to take away on holiday abroad with her not only reveals the GP's lack of knowledge about lymphoedema after breast cancer treatment but also an unwillingness to accept patient understanding as a legitimate knowledge source. The GP's response may be said to be "more authoritarian than authoritative" (Cheek 1997, p. 26). That is, her position as an HCP carries an assumption of "epistemic authority" of one who is well-informed. In fact, on this occasion she can be seen instead to be asserting power over her patient merely by drawing upon the legitimacy associated with her status as a medical professional, irrespective of her level of expertise on the topic. The challenge to patient as expert is to the detriment of good patient care.

The recent development of patient-report tools has the potential to further patient empowerment. A tool to enable patients to monitor themselves for signs and symptoms of breast lymphoedema during radiotherapy which is in development (Probst et al. 2021) will not only promote patient empowerment but could result in faster detection and diagnosis of breast lymphoedema. Elsewhere, a validated patient-report instrument for screening and assessing for breast lymphoedema¹⁵ has been reported to conference (Riches 2021) in addition to a validated QoL questionnaire for women with breast or chest lymphoedema (Riches; unpublished).¹⁶ Meanwhile, the Lymphoedema Patient Reported Outcome Measure (LYMPROM), which is argued to highlight patient priorities, is undergoing psychometric evaluation (Gabe-Walters and Thomas 2021). However, the researchers recognise that the outcomes may not relate entirely to lymphoedema but also to other health conditions or patients' wider social

¹⁵ The Breast Lymphoedema Symptom Questionnaire (BLSQ)

¹⁶ Lymphoedema Quality of Life Tool (LYMQOL) MIDLINE

and economic circumstances. Hence the further refinement of PROMs which can identify BTL symptoms and isolate their impact upon women also has the potential to improve patients' experiences as HCPs gain a better understanding and awareness of BTL.

Implications for practice

This section will consider the findings in relation to the anticipated benefits of addressing the silences which have existed around women's experiences of BTL. This will be presented in the form of recommendations for policy and practice, demonstrating how I intend to address the study objectives to create an environment for raising awareness and promoting positive change for women with BTL. Outputs include a presentation at the British Lymphology Society Conference 2021 (Appendix 29) and to staff and students in radiotherapy and oncology at Sheffield Hallam University in early 2022. The findings will also be shared with other women who have breast cancer through *Breast Cancer Now*.

The following recommendations are drawn from the study findings and informed by research literature. Although the findings arose from interviews with a small number of women, they have been shown to resonate more widely through consultation during TSF's analytic cycle with other individuals and organisations. In this chapter, I have shown that some of the findings are broadly reflected in the literature concerning women's experiences of arm lymphoedema after treatment for breast cancer, although there are some very specific differences for women with BTL which represent new understanding. The recommendations also incorporate suggestions from study participants. Those recommendations relating to information about BTL are aligned with the clinical guideline *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services* (CG138, updated 17 June 2021), section 1.5 'Enabling patients to actively participate in their care.' (National Institute for Health and Care Excellence [NICE] 2012; updated 2021).

Key theme: Mysterious BTL

Key message: Patients who undergo treatment for breast cancer need information about BTL; this needs to be tailored to the individual patient and repeated at different time points in the breast cancer treatment pathway.

None of the women who participated in this study had known about the possibility of BTL as a side effect of their treatment for breast cancer, leaving them unprepared for its development and often resulting in psychological distress.

*Recommendation one: provide patients with information about BTL in a **consistent, personalised** manner at **repeated opportunities**.*

Improving patient awareness is a key recommendation arising from the study findings. Information needs to be delivered in a personalised way regarding the timing, format, content, and level of detail, to ensure that anxiety and distress are alleviated rather than increased. The support of lymphoedema specialists will be valuable in developing suitable strategies and resources.

Patient information needs to be consistent

Women who have treatment for breast cancer are at risk of receiving inconsistent or inaccurate information about BTL and its management due to limited understanding among HCPs. There is a need for consistency to ensure that women understand the symptoms and appropriate management techniques. The fact that clinicians and patients may have different views about patients' information needs (Bolderston 2008) indicates a need for HCPs to be alert to different patient priorities and preferences. For consistency, the optimum approach would be the development of a co-designed information resource for adoption on a national basis.

Patient information needs to be personalised

The accounts of women in this study, and those from the advisory group who provided feedback, demonstrated that women's needs differ, and this is reflected in other research findings (Aunan et al. 2019; Honnor 2009). Some women may want access to as much information as possible, while others may prefer to avoid information. Tran et al.'s (2017) finding that lymphoedema websites are beyond the understanding of the average adult in America in relation to their readability and complexity suggests that for women who do wish to access online information, more work may be needed to ensure that information is clear and comprehensible. Meanwhile, the potential of audio-recorded consultations for improving satisfaction and recall (Ong et al. 2000) indicates that audio as well as visual strategies could be employed.

Patient information needs to be provided at repeated opportunities

Many women in the present study reported that they could not recall being told about lymphoedema (of any type) as a potential side effect of surgery or radiotherapy for breast cancer. These findings are reflected in a systematic review of qualitative research which was conducted to determine the effect of information about BCRL upon women's experiences (Conway 2016). This review of four studies found that 43 out of 88 women reported receiving minimal or no information about BCRL. Patient readiness to receive information appears to be a contributory factor: at the time of consent to surgery and radiotherapy some women may be unable to absorb detail about BTL and other potential side effects alongside the impact of receiving a breast cancer diagnosis. This is supported by Aunan et al.'s (2019) focus group study in the theme *Balancing the need for and the fear of information*. Repetition has been demonstrated to be an important feature of information-giving (Aunan et al. 2019): the circumstances in which women receive information may influence their ability to retain and recall it, reinforcing the need for information to be provided at different stages of the treatment pathway. Possible timepoints for information-giving about the risk of BTL include at the pre-treatment and treatment stages, followed by more detailed information and signposting to other sources after treatment.

Key theme: You meet a wall

Key message: HCPs' lack of understanding of BTL and its consequences for women threatens the quality of care. Women who remain uninformed about BTL risk being marginalised and disempowered.

The findings indicate a clear and urgent need for increased understanding and awareness of BTL among HCPs in clinical breast cancer settings. This is supported by the 'collective voices' and the experiences of other patients gleaned from posts on online breast cancer support forums, demonstrating their transferability beyond the study participants. The study revealed many examples of the negative impact on women of poor awareness and understanding of BTL among HCPs. One aspect related to patient readiness: some HCPs appeared to have unrealistic expectations about patients' ability to retain information at the time of consent to treatment, such that they assumed that women were aware thereafter about lymphoedema as a potential side effect. In this study, Alice commented upon the potential for HCPs to make false assumptions about patients' levels of knowledge and understanding and their willingness and ability to seek advice about symptoms.

Recommendation two: improve HCPs' knowledge and understanding about the symptoms of BTL, its management, and the potential impact of a diagnosis upon women

HCPs need education about the symptoms of BTL and its management

Information about the assessment and treatment of BTL should be provided to HCPs who treat women who have breast cancer. Education for HCP students will ensure that future practitioners have the knowledge to provide good patient care. One of the benefits would be preventing misdiagnoses and inappropriate treatment, such as antibiotics for presumed cellulitis. HCPs should also be aware that BTL can be managed and have knowledge of the referral pathway to their local lymphoedema service. They should be alert to the possibility of lymphoedema developing in different regions of the trunk as well as the breast, including the chest wall, back or armpit. In

conjunction with HCP education, patient self-monitoring of breast symptoms (Probst et al. 2021) will improve communication between women and HCPs. The benefits could include recording the fluctuating nature of symptoms such as swelling, preventing an over-reliance on HCP assessment at the time of the appointment only.

HCPs need education about the potential impact upon women of a diagnosis of BTL

The findings of this study demonstrate the potential physical, emotional, and practical consequences for women of developing BTL. Often women reported feeling overwhelmed when they were first diagnosed with lymphoedema - a life-long condition - following their treatment for a life-threatening disease. The attitude of HCPs is an integral part of women's experiences. Apportioning blame to women for developing lymphoedema is clearly unhelpful and may cause psychological harm. Verbelen et al. (2021) noted that there is no consensus within the literature about risk factors for breast lymphoedema and anticipated that women are probably unable to alter those risks. Therefore, HCPs should be sensitive to their position of power over patients at a time when they are vulnerable and ensure that they do not inappropriately place responsibility upon women for developing BTL.

Theme: The silent consequences

Key message: Many women with BTL reported negative physical, emotional, and social consequences of developing BTL which remain unheard by others

Despite their experiences of physical and emotional pain and discomfort, many participants told stories of not feeling heard either by HCPs, friends, or bra retailers, resulting in feelings of isolation and exclusion. The side effects of treatment for breast cancer such as BTL were not accorded the same significance or understanding as breast cancer itself. Frequently, women appeared to be stifled by the dominant discourse of positivity and survivorship, such that they felt compelled to remain silent about their concerns with friends and family. The sub-theme *The final straw* captured

some women's despair at the new and unanticipated challenges of BTL after having coped with breast cancer and its treatment.

Recommendation three: raise awareness of the psychosocial and physical impact of living with BTL among HCPs and more widely

Information about the impact of BTL needs to be captured within HCP and patient education resources, ensuring a patient-centred rather than a symptom-driven approach to care and lifting the silence around BTL's consequences for women.

Theme: Adapting to BTL

Key message: Participants developed expertise through their experiences of BTL. Not only was this empowering for them, but sharing their expertise has the potential to help and empower other women.

All the participants spoke about ways in which they had adapted to BTL. Participants' developing expertise was empowering; and they were able to identify ways in which their knowledge and understanding could improve services and help other women.

Recommendation four: Harness patient knowledge and experiences of BTL within resources for patients and HCPs.

It was evident in the study that participants had gained expertise in managing their BTL, knowledge that could be drawn together to produce a resource for future patients. Several participants indicated that by taking part in this study, they hoped that the experiences of future women with BTL would be improved through raised awareness and education. That they appreciated the opportunity to take part is indicative of the marginalised status of their experiences of BTL (Ridner, Bonner et al. 2012).

Recommendations for follow-on research

The recommendations in the previous section are addressed below in a series of proposals for future research.

Proposal one: Development of patient resources about BTL

Develop *resources about the diagnosis and management of BTL* which are co-produced by patients who have experienced BTL to equip women with the information required to identify symptoms, gain appropriate support, and manage their symptoms effectively. Resources should meet a range of needs, allowing access to more detailed information to those women who want to know more about the condition. In addition, it would be valuable to draw upon the expertise of the lymphoedema specialists for information about aspects of BTL management.

It is also proposed that *an approved educational video* to support training in self-care techniques, including simple lymphatic drainage, should be co-designed with patients, lymphoedema specialists and the British Lymphology Society. While the COVID-19 pandemic has heightened the potential detrimental impact of a lack of access to lymphoedema clinics, it has created an opportunity to broaden patient support by developing effective remote support resources alongside in-clinic face-to-face contact. An educational video could address the lengthy waiting times for assessment by a lymphoedema specialist in some parts of the country. The length of delay is important because breast lymphoedema can significantly worsen if left untreated. This resource could also supplement the training offered to patients at the lymphoedema clinic once they have been seen, alongside early signposting to appropriate websites to counter the misinformation available on the internet.

Finally, under this proposal it is suggested that a patient resource be developed, in conjunction with the Lymphoedema Support Network, of *tips and recommendations from women* about managing BTL. It was evident from the women who participated in the study that they had a wealth of expertise; and many were willing to share this for the benefit of others. Developing such a resource may provide the impetus for creating other forms of mutual support for women with BTL.

Proposal two: develop methods and resources to increase the speed of BTL diagnosis and treatment

The findings of this study confirm the need for prompt diagnosis and treatment of BTL. It is suggested that women who have been treated for breast cancer have *access to symptom advice about side effects* from treatment, including BTL. Several participants in this study made suggestions for improvements in how women's unfamiliar symptoms could be addressed by the health service. Their suggestions tackle the perception of a compartmentalised health service in which there are dedicated HCPs for one aspect of care, such that HCPs are often unable to obtain a more holistic overview of the patient. Proposals included a keyworker, or a HCP with the expertise and time to listen to women's concerns about their symptoms and consider possible diagnoses; or a drop-in service to allow for early symptom assessment, thereby providing reassurance to women who may be anxious.

It is proposed that *affordable methods of detecting BTL* in healthcare settings are developed to expedite an accurate diagnosis. Feedback from the lymphoedema specialists engaged with this study revealed that currently breast lymphoedema is often not detected until the patient is assessed at the lymphoedema clinic, with the original referral often having been made for lymphoedema in the patient's arm. There is some evidence that tissue dielectric constant (TDC) measurements could be used to screen for women with breast lymphoedema, with onward referral to the lymphoedema clinic for a more in-depth assessment (Riches 2020). TDC measurements have also been found to detect trunk lymphoedema (Koehler and Mayrovitz 2020). Future research is also planned to determine whether surface imaging as an objective assessment technique could identify breast lymphoedema, taking measurements at the start, during and post-radiotherapy to potentially identify early onset of lymphoedema and expedite onward referral.

While ultrasound measurements (US) are an alternative, the associated costs and training needs may prohibit the wholesale introduction of this technique. In addition, Kilbreath et al. (2021) reported a poor to non-existent association between measurements of dermal thickness in the breast using ultrasound and PROM scores for

the EORTC QLQ BR23 and LSIDS, indicating the importance of establishing the patient perspective. A PROM which may be beneficial in the clinic setting is the Breast Edema Questionnaire (BrEQ). Originally developed in Dutch and taking five minutes to complete, it has been translated into English although further research is required for the translation to be validated (Verbelen et al 2021). Not only does the questionnaire assess for breast lymphoedema, it also contains items which enable clinicians to understand the impact of breast lymphoedema on daily functioning.

Patients should also be consulted about the feasibility of *a symptom alert system for breast lymphoedema*. This proposal is prompted by the experiences of some participants who had feared that their symptoms were a cancer recurrence. A self-assessment tool has the potential to improve women's understanding and confidence to seek help, thus empowering them. In the present study, there was some evidence that breast swelling may not be understood as a sign of lymphoedema, supporting use of a self-monitoring tool to encourage the early identification of signs and symptoms of breast lymphoedema (Probst et al. 2021). Not only would this enable HCPs to diagnose and refer for treatment as early as possible, but it would also reduce patient anxiety and improve women's confidence in the HCPs treating them. Support for this strategy is provided by Nahum et al. (2021) who report a study into the use of a touchscreen device by patients to record lymphoedema symptoms while waiting in the outpatient clinic for their appointment. The finding that more than 70% of 321 patients indicated that the tool had enhanced their knowledge of lymphoedema symptoms and prompted self-monitoring is further evidence for this approach.

Assessment tools must also reflect the development of hypo-fractionated radiotherapy schedules such as those in the FAST-Forward trial (Brunt et al. 2020) which provide patients with one week rather than three weeks of treatment but risk more severe side effects from a higher radiation dose per treatment fraction.

This study indicates that there is limited access to lymphoedema services and limited treatment options. It appears that lymphoedema services are currently not accorded high priority and may even be reduced in some areas; in this study, Charlotte reported that to date, she had been unable to get any treatment for her trunk lymphoedema. Quicker access to treatment has the potential to improve outcomes for women. There may be opportunities to broaden patient support by developing effective remote

support resources alongside in-clinic face-to-face contact. This is aligned with the proposal to develop an approved educational video for patients to consolidate learning about self-massage techniques for simple lymphatic drainage.

BTL and its consequences, such as fatigue, may warrant formal recognition as long-term health conditions to support the proposed developments.

Proposal three: Develop an understanding of the experiences and needs of Black and Asian women who have BTL

As no Black or Asian women engaged with this study, their experiences are not represented in the findings. Further research is warranted to *develop an understanding of the needs of Black and Asian women with BTL*. There needs to be a considered approach to engaging Black and Asian women which does not rely upon White, Western assumptions of their needs and expectations, and instead involves developing relationships with Black and Asian communities to increase trust and understanding. In Chapter 4, I commented upon poorer QoL outcomes for younger Black women (Samuel et al. 2016) and African American women (Ashing-Giwa et al. 1999) than White women who have breast cancer. Hence the experiences of Black and Asian women who have BTL may be different from those of White women. The interplay of higher comorbidity levels and poorer socioeconomic status among Black and Asian women, as well as other variables such as the impact of women's spiritual and religious beliefs, may become clearer if Black and Asian women can be engaged in future qualitative research about their experiences.

Proposal four: Raise public awareness about BTL as a side effect of treatment for breast cancer

The ongoing consequences for women of BTL such as fatigue appear to be under-recognised in the workplace. It is proposed that *an educational resource* is produced for *workplace settings* about the impact of possible side effects from treatment for

breast cancer including BTL, so that suitable adjustments can be made for women at work.

Likewise, it is proposed that designers and developers are provided with information about the needs of women who have BTL. In this study, experiences of discomfort and changing body shape were shared by participants, some of whom were living with breasts of different sizes. The need for adjustable bras was highlighted, although bespoke bras were noted to be expensive and may not appeal to all women. There is other evidence of the need for improved bra designs. In a survey by Gho et al. (2010) of women who had been treated for breast cancer ($n = 74$), bra discomfort was reported to interfere with physical activity; while a subsequent survey ($n = 432$) determined design features of an exercise bra (Gho et al. 2014). Meanwhile, LaBat et al. (2017) obtained the views of 51 women who had treatment for breast cancer about wearable products, urging designers to make improvements. Further developments include an application for research to test the effectiveness of bespoke bras made of materials which promote lymph drainage, providing massage to the oedematous breast (National Breast Cancer Foundation; Grant number: NC-06-02). In the present study, Lisa reported having ongoing difficulties over several years getting her prescription for lymphoedema compression garments correctly fulfilled from a private company. While this relates to compression sleeves in this instance, the concern that patients may not realise that they have been provided with an unsuitable garment which could worsen their lymphoedema is important to note for any future developments.

Study limitations

Sources of bias

I am conscious of sources of potential researcher bias, such as the inclusion of one study participant who was already known to me as a colleague and friend. In fact, her academic background is likely to have attuned her to my needs as a researcher and I felt that the resultant interview was rich in terms of a narrative which was on-topic and supported by images with the potential for high impact in awareness-raising

activities. There was also bias in the researcher-found photograph set. In selecting some copyright-free images from websites, I noticed that many of the photographs depicted young, White females; I was unable to represent a range of ethnic backgrounds and older women. Despite this, during her interview Sharon drew several times upon the one photograph of an older woman that I had located: a picture of an Asian woman who was perceived by Sharon to be expressing despair. Evidently the image resonated with Sharon due to the emotion portrayed, suggesting that a shared ethnicity was of secondary importance.

Participant empowerment and photographic methods

Although many participants were likely to have owned digital devices with camera functions, I could not assume that they would all be willing and able to use them. Sharon clearly had her own digital device and yet chose to use a disposable camera, placing her in control of the choices made. However, there were limitations associated with her use of a disposable camera which carried implications to the extent that it could be an empowering method. Specifically, Sharon was unable to see the images that she had captured before they were developed from the camera. She commented on her inability to review her pictures beforehand during her interview. It transpired that several of her images were obscured shots. If Sharon had control of the images herself, she could have reviewed, retained, deleted, and retaken them as she wished. Hence this method served to keep control in my hands as the researcher and made Sharon vulnerable to feelings of uncertainty about the images and inadequacy if they did not meet her expectations (Packard 2008).

The adequacy of the research question

It is claimed that a qualitative research question can signpost the underpinning theory, which may be explicit or implicit (Agee 2009). As my research question - what are women's experiences of developing and living with breast or trunk lymphoedema after surgery and radiotherapy for breast cancer? - lends itself to a purely descriptive answer, I appreciate that my aim to explore these experiences critically is not clear from the question alone. Nevertheless, TSF prompted me to consider the social and

cultural contexts which influenced the stories that women shared with me. In addition, one of the questions put to all the participants at the end of their interview – do you think that there is anything specific about living in today’s society that has affected your experience of breast or trunk lymphoedema? – was intended to reflect the theoretical underpinnings of the study by allowing participants to consider the social, political, and cultural context of their experiences.

The effectiveness of the recruitment strategy

Although the recruitment poster and patient information sheet had been reviewed by the study advisory group, it transpired that the recruitment material was confusing to some potential participants, or contested by them. Some women believed that I was requesting photographs of their BTL - that is, of their breasts or trunk - even though the role of photographs in the study may have been explained to them by the lymphoedema specialists at the recruiting clinic. To address this confusion once I became aware of it, I shared with subsequent potential participants an example of an image from the researcher set and provided some suggestions for how it might be used to convey an experience. Lisa’s strong negative reaction to the visual component of the recruitment material also indicated that some women would be more comfortable expressing themselves in words only. Meanwhile, I had taken it for granted that potential participants would be familiar with terms such as ‘trunk’; however, one participant mistook it for reference to the arm. Similarly, the word ‘transcribe’ was not universally understood. In another example, Sandra took issue with my use of the phrase ‘living with’ in relation to BTL, as she felt that she was managing rather than living with the condition.

The lack of ethnic diversity in the study sample is an important limitation. No participants from Black or Asian ethnic backgrounds were recruited to the study, despite people from ethnic minority backgrounds comprising 13% of the population in England and Wales (ONS 2013). The study was advertised to Black and Asian women via several local and national organisations (detailed in Chapter 5) but there was no response. There may be several reasons for this apparent lack of interest in the study. A large prospective study which included 5877 South Asian and 4919 Black women

showed that the incidence of breast cancer was lower in South Asian and Black women than in White women (RR = 0.82 and 0.85 respectively; 95% CI 0.72-0.94 and 0.73-0.98 respectively) (Gathani et al. 2014); consequently there will be fewer women who have BTL among Black and Asian populations. At the same time, there are cultural sensitivities to consider which may prevent Black and Asian women from participating in research. In their literature review, Bedi and Devins (2016) reported a stigma surrounding breast cancer in South Asian culture; an expectation that South Asian women with breast cancer will downplay their health concerns; and embarrassment among women about discussing issues related to their breasts. Women may also be reluctant to talk about breast cancer (Baird et al. 2021), even with members of their own communities (Thomas et al. 2005) due to the perception that a family's social status will be affected by the disease (Bedi and Devins 2016) and more widespread fatalistic beliefs among Black and South Asian women about God controlling their breast cancer (Patel-Keraiet al. 2017).

Style of interviewing

Adopting an open-ended interview approach enabled participants to direct their storytelling. As some participants spoke about the impact of BTL on their close relationships, it can be argued that this style of interview was successful in making women feel comfortable to share information that was important to them. However, the approach prevented me from probing for answers to specific issues which could have been achieved using an interview guide (Acebedo et al. 2021). For example, in TSF stage 1: *working in silences* which was discussed in chapter 4, the significance of spiritual beliefs was highlighted as a mediating factor in some women's responses to managing arm lymphoedema (Ridner, Bonner et al. 2012). Although religion was not mentioned by any of the participants in this study, it cannot be assumed that this was not an important feature for some of them.

In maintaining an open approach during the interview, on reflection I would say that I adopted a relatively 'non-responsive' stance, other than occasionally seeking further detail by encouraging participants to 'tell me a bit more.' Similarly, other researchers such as Golding and Hargreaves (2018) reported that they refrained from disturbing

the 'flow' of the participant as far as possible, in keeping with an oral history interview. However, in her discussion of the LG, Gilligan (2015) described the 'relational moves' required of a researcher who is working within a relational approach. This means that rather than accepting the apparent meaning of a participant's comments, a relational attitude might prompt the researcher to ask why the participant thought in a certain way, thereby providing an opportunity for the participant "to say or even to know what they know" (Gilligan 2015, p. 73). Gilligan (2015) provided an illuminating example in which the 'voice' initially used by the participant is joined by another, quite different 'voice', which is only uncovered by this form of careful, responsive questioning.

During the interviews I focussed upon the verbal and visual rather than embodied cues from participants; in my reflective diary I make no mention of body language, even though this has been argued as important to attend to (Parr 1998). However, there were limitations imposed by the interview design, as at times the participant and I were looking at photographs rather than at each other; and of course, some interviews were conducted over the telephone. In the end, whether the interview took place on the telephone or face-to-face did not feature in the analysis. This may not have been a significant limitation: Sturges and Hanrahan (2004) reported no differences in the richness of the data collected during telephone interviews compared with face-to-face encounters. Moreover, a telephone interview may have appealed to some participants who were more inhibited about talking of their experiences of BTL, as well as widening the study to include women who lived far away (Elmir et al. 2011).

Another outcome of using an open style of interviewing was that women's accounts were not always strictly on-topic. Inevitably, women's experiences of developing and living with BTL were bound up in those of breast cancer and its treatment; moreover, some women were living with arm as well as BTL. It seemed that there were times when it was not possible for participants to separate out their experiences and share with me solely those that related to BTL. This difficulty was recognised by participants themselves, such as Samantha: "I know you can't untangle how much of that is the lymphoedema ... it all merges in, doesn't it?" and Sarah: "I suppose it's difficult, in a way, to separate the trunk lymphoedema from the arm ... from the fact that I had the breast cancer and the treatment." While this is to be expected due to the nature of

human experience, it presents a challenge during the analysis to attempt a focus upon BTL to support the credibility of the findings. Throughout the analysis, I have made decisions about what counts as evidence to support the research question and what could be considered contextual but not directly relevant. In excluding direct reference to these other experiences from the analysis, such as some women's descriptions of chemotherapy and its side effects, my intention was not to silence women further but to maintain the integrity of the analysis. However, I acknowledge the significant physical, mental, and emotional impact of these experiences which could also affect their experience of BTL. Other issues raised by participants which inevitably impact upon women's overall experience of breast cancer and not just BTL included the consequences of ageing.

Limitations relating to the process of data analysis

In seeking participants' feedback on their individual draft themes, I sent participants a document containing the themes (with accompanying explanations) alongside their anonymised interview transcript. With hindsight, I realised that I provided no explanation for sending the transcript, although my naive intention was for it to act as a reference and a reminder to help participants make more sense of their themes. In fact, Forbat and Henderson (2005) noted that presenting participants with their interview transcript can be intimidating rather than empowering. For example, the transcript may capture the ungrammatical speech of informal talk. Although unsolicited information, several participants commented on their transcripts in relation to how they were represented. Samantha remarked on how much she had talked. Tilly, on the other hand, voiced concerns about how other women might perceive some of her responses; and she noticed that she 'gave my feelings a lot,' indicating a sense of vulnerability. These concerns were reflected by those of participants in two studies about informal care (Forbat and Henderson 2005). In the present study, Catherine raised the question of whether some women might have benefited from being alerted to the potential impact of reading their transcript. I returned to those participants who I identified as potentially having been caused some distress by reading the documents, to acknowledge this possibility and to signpost them to support; however, no participant reported having been harmed by the

process. On the contrary, Leah indicated that reading her transcript had been a positive experience, observing a 'marked improvement' in her emotional state since the time of her interview.

The length of time between participant interviews and seeking their feedback (in some instances, up to two years) had clear implications for the ability of some women to comment on the themes, notably Zoe remarking that she did not recognise herself in them, "but it seems a long time ago." From a methodological perspective, presenting participants with a 'frozen' narrative is antagonistic to the changing nature of accounts according to social constructionist beliefs, although obtaining the *silences dialogue* from participants using TSF allows for adjustments to be made to the resulting themes.

Conclusion

To my knowledge, this small, exploratory study is the first published research to investigate women's experiences of developing and living with BTL. Adopting TSF as the study's theoretical underpinning enabled me to critically examine the silences surrounding women's experiences. The findings confirm silences around BTL in healthcare settings, across a range of HCPs responsible for breast cancer treatment and follow-up. They also reveal silences in workplace settings in the form of a lack of acknowledgement of women's needs; and within the retail industry, reflected in the limited availability of suitable bras. As a result of the silences, participants are shown to experience several forms of disempowerment.

Employing a method of analysis that places women's voices at its centre ensured that women's perspectives were not lost in the researcher interpretation. Women were offered some authority as they were provided with an opportunity to influence the final findings during TSF's cyclical process of analysis. Moreover, the credibility of the findings and their potential for wider application was enhanced by securing the opinion of the wider network of individuals or organisations with experience of BTL. This is significant for attempts to raise awareness among clinicians, patients, and

patient organisations if the results are to be taken seriously in the healthcare context and beyond.

The findings demonstrate important new understanding about the complexities of developing and living with BTL, much of which is distinct from women's experiences of arm lymphoedema and provides an original contribution to knowledge. Women with BTL are marginalised due to an absence of patient information and a lack of understanding of BTL among HCPs. In addition, the social sensitivity and relative invisibility of the breast area, alongside a failure to legitimise BTL symptoms as they remain poorly understood, create a situation where women do not appear to be routinely physically examined or otherwise monitored for BTL after treatment for breast cancer. For women with breast or chest wall lymphoedema, the fact that swelling occurs around the site of their breast cancer is seen to generate anxieties about the possibility of a cancer recurrence. Meanwhile, the tension between the patient's growing expert knowledge and the relative ignorance of the HCP about BTL is clearly demonstrated in examples of HCPs asserting their medical status to the detriment of some participants' health. Women are seen to be further marginalised in their relationships with friends and family and at work due to the relative invisibility of BTL and its consequences, such as fatigue. Moreover, BTL negatively impacts upon women's feminine and sexual identity due to the requirement to wear compression garments on the breast or chest area. There is also a complex relationship between HCPs' poor understanding about BTL and the ability or readiness of some women either to take in information about treatment side effects or to acknowledge their BTL symptoms. The high profile of arm lymphoedema in patient information compared to that of BTL reinforces the lack of attention accorded to BTL. These silences around BTL combine to promote inaction, leading to diagnostic and treatment delays.

This study also adds to the existing body of knowledge about the use of visual methods to increase understanding about human experience. Photographs and drawings were found to be an acceptable way of supporting and enhancing the verbal account of many of the participants. The images used by participants provide an additional medium through which the findings can be presented; and as a result, they may have a broader appeal to a variety of audiences, improving understanding about women's experiences of BTL.

There are silences which remain and were created by undertaking this research. These include the lack of representation from Black and Asian women, who remain silenced as a result. Other remaining silences include the voices of women who may have been deterred from participating by the invitation to use photographs. Finally, some of my own actions or status as an HCP, as the researcher or as an outsider may have had a silencing effect upon participants.

Nevertheless, the findings from the study have several implications for practice to improve women's experiences of developing and living with BTL. They include the need for better information and education of both HCPs and women themselves, with suggestions made for harnessing women's expertise about BTL to create patient resources. This study has also indicated several avenues for future research, including co-developed educational material and self-monitoring tools for signs and symptoms; and research to understand the experiences of Black and Asian women. I have also made suggestions for service improvements to increase the speed of diagnosis and treatment of BTL, as well as proposals to improve women's experiences outside of the healthcare setting, such as raising public awareness in workplaces and engaging with bra designers and developers.

Nielson (2019) advocates "criticality" to appreciate patients' disparate and complex experiences of illness. In presenting the findings from this study, I have attempted to draw out the key features of women's stories, both positive and negative. Drawing upon Nielson's reflection upon 'ethical storytelling' prompts me to consider the impact of these findings for other women. Many of the findings from the present study relate to negative experiences recounted to me by participants. As they run counter to many of the accepted breast cancer narratives available to women which emphasise positivity and successful outcomes, they may be uncomfortable for other women to hear. As an honest account of women's experiences, however, they are arguably more empowering to other patients in enabling them to be better informed and prepared for the possibility of BTL.

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Appendices

Appendix 1: Breast cancer – medical context

1. Epidemiology

Although there are many factors associated with the risk of breast cancer, in fact it is thought that for approximately half of all women who develop the disease there is no recognisable risk factor beyond being female and getting older (Jagsi et al. 2019). The incidence of breast cancer rises with increasing age: across Europe in 2020, there were an estimated 62 806 new cases of breast cancer in women under 45 years old, compared to 468 280 new cases in women aged 45 years and older (World Health Organization International Agency for Research on Cancer (IARC) (2020c). Incidence by age increases until menopause when it flattens out (Jagsi et al. 2019).

Family history is also an established risk factor for breast cancer, although it is estimated that between only 5% and 10% of breast cancer cases are due to a genetic susceptibility (McPherson et al. 2000; Jagsi et al. 2019). Specifically, mutations in the breast cancer genes BRCA1 and BRCA2 are believed to be responsible for 5%-10% of cases of breast cancer in women. According to a meta-analysis of ten studies, the cumulative risk at 70 years old is estimated to be 57% for BRCA1 (95% CI, 47% to 66%) and 49% (95% CI, 40% to 57%) for BCRA2 mutation carriers (Chen and Parmigiani 2007). Women who are deemed to have a significant family history of breast cancer in the absence of BCRA mutations are estimated to have a four-fold risk of developing breast cancer (Metcalf et al. 2009). Other cancers, including male breast cancer, are also associated with BCRA1 and BCRA2 mutations (Jagsi et al. 2019); and current clinical guidelines include updated information on the hereditary link associated with the PALB2 gene (Tischkowitz et al. 2021).

For many women, there appears to be an association between developing breast cancer and reproductive hormones, especially oestrogen. An early age at menarche, nulliparity, a first full-term pregnancy at a later age and late-age menopause are factors which increase breast cancer risk (Jagsi et al. 2019). For women who are nulliparous, the risk ratio (RR) is 1.4 compared to women who have given birth. After the menopause the risk is increased in women who are obese and in those using post-menopausal hormone replacement therapy (HRT). In a randomised trial with 16 608

women, using oestrogen combined with progestin was found to increase the risk of developing breast cancer (hazard ratio (HR) 1.24, $p < 0.001$) (Chlebowski et al. 2003).

Contrary to the findings of some observational studies, there is evidence that fat intake is not associated with risk of breast cancer (Alexander et al. 2010; Prentice et al. 2006). However, alcohol consumption is positively associated with risk of the disease (Jagsi et al. 2019). Women who are obese, that is with a body mass index (BMI) > 30 compared to < 25 , have an increased risk (Willett et al. 2014), although the association is complex as there is a lower incidence of breast cancer in obese women before menopause (Jagsi et al. 2019). Hence there is evidence for the benefits of physical activity in managing weight gain in postmenopausal women (Willett et al. 2014).

The density of the breast has been shown to be a clear risk factor for breast cancer (Jagsi et al. 2019). Compared to women with $< 10\%$ breast density, those with 75% density or greater were shown to carry an increased breast cancer risk (odds ratio 4.7, CI 95% 3.0-7.4) (Boyd et al. 2007). Breast density is influenced in large part by genetic factors although it alters with the presence or absence of postmenopausal HRT. Meanwhile, proliferative benign breast tumours are associated with an increased risk of breast cancer (Willett et al. 2014), in particular atypical tumours where $RR = 4.0-5.0$ (Jagsi et al. 2019).

Breast cancer risk is increased by exposure to radiation. This is more pronounced for younger women; exposure before the age of 30 has a relative risk > 4 (Jagsi et al. 2019). Meanwhile, women who received thoracic mantle radiotherapy for Hodgkin lymphoma are at greater risk of developing bilateral breast cancer (Elkin et al. 2011). Neither organochlorines nor electromagnetic fields appear to carry a significant breast cancer risk (Jagsi et al. 2019; Willett et al. 2014), however.

2. Natural history of breast cancer

Although incidence rates of ductal carcinoma in situ (DCIS) have increased since mammographic screening was introduced (Chootipongchaivat et al. 2020), there is limited knowledge of the natural history of preclinical DCIS. At the same time, an inadequate understanding of the natural history of DCIS presents difficulties for its

management (Jagsi et al. 2019). Knowledge of the natural history of breast cancer is not straightforward as it suggests examining the natural course of breast cancer without any treatment. However, several methods have been employed to define the natural history of DCIS. One is the use of observational studies to explore the outcomes for women who are diagnosed with DCIS but do not have surgery. In a review of 89 women whose DCIS remained un-resected for at least one year post-diagnosis, Maxwell et al. (2018) identified risk factors for the development of invasive breast cancer including high grade DCIS (cumulative incidence of invasion $p = 0.0016$, log-rank test). The frequency of invasion was higher in tumours with calcification ($p = 0.042$) and in younger women ($p = 0.0002$). The absence of endocrine therapy was also a risk factor.

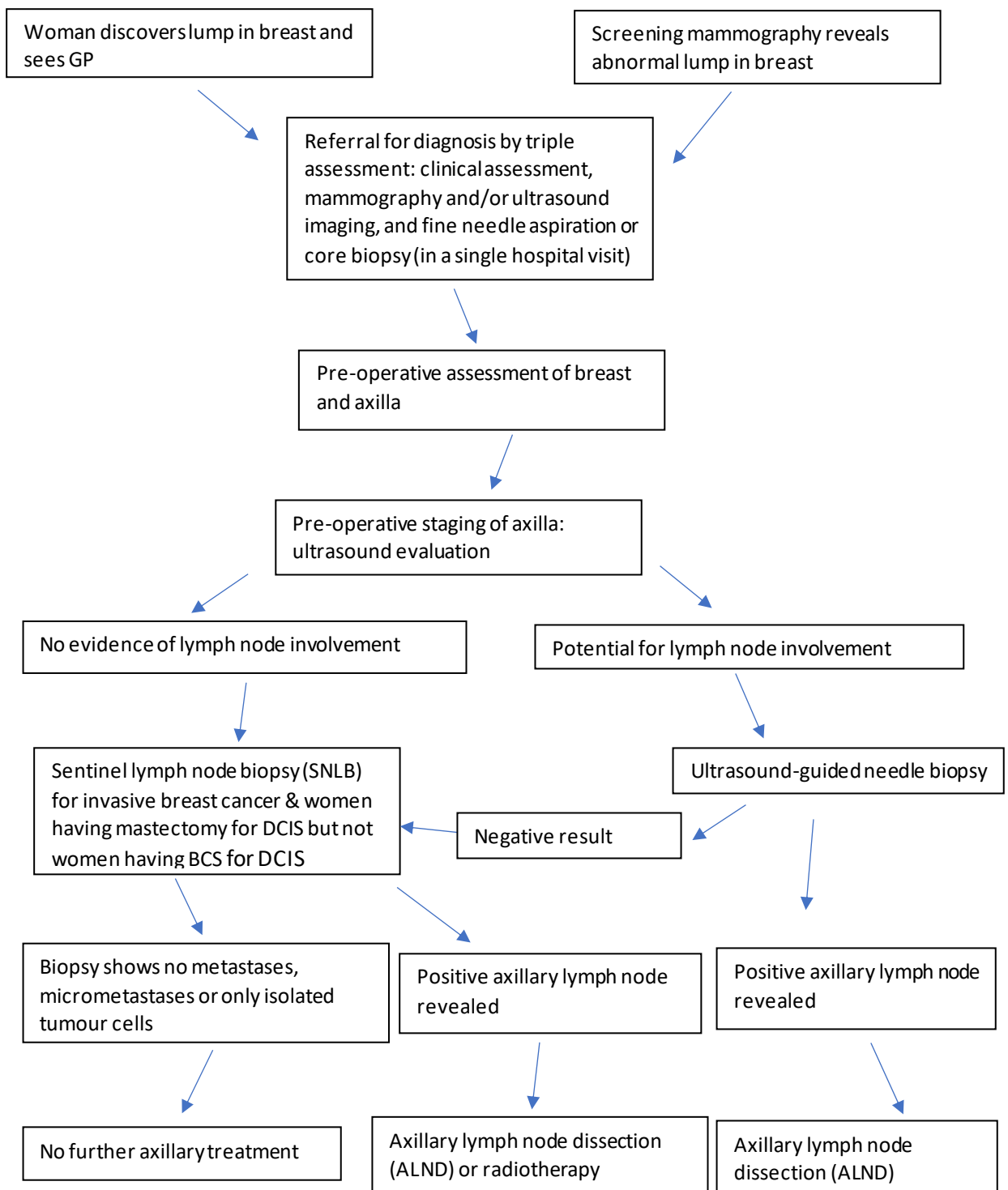
Another approach to determining the natural history of DCIS employs mathematical models incorporating clinical data and data from studies of mammographic screening to estimate disease progression (de Koning et al. 2005). Chootipongchaivat et al. (2020) developed an alternative modelling method that adopted validated population-based models of incidence and progression which incorporated incidence data on breast cancer. The findings indicate that most DCIS tumours which are detectable by screening but have not been biopsied do progress to invasive breast cancer. However, the range of DCIS subtypes indicates that further research is required for a fuller understanding.

3. Presentation and diagnosis of breast cancer

Breast cancer diagnosis in the UK occurs through two main routes: through the national screening programme or through self-referral to a GP following identification of a breast lump. Patients with suspected breast cancer subsequently undergo a triple assessment at a breast clinic involving a clinical assessment, mammography and/or ultrasound imaging, and core biopsy and/or fine needle aspiration cytology (see Figure i).

Figure i: Breast cancer treatment pathway for England and Wales, with particular reference to axillary treatment

Information obtained from NICE guideline NG101 'Early and locally advanced breast cancer: diagnosis and management' at <https://www.nice.org.uk/guidance/ng101> 18 July 2018; and Quality standard QS12 at <https://www.nice.org.uk/guidance/qs12> updated 16 June 2016



In the absence of screening, DCIS is likely to remain undetected; or else it is detected as an incidental finding during biopsy. On rare occasions it is revealed when it develops into a palpable mass (Chootipongchaivat et al. 2020).

Mammographic screening is recommended in most Western countries. Its purpose is to detect breast cancer at an early stage when it is more likely to be curable: screening enables microcalcifications to be observed before a palpable mass develops. In the UK, the NHS Breast Screening Programme invites women between the ages of 50 and 70 – or 47-73 if in a pilot area – for screening every three years, resulting in over 2 million women undergoing screening each year (Cancer Research UK 2020). However, screening for breast cancer is not without controversy. In a Cochrane review which included 600 000 women across seven randomised trials, it was estimated that amongst 2000 women invited for screening over 10 years, one will be prevented from dying whilst 10 healthy women will be unnecessarily treated (Gøtzsche and Jørgensen 2013). The authors also concluded that over 200 women will suffer from distress due to false positive findings. In the same year, the findings of an independent review of the benefits and harms of breast cancer screening were published (Marmot et al. 2013). The panel drew upon eleven RCTs and estimated that breast cancer mortality is reduced by 20% amongst women who are invited for breast screening. Nevertheless, the degree of statistical uncertainty around this estimate (CI 95%, 11-27%), the potential for bias in trial design, and the length of time since the trials were conducted (18-50 years) all serve to undermine the credibility of this estimate (Marmot et al. 2013).

Although observational studies provide more recent estimates, the risk of bias was considered to have the potential to overestimate the benefit of breast screening. Allowing for the fact that screening is agreed to confer benefits to patients in terms of a reduction in mortality risk, there remains a risk of over-diagnosis. There is limited evidence on which to base estimates of over-diagnosis (Marmot et al. 2013); although it means that a woman may have a breast cancer detected and thereafter treated when in fact it may never otherwise have been recognised during her lifetime. These review findings reinforce the need for women to be provided with clear information about the advantages and disadvantages of screening.

Ductal carcinoma in situ (DCIS) is "the proliferation of malignant-appearing mammary ductal epithelial cells without evidence of invasion beyond the basement membrane" (Jagsi et al. 2019, p. 1274) and accounts for between 15% and 30% of breast cancers which are detected during mammographic screening. It may also be found during self-examination since it can present as a palpable lump, although this is rare (Chootipongchaivat et al. 2020). Lobular carcinoma in situ (LCIS) represents a less common form of non-invasive breast cancer; it is sometimes grouped together with similar lesions displaying 'atypical lobular hyperplasia' (ALH). The term *lobular neoplasia* (LN) is sometimes used to describe both LCIS and ALH (Jagsi et al. 2019). In fact, the latest (eighth) edition, the American Joint Committee on Cancer (AJCC) manual no longer includes LCIS in its staging system; but it includes a second form of non-invasive cancer, Paget disease of the nipple (Hortobagyi et al. 2017).

Invasive forms of breast cancer have been traditionally classified according to their microscopic appearance, ie histologically. Invasive ductal carcinoma has been reported to account for 70%-80% of cases of breast cancer (Jagsi et al. 2019). The remaining 20-30% are special types of cancer which are classified by the *AJCC Staging Manual* as follows: not otherwise specified (NOS); ductal; inflammatory; medullary, NOS; medullary with lymphoid stroma; mucinous; papillary (predominantly micropapillary pattern); tubular; lobular; Paget disease and infiltrating; undifferentiated; squamous cell; adenoid cystic; secretory; and cribriform (Hortobagyi et al. 2017).

Breast cancer staging system

The TNM system refers to primary tumour size (T), involvement of regional lymph nodes (N) and the presence of metastases (M). Developed in 1959, the system has been revised over several editions of the AJCC manual in line with developments in scientific understanding about breast cancer. At the time of writing, the eighth and latest edition of the manual represents a significant departure from previous editions due to advances in knowledge about breast cancer biology and biomarkers. As well as drawing upon anatomical information about the tumour, regional nodes and distant metastases, stage is designated according to additional factors such as tumour grade, HER2 status, oestrogen receptor status, progesterone receptor status, and genomic

tests (Hortobagyi et al. 2017) (see Appendix 2, page 624 onwards). Staging is classified according to the degree of anatomical spread alongside the prognosis with treatment; this is a conceptually different approach for clinicians compared to previous methods. Hence the latest TNM staging system includes biomarkers which are widely used and have demonstrated clinical usefulness, whilst retaining the familiar TNM classification to enable anatomical staging globally.

Breast cancer staging will influence the treatment options for women diagnosed with breast cancer and will vary depending on the stage and type of the disease, patient characteristics, and biomarkers (such as hormone receptor status and genomic test results). The AJCC cancer staging manual (eighth edition) acknowledges that the anatomical and histological features of the TNM system are helpful for prognosis. However, combining this information with detail about biomarkers improves prognostic ability and helps to tailor the most appropriate systemic treatment for each patient, promoting enhanced outcomes. For example, growing numbers of women who have stage two or stage three breast cancer undergo neoadjuvant systemic therapy (NST), contrary to the previous practice of offering surgery initially and systemic therapy afterwards. As a result, decisions about the degree of surgery and radiotherapy required are underpinned by staging at diagnosis alongside the patient's response to NST (Burstein et al. 2019).

4. Treatment for breast cancer

Overview

Patients who have either stage I or stage II disease are usually considered for surgery (Jagsi et al. 2019). Women who are diagnosed with early-stage breast cancer are often eligible for BCS: it is a suitable treatment option for between 60% and 80% of women in Western European countries (Senkus et al. 2015). However, the option of mastectomy (with or without reconstruction) is part of the assessment with the patient. Surgery may be preceded by systemic therapy to reduce the tumour size for women who would otherwise need mastectomy. It is once the tumour is removed that it is tested to identify hormone receptor status as well as a range of biomarkers

such as HER2 and Ki-67 in order to select appropriate systemic treatments. The woman's menopausal status will also determine the use of hormone therapy and other adjuvant treatments such as bisphosphonates.

Breast-conserving surgery

Breast-conserving surgery (BCS) involves a wide local excision to remove the tumour and a margin of normal tissue surrounding it; hence it is also referred to as a wide local excision (WLE). Combined with radiotherapy (RT) it constitutes breast-conserving therapy (BCT) whose aim is "to provide survival equivalent to mastectomy with preservation of the cosmetic appearance and a low rate of recurrence in the treated breast" (Jagsi et al. 2019, p. 1283). This statement is supported by an extensive overview of randomised trials (n = 42 000) which concluded that BCT and mastectomy have similar survival outcomes (EBCTCG 2005). Nevertheless, surgical removal of the breast is indicated in women for whom there are contraindications to BCT (Jagsi et al. 2019), such as a diagnosis of DCIS with a tumour size too great for it to be removed with negative margins and with an acceptable degree of cosmesis. Alternatively, the patient may opt for a mastectomy for other reasons. A mastectomy removes the breast tissue between the sternal edge and the latissimus dorsi and between the clavicle and the rectus abdominis muscles. In addition, the nipple-areolar complex (NAC), the excess breast skin and the fascia of the pectoralis major muscle are all removed (Jagsi et al. 2019). A modified radical mastectomy also includes an axillary lymph node dissection (ALND). Most women having mastectomy can choose to opt for an immediate reconstruction, for which the skin encasing the breast is preserved. The breast shape is usually created either using implants, tissue expanders or myocutaneous tissue flaps. There is evidence that a nipple-sparing mastectomy (NSM) could be suitable for patients with specific histologic and tumour features (Jagsi et al. 2019).

A pre-operative assessment will determine the extent of surgery required to the axilla by establishing if there are cancerous cells present in the lymph nodes. Figure i above demonstrates the NICE recommendations for the breast cancer treatment pathway for England and Wales with a particular focus on the decision process for axillary surgery. For women with invasive breast cancer, sentinel lymph node biopsy (SLNB) is

recommended as the most minimally invasive technique for detecting the presence of cancerous cells. This is because the absence of cancer cells in the sentinel node (nearest the breast) offers a high specificity against further axillary disease. Most women diagnosed with DCIS will not require a SLNB due to the localised nature of the cancer although Jagsi et al. (2019) note that a SLNB should be performed selectively for those patients deemed to be at substantial risk of an additional invasive carcinoma. However, for women who undergo mastectomy for DCIS, SLNB is recommended at the same time; otherwise, the disruption of lymph vessels can prevent reliable mapping (Price et al. 2020).

More extensive surgery to remove all the lymph nodes in the axilla (axillary lymph node dissection (ALND) or axillary clearance) was long accepted as the treatment for patients with invasive breast cancer (Jagsi et al. 2019). Nevertheless, evidence has emerged that SNLB rather than the more radical ALND is suitable for clinically node-negative women. A trial of 5611 women with invasive breast cancer who were randomised to either sentinel node removal plus ALND or to SLND only (followed by ALND if the SLNs were positive) found that in cases where the SLN was negative, survival (overall and disease-free) and regional control were statistically equivalent between the groups (Krag et al. 2010). It was also found that in women who underwent SLND, 8% experienced arm volume differences of at least 10% at 36 months, compared to 14% of women who underwent ALND (Ashikaga et al. 2010), indicating a stronger likelihood of lymphatic disruption with ALND procedures.

In patients who are clinically node-negative for whom neoadjuvant chemotherapy is provided, SNLB can be performed after chemotherapy and may avoid the need for ALND. In the National Surgical Adjuvant Breast and Bowel Project (NSABP) randomised trial B-18, the positive node rate is reported to have reduced from 57% to 41% after neoadjuvant chemotherapy ($p < 0.001$) (Jagsi et al. 2019). Nevertheless, there is evidence from prospective studies that false-negative rates of $< 10\%$ are only achievable when a minimum of three sentinel nodes are identified, leading to the conclusion that ALND should still be performed in patients who are clinically node-positive unless three or more sentinel nodes have been identified (Jagsi et al. 2019). Meanwhile the equivalence of axillary radiotherapy (ART) and ALND has been the subject of recent trials and will be considered in the next section.

Radiotherapy

Radiotherapy (RT) often follows breast-conserving surgery (BCS) for women who are eligible for BCS. The intention of RT is to reduce the risk of local recurrence of the tumour and to improve survival (NICE 2009) and this is supported by evidence from several randomised trials. Jagsi et al. (2019) report on the results of four randomised trials involving a total of over 4500 patients with DCIS which compared treatment with BCS alone or with BCS and RT. The results demonstrated that the risk of an ipsilateral breast tumour recurrence (IBTR) was significantly reduced in those patients who received RT (range of equivalent risk reductions = 47%-63%). Additionally, a meta-analysis of the trial data was conducted by the Early Breast Cancer Trialists' Collaborative Group (EBCTCG) involving 3729 women who had been diagnosed with DCIS and were eligible for the analysis (EBCTCG 2010). It showed that the rate of ipsilateral breast events was approximately halved in women who had RT (rate ratio 0.46, standard error [SE] 0.05, 2P < 0.00001) and that this was the case in all four of the trials examined. The rate was reduced in women irrespective of age, although for women aged 50 or more the proportional reduction in ipsilateral breast events was greater than for younger women (2P < 0.0004). Meanwhile, for patients with invasive breast cancer, a large meta-analysis of data for 10 801 women across 17 randomised trials sought to establish the absolute size of the reduction in recurrence and death from breast cancer due to RT after BCS (EBCTCG 2011). It was found that the rate of recurrence (local recurrence or distant metastases) was reduced to approximately half (rate ratio (RR) = 0.52 95% confidence interval (CI) 0.48-0.56) and the rate of breast cancer death by about one sixth (RR = 0.82, CI 0.75-0.90). This meta-analysis reveals the benefits of RT after BCS for local control and on survival; however, a reliable means of identifying patients who are at low risk of local recurrence and can therefore be treated with BCS alone is yet to be identified (Jagsi et al. 2019).

For several decades, the standard radiotherapy regime for women with early-stage breast cancer was 25 fractions (divisions of the total dose) of 2 gray (Gy) delivered over 5 weeks. Since then, evidence has emerged for the efficacy and safety of shorter regimes of RT delivered in larger fractions providing a lower overall dose, such as is

shown in the long-term follow-up of trials reported by Whelan et al. (2010) and Haviland et al. (2013). This technique, known as hypofractionation, has been further developed and more recently the findings of the FAST-Forward study (Brunt et al. 2020) demonstrated that five fractions of 5.2 Gy (total 26 Gy) delivered over five days was non-inferior to 40 Gy in 15 fractions over three weeks. In the UK, the Royal College of Radiologists (RCR) consensus statements *Postoperative radiotherapy for breast cancer: hypofractionation* (The Royal College of Radiologists 2021) reflect this latest evidence. The latest consensus statements also support the delivery of accelerated partial-breast irradiation (APBI) which delivers RT to the part of the breast encompassing the primary tumour. This guidance follows the findings of the UK IMPORT LOW trial (Coles et al. 2017) which demonstrated non-inferiority of partial-breast techniques, in conjunction with the FAST-Forward study's finding of non-inferiority of accelerated techniques.

In relation to RT to the axilla, the AMAROS trial demonstrated that axillary RT (ART) had equivalent outcomes to axillary lymph node dissection (ALND) (Donker et al. 2014) (n = 4806) for patients with a positive sentinel node. Importantly, arm lymphoedema developed significantly more often following ALND than after ART ($p < 0.0001$ at one year and five years following treatment). The results of this and other trials have influenced the UK consensus guidelines for axillary management (The Royal College of Radiologists 2016; updated 2021), such that recent years have seen an increase in the use of ART. Meanwhile, the ATNEC study (estimated n=1900) aims to determine whether patients who have early-stage breast cancer with axillary node metastases for whom no residual cancer is detected on SLNB after NACT have non-inferior outcomes without either ALND or ART (Goyal, A.; Identifier: NCT04109079).

For women who have undergone mastectomy for early breast cancer the recurrence of cancer in the chest wall is a possibility, affecting mortality as well as having a psychological impact (NICE 2018). The risk of recurrence is reduced by post-mastectomy radiotherapy (PMRT) although factors such as size of tumour, the involvement of axillary nodes and positive resection margins will all influence the degree of risk (NICE 2018). Current guidance for England and Wales recommends offering PMRT to women with invasive breast cancer who have macro-metastases (i.e., are node-positive) or have positive resection margins (NICE 2018). NICE guidelines also

suggest that PMRT should be considered for patients with node negative T3 or T4 invasive breast cancer (where T = tumour and the number relates to tumour size), although the degree of benefit is less certain. The function of PMRT in women who are at intermediate risk of breast cancer recurrence (i.e., who have between one and three positive nodes) is being investigated by the Selective Use of Postoperative Radiotherapy after Mastectomy (SUPREMO) randomised trial, with ten-year survival results expected in 2023 (Velikova et al. 2018).

Systemic therapy

Almost all women treated for breast cancer will be offered some form of systemic therapy, such as endocrine therapy, chemotherapy or anti-HER2 therapy. Neoadjuvant treatment (prior to surgery) may be given to shrink the primary tumour to enable some women to have BCS who would otherwise need mastectomy. Depending upon menopausal status and tumour receptor status (hormone receptor and HER2 status), neoadjuvant chemotherapy or neoadjuvant endocrine therapy may be offered (NICE 2018). Neoadjuvant chemotherapy is recommended for patients with ER-negative invasive breast cancer and those with HER2-positive invasive breast cancer (NICE 2018). It should also be offered to patients with ER-positive invasive cancer if chemotherapy is deemed suitable (NICE 2018).

Meanwhile, adjuvant systemic therapy aims to prevent breast cancer recurrence by removing undetected micro metastases (Jagsi et al. 2019). The form of adjuvant treatment will be determined by the tumour's hormone receptor and HER2 status (Jagsi et al. 2019) as well as menopausal status (NICE 2018).

Endocrine therapy

Tamoxifen is recommended for men and premenopausal women with ER positive invasive breast cancer, as well as to postmenopausal women who are at low risk of cancer recurrence. Tamoxifen acts to bind to the oestrogen receptors, thus preventing cell growth. Evidence for the extended effectiveness of tamoxifen was demonstrated in the global Adjuvant Tamoxifen: Longer Against Shorter (ATLAS) randomised trial

(Davies et al. 2013). A total of 12 894 women with early breast cancer were randomly allocated to continue treatment with tamoxifen for a further 5 years (ie 10 years in total) or to cease at 5 years. It was found that for women with ER positive breast cancer, recurrence and mortality were further reduced such that using tamoxifen for 10 years is estimated to reduce mortality by approximately half in the following 10 years (i.e., 11-20 years after diagnosis).

For postmenopausal women who are at either medium or high risk of breast cancer recurrence, an aromatase inhibitor (AI) is recommended as the initial adjuvant endocrine treatment (NICE 2018). The AI suppresses the aromatase enzyme which would normally transform androgens into oestrogens, significantly reducing oestrogen levels. There is evidence that combining an AI with five years of tamoxifen use has a moderate effect in improving disease-free survival, although both tamoxifen and AIs are associated with side effects including joint pain and menopausal symptoms such as hot flushes (Garreau et al. 2006; Murphy et al. 2012). AIs also carry a risk of hastening osteoporosis, such that bone mineral density monitoring is required. As well as treatment side effects, a systematic review concluded that women who were older or younger, financial constraints and changing from one type of therapy to another, were amongst factors found to be negatively associated with adherence to therapy (Murphy et al. 2012). However decision-making tools, including PREDICT Plus (an updated version of the PREDICT tool which includes HER2 status) can assist in estimating the costs and benefits of systemic therapy (Cardoso et al. 2019).

Chemotherapy

It is recommended that women deemed to be at 'sufficient' risk (NICE 2018) are offered adjuvant chemotherapy as it has been shown to reduce the risk of cancer recurrence and to have a beneficial effect on overall survival. The Early Breast Cancer Trialists' Collaborative Group (EBCTCG)'s report on a meta-analysis of the long-term outcomes for 100 000 women across 123 randomised trials (EBCTCG 2012) showed that chemotherapy was beneficial regardless of age, oestrogen receptor status or use of adjuvant endocrine therapy. In addition, receiving four to eight cycles of

chemotherapy rather than adopting a single-cycle regime appears to be advantageous. NICE guidance (2018) recommends a regime that includes a taxane and an anthracycline for those patients whose level of risk indicates that chemotherapy should be administered. However, Jagsi et al. (2019) note that there is a need to identify patient subsets for whom chemotherapy may be either particularly effective or may in fact not be required. The OPTIMA (Optimal Personalised Treatment of early breast cancer using Multi-parameter Analysis) study (NIHR-funded; project reference 10/34/501) which is currently recruiting will examine whether these subsets can be distinguished, using recent developments in molecular subtype testing. The advantage of such assays is that they can provide an estimate of the risk of breast cancer recurrence. Tests include Oncotype Dx may be used with women who have early stage invasive breast cancer without nodal involvement and who have either oestrogen receptor positive (ER+) or HER2 negative (HER2-) breast cancer.

Therapy for HER2-positive invasive breast cancer

It is recommended that the monoclonal anti-body trastuzumab (brand name Herceptin) is offered to people who have HER2-positive invasive breast cancer and who have a primary tumour classified at stage T1c and above (NICE 2018) alongside other appropriate treatment (i.e., surgery, radiotherapy and/or chemotherapy). However, due to the adverse cardiac effects of trastuzumab and the small subset of people who may benefit, it is suggested as an option rather than a recommendation for people who have invasive breast cancer and a primary tumour classified at stage T1a and T1b (NICE 2018). Additional risk factors for cardiac morbidity with use of adjuvant trastuzumab include prior cardiac disease and being more than 65 years old (Jagsi et al. 2019); all patients on anti-HER2 therapy have standard cardiac function monitoring.

5. Prognosis

The stage of breast cancer - in particular the degree of involvement of the axillary lymph nodes - has been the accepted and reliable determinant of the development of

metastatic disease and of survival (Jagsi et al. 2019). While age has also been demonstrated to be a factor in prognosis, such that the prognosis for patients who are 35 years old or younger has been poorer than for older women, there is now evidence that patient age is less important than molecular subtype (Jagsi et al. 2019).

Nevertheless, the expansion of treatment options for breast cancer has increased the relevance of prognostic and predictive tools which are able to identify patients likely to be suitable for additional treatment such as chemotherapy. Therefore, the benefits of a particular therapy need to be weighed against the risk of mortality from breast cancer. An example is the Nottingham Prognostic Index (NPI), a validated instrument which combines the number of involved lymph nodes, tumour size and histological grade (Lee and Ellis 2008; Fong et al. 2015). These prognostic factors are used alongside others which predict response to a treatment, such as menopausal status. However, a recent systematic review and meta-analysis of nineteen observational studies demonstrated wide variation in the survival estimates, throwing doubt on the use of the NPI in clinical contexts and in economic analyses (Gray et al. 2018). Meanwhile, the prognostic tool named PREDICT (www.predict.nhs.uk) is based upon a wider range of factors. Originally developed in 2010 (Wishart 2010) the tool has subsequently been updated to include patients with HER2 status (v2) (Wishart et al. 2012) and the protein K167 (v3) (Wishart et al. 2014) to facilitate prognosis for those who are oestrogen receptor positive. It was proposed that version 3 would enable the benefit of chemotherapy to be more precisely predicted, enhancing the clinical decision-making process. Similarly, gene assays are deemed to be more accurate prognostic and predictive methods for determining treatment outcome; they include Oncotype Dx which is currently being trialled for its effectiveness.

6. Treatment outcomes

Following treatment for breast cancer, patients require monitoring for local-regional cancer recurrence, cancer in the contralateral breast, and distant metastases. The risk of recurrence is reported to be highest during the first five years after diagnosis of breast cancer (Jagsi et al. 2019) although there are ongoing risks, particularly for

women who are diagnosed with hormone receptor-positive breast cancer. NICE (2018) recommends breast cancer screening (mammography) on an annual basis for five years for all those who have been diagnosed with breast cancer. Patients who are at higher risk of distant recurrence will also be staged with a CT scan with or without a bone scan. Although local recurrence is regularly associated with metastatic disease, early evidence from randomised trials (published in 1994) which compared intense surveillance (imaging and laboratory tests) with standard care (physical examination and mammography) suggested limited gains in detecting metastatic breast cancer and no improvement in overall survival (Jagsi et al. 2019). Inherited susceptibility and age are the main determinants of patient-related risk factors for local recurrence (Jagsi et al. 2019). Tumour-related factors of significance include the margin of excision: a negative margin (ie free of cancer cells at the margin of the surgical excision) is associated with low rates of local recurrence after conservative surgery and RT (Jagsi et al. 2019).

Adjuvant treatments have been shown to have a beneficial effect on local control. In a European Organisation for Research and Treatment of Cancer (EORTC) randomised trial including 5318 patients with negative margins, the use of a radiation boost of 16 Gy alongside 50 Gy to the whole breast was found to improve local control across all age groups (cumulative incidence of local recurrence = 10.2% without boost versus 6.2% with boost, $p < 0.0001$) (Bartelink et al. 2007). There is also strong evidence for the benefits of systemic therapy on local control: between 1990 and 2011 there was a decrease in the local recurrence rate from 30% to 15% amongst 86 598 women across 53 randomised trials (Jagsi et al. 2019).

Patients should be monitored for the development of any late effects of surgery, RT, or chemotherapy, as well as side effects from current treatment such as anti-oestrogen therapy (Jagsi et al. 2019). Side effects are described below, although lymphoedema as a side effect of surgery or radiotherapy is addressed separately in Chapter 1.

Side effects from surgery

Although developments in understanding and treating breast cancer have resulted in improved survival rates, many women are now living with the side effects of treatment. Amongst the most common complications from surgery for breast cancer are wound infections, seromas, and haematomas. In an examination of prospectively collected data relating to 1660 women who underwent mastectomy and 1447 women who had BCS with axillary treatment, the most common complication was wound infection (4.34% for women who underwent mastectomy versus 1.97% for breast-conserving surgical patients) (El-Tamer et al. 2007). In addition, a small percentage of women who underwent mastectomy experienced cardiac (0.12%) and pulmonary (0.66%) complications compared to no women who underwent BCS. Other side effects from surgery include mobility restrictions in the arm and shoulder (Scaffidi et al. 2012). Lymphoedema in the arm, breast or trunk may develop after surgery; this is discussed in Chapter 1.

Side effects from radiotherapy

RT has clearly provided benefits to overall survival for women with early breast cancer. At the same time, it has been shown that whole breast RT carries an increased risk of ischaemic heart disease (Darby et al. 2013), symptomatic pulmonary fibrosis and a second primary cancer of the lung (Grantzau et al. 2014; Käsmann et al. 2020; Taylor et al. 2017). Whilst the survival benefit from RT after BCS outweighs the risks of cardiac irradiation, techniques such as deep inspiration breath hold can reduce these risks in patients with left-sided breast cancer so that the radiation dose to the heart is minimised (Bergom et al. 2018).

Additional side effects include fatigue, skin reactions (redness, itching, dryness, blistering) and pain in the breast or chest wall and the ipsilateral arm (Sjövall et al. 2010) which may be acute and appear during RT. Late side effects occurring weeks or months after treatment include radiation-induced pneumonia and fibrosis in the breast (Andrieu 2012). Later effects include shoulder stiffness and cardiac toxicity; and

more rarely rib fractures and brachial plexopathy. Lymphoedema can occur as a side effect of RT and is discussed in Chapter 1.

Side effects from chemotherapy

Chemotherapy is noted to have some significant side effects which include fatigue, nausea, vomiting, diarrhoea, neuropathy, alopecia, and myelosuppression (Jagsi et al. 2019). Increases in life expectancy also place older patients who are diagnosed with breast cancer at risk of age-related co-morbidities such as cardiovascular disease (CVD). In a recent retrospective study data from 761 patients revealed that following chemotherapy, the proportion of patients developing CVD was significantly higher in those aged 50 years or older ($p = 0.003$) (Jeon et al. 2020).

Side effects from endocrine therapy

It is recognised that endocrine therapy causes side effects such as hot flushes, joint pain, and gynaecological symptoms (Cella and Fallowfield 2008). An analysis of data of postmenopausal women up to eighty years old who had surgery for non-metastatic breast cancer between 1998 and 2008 ($n=400$) revealed that 19.5% experienced severe side effects that necessitated changes to their endocrine therapy (Güth et al. 2011). Whilst severe side effects were also predictive of patients discontinuing use of tamoxifen, in fact the presence of hot flushes predicted the opposite behaviour ($n = 881$) in a prospective cohort study by Kahn et al. (2007). However, the rate of discontinuation was higher amongst patients who stated in the study survey that they had not previously been informed about side effects than those who were informed (72% vs 82%, $p = 0.0016$), suggesting the importance of the role of patient information.

Appendix 2: Breast cancer staging

Source:

AJCC Cancer Staging Manual, Eighth Edition © The American College of Surgeons (ACS), Chicago, Illinois

Reference:

Hortobagyi, G.N., Connolly, J.L., D’Orsi, C.J., Edge, S.B., Mittendorf, E.A., Rugo, H.S., Solin, L.J., Weaver, D.L., Winchester, D.J. & Giuliano, A. (2017) Breast. In Amin, M.B., Edge, S.B., Greene, F.L., Byrd, D.R., Brookland, R.K., Washington, M.K., Gershengwald, J.E., Compton, C.C., Hess, K.R., Sullivan, D.C., Jessup, J.M., Brierley, J.D., Gaspar, L.E., Schilsky, R.L., Balch, C.M., Winchester, D.P., Asare, E.A., Madera, M., Gress, D.M. & Meyer, L.R. (Eds). *AJCC Cancer Staging Manual* (8th ed, pp 589-636). Springer International.

‘Used with permission of the American College of Surgeons, Chicago, Illinois. The original source for this information is the AJCC Cancer Staging System (2020)’

This source was used only for the purposes of the viva examination for this thesis and was provided separately.

Appendix 3:

Risk factors for lymphoedema: patient information

<https://breastcancer.org/information-support/facing-breast-cancer/going-through-treatment-breast-cancer/side-effects/lymphoedema>

<https://www.cancerresearchuk.org/about-cancer/coping/physically/lymphoedema-and-cancer/lowering-your-risk>

https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/lymphoedema/reducing-your-risk-of-lymphoedema#take_care_when_travelling

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/lymphoedema/compression-to-treat-lymphoedema>

Appendix 4:

Initial literature review on qualitative studies about women's experiences of arm lymphoedema: summary of articles

Lead author ¹⁷ /year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Burckhardt 2014 Synthesis additional articles:	to describe and therefore gain a comprehensive understanding of the experience	a qualitative metasynthesis	includes 13 articles	5 databases were searched	4 themes: experience of everyday life; energy sapping; personal empowerment; contribution of others.
Fu 2005 USA	to describe the experience of managing lymphoedema	a descriptive, phenomenological method	12 participants	three semi-structured interviews with each participant, at intervals of 1-3 weeks (to ensure data reliability/stability)	developed a taxonomy of 3 levels to describe the essential structures of experience, ranging from specific to mediating to general (found in all participants). Revelatory (general) intentions (ie consciousness of actions) were: keeping in mind the consequences; preventing lymphoedema from getting worse; getting ready to live with lymphoedema; integrating care of lymphoedema into daily life

¹⁷ unless author is lead for more than one article, in which case subsequent author/s are also listed

Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Fu 2008 USA	to describe the experience of work for women with BCRL	a descriptive, phenomenological method	22 participants. The credibility of the findings was supported through discussions with participants (and expert researchers)	in-depth interviews, three with each participant	3 essential themes: having a visible sign: disability versus a need for help; having physical limitations: being handicapped versus the inconvenience; worrying constantly versus feeling fortunate
Fu 2009 USA	to explore and describe women's experiences of lymphoedema-related symptoms in their daily lives	a descriptive, phenomenological method	34 participants. The credibility of the findings was supported through discussions with participants (and expert researchers)	in-depth interviews, three with each participant	4 essential themes: living with a perpetual discomfort; confronting the unexpected; losing pre-lymphoedema being; feeling handicapped the authors noted temporal, situational and attributive dimensions of distress elicited by their physical symptoms, which may not be fully captured in QoL measures

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Heppner 2009 USA	to gain an understanding of the stressors and coping processes of women with BCRL	the 'consensual qualitative research' method was used. analysis conducted by 3 graduate students and the first/third authors as auditors	10 participants	semi-structured interviews	domains agreed from the literature & interview protocol: stressors (under which 11 categories were identified); coping strategies (9 categories); social support & social resources for coping (6 categories)
Thomas-Maclean 2005 Canada <i>largely rural area with limited medical resources</i>	to explore experiences of BCRL and its treatment	no detail on context. The transcripts were 'analyzed using established guidelines for qualitative research' Saturation was reached by the 12 th interview; however, 3 more were conducted to ensure a diverse sample	22 participants	one focus group and subsequently 15 individual, in-depth interviews	4 themes: lack of information (poorly informed about the possibility of developing BCRL); triggers and symptoms (varied); (poor) access to treatment (costly compression garments, difficulty accessing physiotherapists); the effect of BCRL on daily life (is profound)

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
<p>Wanchai 2012</p> <p>USA</p> <p><i>I didn't agree with the interpretation of some of the findings from this study</i></p>	<p>To compare and contrast lymphoedema experiences & management, USA & South Africa.</p> <p>Finding: Similarities and differences between the two countries.</p>	<p>ethnonursing research method, focussed on naturalistic and open inquiry to discover the participant's world of knowing and experiencing life.</p> <p>common themes were 'captured'</p>	<p>29 women: USA - 18; SA - 11</p>	<p>Semi structured interviews</p>	<p>Six themes (effects of lymphoedema): difficulties with daily activities; unmet lymphoedema preparations; USA participants only:- facing public curiosity; time-consuming wrapping; trouble with fitted clothes reminder of breast cancer</p> <p>Four themes (lymphoedema management): compression garments; physical activities; faith (spirituality); other strategies - compression pumps, antibiotics for infection</p>
<p>Whyte 2010</p> <p>PhD dissertation</p> <p>USA</p>	<p>to explore the lived experience of women aged 30 to 50 years old</p>	<p>hermeneutic phenomenological methodology</p> <p>a 'blended framework' (Kleinman 1988)</p>	<p>10 participants (saturation reached)</p>	<p>semi-structured interviews; data analysis began with van Manen's hermeneutic phenomenological criteria for conducting TA</p>	<p>five themes: it never bothered me but; unwanted baggage; who knew?; self-preservation; hopeful determination</p>

Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Anbari 2019 USA	RQ: How does being diagnosed and living with BCRL impact a woman's QoL?	Uses the concept of QoL rather than HRQoL as BCRL is also known to affect non-health aspects. Knowledge of QoL led to use of a-priori categories. Deep interpretation not possible as no opportunity for follow-up: the aim was therefore to describe and quantify the impact, using content analysis.	97 participants	open-ended questions about changes in mood and lifestyle, through annual interviews and surveys (the Lymphedema and Breast Cancer Questionnaire).	Physical function: pain, fatigue & being less active Daily living and social function: limited in jobs and roles, body image concerns Psychological function: frustration, depression and being more irritable
Greenslade 2006 Canada	to explore womens' experiences in order to understand the	a hermeneutic phenomenological approach; data analysis incorporated van	13 participants. participants were contacted to verify interpretation of	semi structured interviews	5 major themes: constancy; yearning for normalcy; continually searching; emotional impact;

	meaning of those experiences for women	Manen's (1990) six research activities, with thematic analysis beginning with the first interview soon after data collection	the findings and obtain further explanations when required.		abandonment prevailing essence = Existential Aloneness
Hare 2000 UK	to explore the meaning of 'surviving with' BCRL; to identify & explore the psychosocial impact; to make recommendations for practice	grounded theory used for the data analysis	20 participants (being treated for lymphoedema). Each group agreed a verbal summary at the end of each session; copies of the transcribed data were read and approved by members of the groups. A findings summary was shared with each participant; and the full report was made available to them.	four focus groups (random allocation of the 20 participants to one of the groups)	3 main themes: finding information; suffering silently; counting blessings <i>notes:</i> 1) 'in-depth structured interview technique' surely unstructured ? 2) why did the ethics committee require a hypothesis? 3) finding out and receiving information was the most important issue for participants

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Jeffs 2016 UK clear article with many relevant issues to consider **	to identify factors influencing patient perception of success and benefit with self-management of BCRL	grounded theory approach (it was envisaged that the research approach would generate clinically relevant findings to guide professional practice.	21 participants	in-depth interviews	seven enablers & blocks to self-management were identified: routine; recognising benefit of self-management & consequences of not; owning treatment; knowledge & understanding; problem-solving; time required for treatment; aesthetics of hosiery Women showed varying degrees of acceptance & adjustment, which directly impacts their ability to self-manage.
Johansson 2003 Sweden	to explore employed women's experiences of light or moderate arm lymphoedema	a phenomenological approach (the focus on the meanings, not the facts presented). Analysis developed by Karlsson A critical incident method was used.	12 participants; findings to a validation gp of 5 women with BCRL, reflecting the study group by age & oedema duration: relevant to own experiences? anything of own not expressed?	semi-structured interviews	three main themes common to all the women: reactions from others; being bound to the chronic disease; coping (emotion-focussed more commonly represented than problem-focussed).

Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
McGrath 2013 Ireland	to report on the experiences of a group of Irish women of living with BCRL in terms of their prescribed self-management conservative treatments	existential phenomenological methodology IPA for analysis (a narrative analysis method)	First interview: 10 women 10 crochet classes (filmed & photographed): 7 women Second interview (approx 18 months after first): 7 women Third interview (one year later): 7 women 6 had BCRL nb inclusion criteria included needing to be new to the creative craft of crochet.	longitudinal study- three rounds of in-depth semi-structured interviews collected over three years	Women found compliance with self-management protocols for BCRL a difficult dilemma. Most deliberately risked their vulnerable arms to preserve familiar occupational performance and express their occupational identities. Not revealed to healthcare providers, ie frequently hidden. Living with BCRL was a complex experience & compromised function caused great distress. The women attempted to relieve this distress with attempts to force the affected arm to perform normally. Can add to understandings of non-compliance. There is an important role for OTs to enable occupation in ways that accommodate compliance with self-care protocols.

Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Radina 2014 USA	To explore the self-care experiences of women within the contexts of complex & demanding familial & work-related responsibilities; to gain an understanding of factors that may help or hinder compliance, to provide guidance for patient education for HCPs.	Informed by feminist family theory. A secondary analysis of qualitative data, involving thematic analysis informed by the central tenets of feminist family studies and the concepts of self-silencing and self-sacrifice.	14 women who were enrolled in a behavioural-educational intervention aimed at LE risk reduction (a feasibility study of a nursing intervention).	questionnaire with 19 open-ended questions (either completed by mail or in a telephone interview)	Included: Making the Time: participants' struggles with time management; Struggles with Putting Myself First: prioritising self-care over care of others; Making a Commitment to Self-care
Radina 2015 USA	to compare the sexual experiences of women with and without BCRL:	quantitative & qualitative (mixed method); a cross-sectional design.	with BCRL = 176; without = 84 (for the analysis)	Forced-choice question re. the degree of impact (5 choices); and 'please	women with BCRL were more likely to report greater effects of their symptoms on their sexual and intimate relationships.

	in what ways does the experience of BCRL symptoms contribute to changes in sexual functioning?	Heideggerian hermeneutics - qualitative understanding	NB. 68.4% had arm & hand swelling; 42.8% breast swelling; 45.7% chest swelling	describe in detail your sexual experience in the context of your breast cancer-related lymphedema symptoms'	narrative responses from 47 women with BCRL - two overarching themes: effects of garments; negative feelings about sex/intimacy
Radina 2008 USA	to investigate the effect on QoL of the sexual relationships with intimate partners for women with LE	a co-operative, inductive approach to data analysis.	11 women subset of a larger qualitative study looking at the effects of BCRL on QoL credibility of the data & findings was enhanced due to the rapport with participants	in-depth semi-structured interviews (face-to-face or telephone), to elicit descriptions of QoL with BCRL & in what ways it impacted on their sexual relationships	BCRL has an important & often negative influence; the findings demonstrate the influence of sexuality upon self-perception and relationships. Themes: not feeling sexy anymore; changes in intimate relationships <i>the authors comment on their intention to tease apart the complex issues relating to breast cancer and relating to BCRL.</i>
Radina 2001 USA	to investigate how BCRL affects women and their families in terms of task completion and family functioning	an ethnographic approach to data collection. Multiple sources to increase understanding (eg. of the role of context);	part of a larger study 6 women & 2 professionals	included interviewing participants and healthcare professionals as well as observing a lymphoedema support group	Many women modify daily tasks due to BCRL (ie change the task or employ help from others); many women & their families must cope with changes

		<p>consideration of women's role within the family, ie caregiver, housekeeper & others related to maintaining the daily functioning of the family;</p> <p>also uses a family systems framework in which families are viewed as having a structure & function (ie relationship patterns). The Family Adjustment and Adaptation Response (FAAR) Model - developed from this framework - is used to interpret the findings.</p>	<p>member checks with 2 support group members who had not been interviewed</p>		<p>Families who are more flexible in modifying daily tasks and who have pre-existing resources for coping with stressors have more positive outcomes than do those families who are rigid and cope with stressors poorly.</p>
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Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Ridner, Bonner et al. 2012 USA	to explore perceptions and feelings about how BCRL impacts participants' lives	Instructions for the writings were based on Pennebaker's expressive writing paradigm content analysis used for the data analysis.	39 of the 52 participants (the experimental group of a larger, parent RCT). The writings were placed in random order & analysed until thematic saturation was achieved (at the 39 th participant). Participants were involved in real-time member checking by completing a questionnaire about the extent to which they had just revealed their emotions	expressive writing. writing sessions (20 minutes) were spaced over 2 weeks; each week's writings were spaced 48 hours apart to allow time for rumination	4 major themes: marginalisation & minimization (from healthcare providers) - <i>present in the writings of 90% of participants</i> ; multiplying losses (eg. body image disturbances, loss of function & control over time, permanent uncertainty & adverse effects on relationships); yearning to return to normal (cumulative frustration & resentment contributing to a failure to perform self-care); uplifting resources (support from others & their spiritual beliefs) - <i>religious beliefs, 41% of participants</i>

Lead author/year	Study aims	Methodology/theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Ridner, Sinclair et al. 2012 USA	to determine whether BCRL is a disabling condition for women	the notion of whether a disability model or a symptom management model may better explain the findings, and the implications for healthcare professional involvement, are discussed.	53 women - the control group of writers in a larger RCT testing the effectiveness of expressive writing in improving health outcomes	mixed methods: symptom data collected with the LSIDS - A (<i>as seeking new knowledge, only those 17 items not reflective of swelling or altered sensations were analysed</i>); bioimpedance readings to measure fluid; participants were instructed to write (objectively & factually; four 20-minute sessions) about eating behaviours, typical daily activities; cigarette use, alcohol use, caffeine intake; and plans during the next several weeks.	(Quantitative - includes the following:) fatigue, difficulty sleeping & concerns about appearance were the three most commonly reported symptoms - the latter two amongst the most intense (rated 5 out of 10); decreased social activity was the least reported but rated as the most distressing (6 out of 10). Some of the most distressing symptoms related to sexual activity. Qualitative -specific themes within each of the four broad topics included: healthy vs 'bad' eating habits; emotional eating; (27) women described leading busy lives; few described perceived limitations; 16 acknowledged that faith/spirituality was important; (26) women did not write about social activities; only 10 reported regular exercise; 48 reported not smoking; alcohol use was minimal; 35 use caffeine; 27 had plans for trips.

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Whatley 2018 UK	to explore the psychological impact of BCRL on daily life and how the use of reflexology for lymphatic drainage affected them.	inductive content analysis	<p>26 participants - a convenience sample of women who were involved in a feasibility study looking at a lymphatic drainage protocol of reflexology.</p> <p>the development of the interview schedule included people recruited by a cancer care charity; those with experience of BCRL were asked about relevant areas of questioning for the schedule.</p>	semi-structured interviews, conducted at the end of the seven-week study.	<p>4 main themes: physical impact of BCRL on daily life; psychosocial impact of BCRL; experiences of physical change during & after reflexology treatment; the return of optimism (- re-engagement with usual activities)</p> <p>RLD was considered pleasant & non-invasive; the reduction in swelling helped with pain & mobility</p>

Additional articles subsequently considered:

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Karlsson 2015 Sweden	to investigate and describe women's perceptions of lymphoedema treatment after surgery for breast cancer	a phenomenographic method was used for the analysis	16 women	semi-structured interviews	<p>5 categories of description: Uncertainty Disappointment Guilt & shame Safety Autonomy</p> <p>based on a 2-dimensional structure: the patients' role (internal vs external locus of control) & an understanding of LE as a chronic disease or as a burden</p> <p><i>Comment: useful article for discussion of some of my study's findings, eg. compliance/autonomy concepts</i></p>

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Maree 2016 South Africa	to explore how people experience living with BCRL.	an exploratory qualitative approach using the Roy Adaptation Model of Nursing: people as biopsychosocial beings who need to adapt to environmental stimuli. The researchers used reflexivity as a continuous process. Tesch's open coding process used for data analysis.	nine purposively selected participants: eight female & one male. The data were summarised and verified with participants to be true and correctly understood. 'The researchers upheld the principles of prolonged engagement with participants and member checking to ensure the accuracy of the data.	unstructured interviews. Interviews conducted either in Afrikaans or English; those conducted in Afrikaans were translated into English.	Four themes: - lymphoedema the unknown and unspeakable; - living with the physical consequences of lymphoedema; - living with an altered body; - coping with the lymphoedema Note: reported that HCPs in SA perceive lymphoedema as normal & that women who develop BCRL should accept it and live with it; Also see discussion for the role of religion (coping with lymphoedema). One participant reported that her BCRL resulted in poor QoL; 5 = reasonable; 1 = good in spite of her BCRL. (no information on remaining participants).

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Sun 2020 USA	to explore the ways in which lymphoedema affects women's work experience	A multiple-case study methodology drawn from Yin's definition. Analogous to multiple experiments where 'replication' logic is adopted. Prior-developed theoretical propositions. By comparing & contrasting cases, the authors identified the factors that predict work-return experiences. Data collection & analysis were simultaneous until saturation occurred.	13 women. Purposeful sampling for maximum variation/diverse perspectives. Follow-up interviews were conducted to validate and enrich specific ideas when the information was not clear. Participants were followed up for feedback on the findings to identify biases.	a survey and a semi-structured interview. Follow-up interviews (see left). A journal entry was written after each interview to summarise and highlight details that might be informative for follow-up & data analysis and document unusual or interesting observations, eg. 'less neutral feelings'.	Four themes: - BCRL affects physical & emotional functioning associated with work; - ongoing treatment creates challenges for work; - environmental factors affect the return-to-work experience; - personal factors play a key role in adjusting to return-to-work

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Fu & Kang 2013 (an evidence summary) - not for direct inclusion in the initial literature review **	to summarise the evidence of and identify factors influencing the psychosocial impact of lymphoedema. Also discussed nursing strategies.	Included 12 qualitative studies, seven of which used descriptive or hermeneutic phenomenological methodology. 6 relate specifically to BCRL.	<i>This is a systematic review that identifies one further article to those already discovered (see below).</i>	- - -	18/23 studies focussed on BCRL; 5 included lower extremity lymphoedema.
Honnor 2009 UK	to explore the LE information needs of patients who have breast cancer	no theoretical concepts evident. data were analysed using constant comparison to determine saturation point.	A sample size of 15 participants was planned for; 16 patients accepted (out of 20 invitations)	interviews using a guide and including open questions ie. semi- structured	Five themes: - physical effects of LE; - psychological effects of LE; - provision of information about LE; - knowledge of lymphoedema; - informed consent The authors comment that the data were anecdotal and that the results about information given may not be accurate.

Lead author/year	Study aims	Methodology/ theoretical context	Sample size & patient involvement in the study	Data collection methods	Key findings (themes, conclusions)
Acebedo 2021 USA	To investigate the lived experience of Hispanic women who have BCRL, with a focus upon women who are of Mexican descent or origin	Interpretive phenomenology - interpretive reading of field notes, journal entries and transcribed interviews. The study sought to give a voice to these women and provide culturally relevant insight to healthcare providers.	13 Hispanic women	Individual, semi-structured interviews	Three main themes: sense of loss (subthemes - fear of hurting self; feelings of helplessness) resignation to the new self (subtheme - my destiny) not knowing - <i>relates to the perceived lack of BCRL education/ lack of understanding</i> The need for cultural awareness of the impact of BCRL on ADL is required for a holistic plan of nursing care
Dönmez et al. 2021 Turkey	To explore the lived experience of the supportive care needs of women with BCRL	Used a descriptive phenomenological approach	19 women, some of whom were involved in member checking during data analysis, ie those that “had provided rich information	Semi structured interviews	Four main themes: Physical supportive care needs (subthemes included <i>difficulties in performing household chores</i> and <i>limitations in performing self-care activities</i>);

			during the interviews”		<p>psychosocial supportive care needs (subthemes included <i>being addicted to someone else in daily life</i> – ie dependent on another – and <i>uncertainty about the future</i> as well as <i>social and religious support</i>– participants were Muslims);</p> <p>healthcare systems and information supportive care needs (subthemes included <i>attention from healthcare professionals</i> – women had not been previously informed about the risk of BCRL – and <i>education and lifestyle advice</i> – need for information about diagnosis and coping)</p> <p>financial supportive care needs– lack of financial support in Turkey (and other countries)</p>
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Aim

To understand women's experiences of breast or trunk lymphoedema following treatment for breast cancer

Objectives

To establish how women's experiences are measured in the literature (eg. numerical measures; narratives)

To examine what women's experiences are (eg. related to home life, work, leisure activities, appearance, emotional response)

To identify & critique (positive and negative) factors that impact women's experiences

To critique any theoretical frameworks used to explain women's experiences

Eligibility criteria

Studies about women who have been treated for breast cancer and have subsequently developed breast or trunk lymphoedema, in which one or more aspects of their experiences of this condition are reported. Only primary studies are eligible, in which breast lymphoedema is either a major or a minor focus of the study. The studies need not have a comparator. There are no age or date restrictions. English language articles only.

Whilst review articles are excluded, they will be cross-checked for relevant primary studies. Men are excluded.

Information sources

CINAHL (EBSCO); MEDLINE (EBSCO); Web of Science (Clarivate Analytics); Scopus (Elsevier); AMED (Ovid); Cochrane CENTRAL (Wiley)

Search strategy

In order to generate as comprehensive a search as possible, a number of approaches will be used:

- a) Using a 'pearl' ie identifying one-two articles already sourced from the literature about experiences of arm lymphoedema and identifying any additional search terms for the search.
- b) Conducting a database search using 1) terms to describe breast cancer patients, and 2) terms to describe breast lymphoedema or trunk lymphoedema, including the range of alternative spellings and synonyms such as swelling; and any other terms retrieved at a). The Boolean operators AND and OR will be used, alongside proximity searching, quotation searching and truncation. Controlled vocabulary terms will be used where available.
- c) Consider narrowing the search to include searching terms for outcomes such as PROMs, experience and quality of life.
- d) The search will include the grey literature, using abridged search terms in the 'Index to Theses' and in www.opengrey.eu/.
- e) Individual hand searching of key journals including *Psychosocial Oncology* and any other journal identified during the above searches.
- f) Search for articles by key authors identified in the literature about experiences of arm lymphoedema after treatment for breast cancer.
- g) Adopt forward citation tracking to search for more recent articles.
- h) Check the reference lists of the key articles identified.

Data management

Citavi reference management software will be used to organise the results of this review. Microsoft Excel will be used to support the screening process.

Selection process

Screening will be a two-stage process. All results yielded from the literature searches will be screened by title and abstract. The full text of all remaining results will then be screened for relevance.

Data extraction

An a priori data extraction form will be used. The template will be created from existing examples with additional fields amended as appropriate (see proposed form at the end of this protocol).

Data items will include: bibliographic information; study information; population information; details about lymphoedema (breast or trunk); whether a control was used; details of the outcomes; any author conclusions.

The data extraction form will be piloted with a member of the supervisory team on two-three studies, either together or blind (ie independently).

Risk of bias in individual studies/Quality appraisal

The Cochrane risk of bias tool will be used for articles describing RCTs. For other quantitative study designs, SIGN checklists will be employed; whilst the COREQ checklist will be used with articles describing qualitative studies (*see Appendix 6 for adaptation to this strategy employed for the review*).

Due to the likely absence of studies in which women's experiences of breast or trunk lymphoedema is the focus, within each selected study women's experiences will be assessed for how they are represented, ie for the level of priority given to women's experiences and for the quality of the methods used to generate and analyse the related data, using questions such as:

- are the qualitative data central to the study or 'bolted on'?
- are there groups of women excluded in the study design?
- what types of experience or outcomes are accepted as legitimate?
- whose 'voice' is prevalent?

Data synthesis

The quantitative and qualitative findings will be analysed separately because it is anticipated that it will not be possible to combine the two types in any meaningful way. That is, the quantitative findings are likely to relate primarily to incidence and severity of symptoms of breast or trunk lymphoedema; whilst the qualitative findings will focus on women's experiences and views.

Quantitative findings are likely to be limited and not amenable to any meta-analysis; hence descriptive statistics will be produced.

For any qualitative findings; or - if the evidence is very limited - for the findings from an initial literature review of the related phenomenon of women's experiences of developing & living with arm lymphoedema, a thematic synthesis will be used. That is, the findings of individual studies will be combined through the development of codes and descriptive and analytical themes.

Cumulative risk of bias

The GRADE system will be used to establish the cumulative risk of bias from the synthesis of the quantitative findings.

GRADE-CERQual will be adopted to determine the degree of confidence in the findings from the qualitative synthesis.

Headings for data extraction form

Author(s)

Title of article

Title of journal

Volume

Study type

Study design

Control used?

Study aims

Country of study

Breast or trunk lymphoedema (which)?

Stakeholder involvement in design/conduct of study?

Sample information

Details of any theory/conceptual models used

Participant characteristics

Methods of data collection and by whom

Analysis used

Description of intervention and by whom

Details of patients' perspectives

Researchers' potential bias/experience

Outcome measures used

Details of outcomes/findings

Strengths/limitations of the study

Authors' conclusions

Reviewer notes/comments

Quality assessment

1. The development of a strategy for searching the literature which addresses women's experiences of developing and living with breast or trunk lymphoedema

When I first conducted a literature review, I set out with a broad remit to examine the literature to determine whether and how women's experiences of breast lymphoedema had been explored. This meant that my search strategy was similarly broad and intended to capture all the literature which addressed breast or trunk lymphoedema. Forty-three articles were identified through this process; twelve of them used patient-reported measures (PROMs) to obtain quantitative assessments of patients' health status or quality of life (QOL).

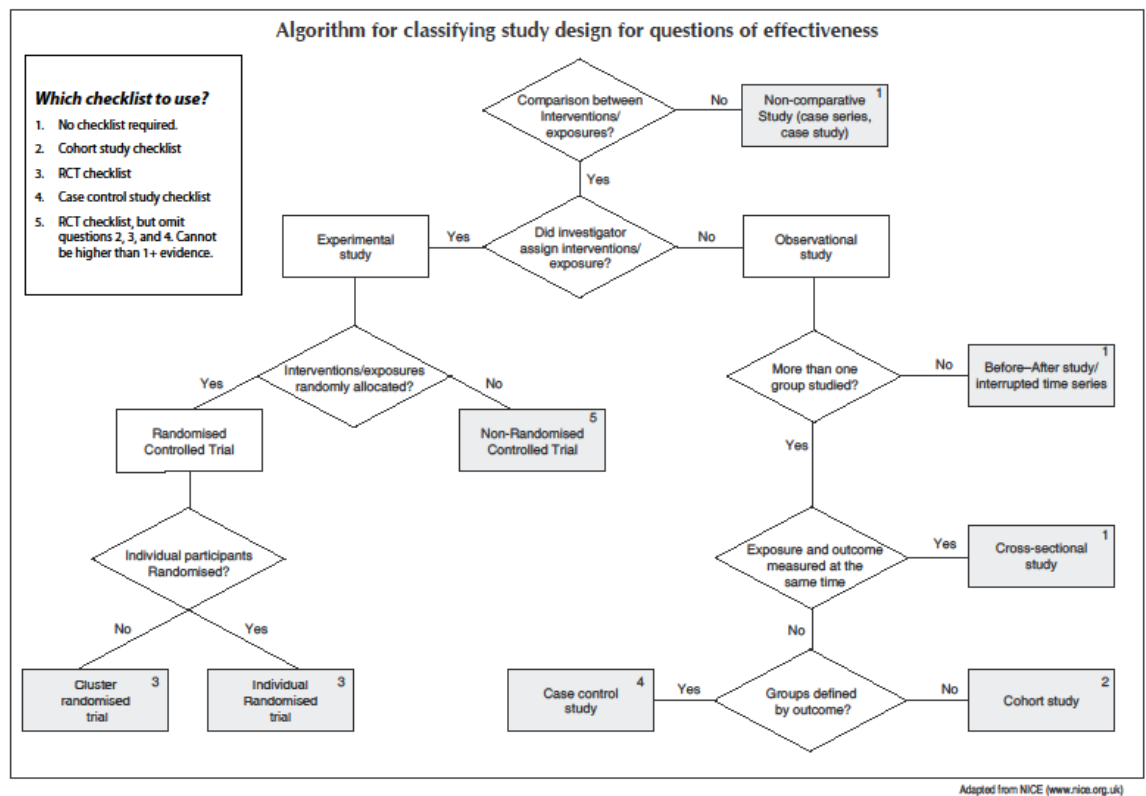
However, in preparing a journal article for publication, I gained feedback as part of the peer-review process which prompted me to articulate more clearly the purpose of my literature review. I realised that of the forty-three articles, it was those using PROMs which were directly relevant to setting the scene for what currently existed in relation to women's experiences of breast or trunk lymphoedema. The remaining articles about incidence and assessment were important for context but were not suitable for the answering the review questions which included 'how are women's experiences of breast or trunk lymphoedema after treatment for breast cancer expressed in the literature?' and 'what is the nature of these experiences?'

By identifying this change in focus for the literature search and adjusting the search terms to reflect patient experience more clearly, I was able to identify the literature which showed that women's experiences of breast or trunk lymphoedema have been captured in a limited way and that more in-depth, qualitative methods are necessary to gain a better understanding of these experiences.

2. Risk of bias assessment (quality assessment)

As described in the description of the systematic review process which I registered with PROSPERO, the following tools were used to undertake a quality assessment for the articles identified from the search:

The Cochrane risk of bias tool was selected for the following articles (referred to by lead author and year, unless author is lead for more than one article, in which case subsequent author/s are also listed): - Collins (2018); Hansdorfer-Korzon (2016); Jahr (2008); Kilbreath (2020); and Petkov (2016).



The selection process for the remaining articles was based upon an algorithm produced by SIGN (above) which was adapted from NICE; I then drew upon NICE preferred checklists, according to study design, as follows:

For studies which were deemed as ‘no checklist required’ (according to SIGN’s algorithm) I employed a self-devised checklist (CRD 2008) which included data extraction questions, internal and external validity questions and a summary of the authors’ and my own conclusions. This was developed by consulting a range of checklists and helped to inform a quality assessment. It was applied to the following studies:

Adriaenssens, Verbelen et al. (2012) (prospective, cross-sectional study)

Degnim (2012) (prospective, longitudinal study)

Goffman (2004) (retrospective cross-sectional study)

Gregorowitsch (2019) (prospective, longitudinal pilot study)

Haen (2012) (cross-sectional, observational study)

Johansson (2019) (randomised controlled pilot study)

Ridner (2010) (a ‘quasi-experimental’ (single group) pre-treatment, post-treatment uncontrolled study)

Teguh (2016) (pre-treatment, post-treatment study)

Wennman-Larsen (2015) (prospective cohort (one group) study)

Young-Afat (2019) (prospective cohort study)

I also used the self-devised checklist as a template for all the studies to allow for some uniformity, incorporating alternative or additional questions from the recommended checklists (see below) as appropriate:

Giacalone (2016); Jacob (2019); Linnitt (2007); Scaglioni (2021) and Tan (2019) – Joanna Briggs Institute (JBI) critical appraisal checklist for case reports.

Although NICE makes no recommendations on checklists for case studies, NICE's recommendations for several other JBI checklists for different study types indicates that the JBI approach is deemed suitable for a review of health-related evidence.

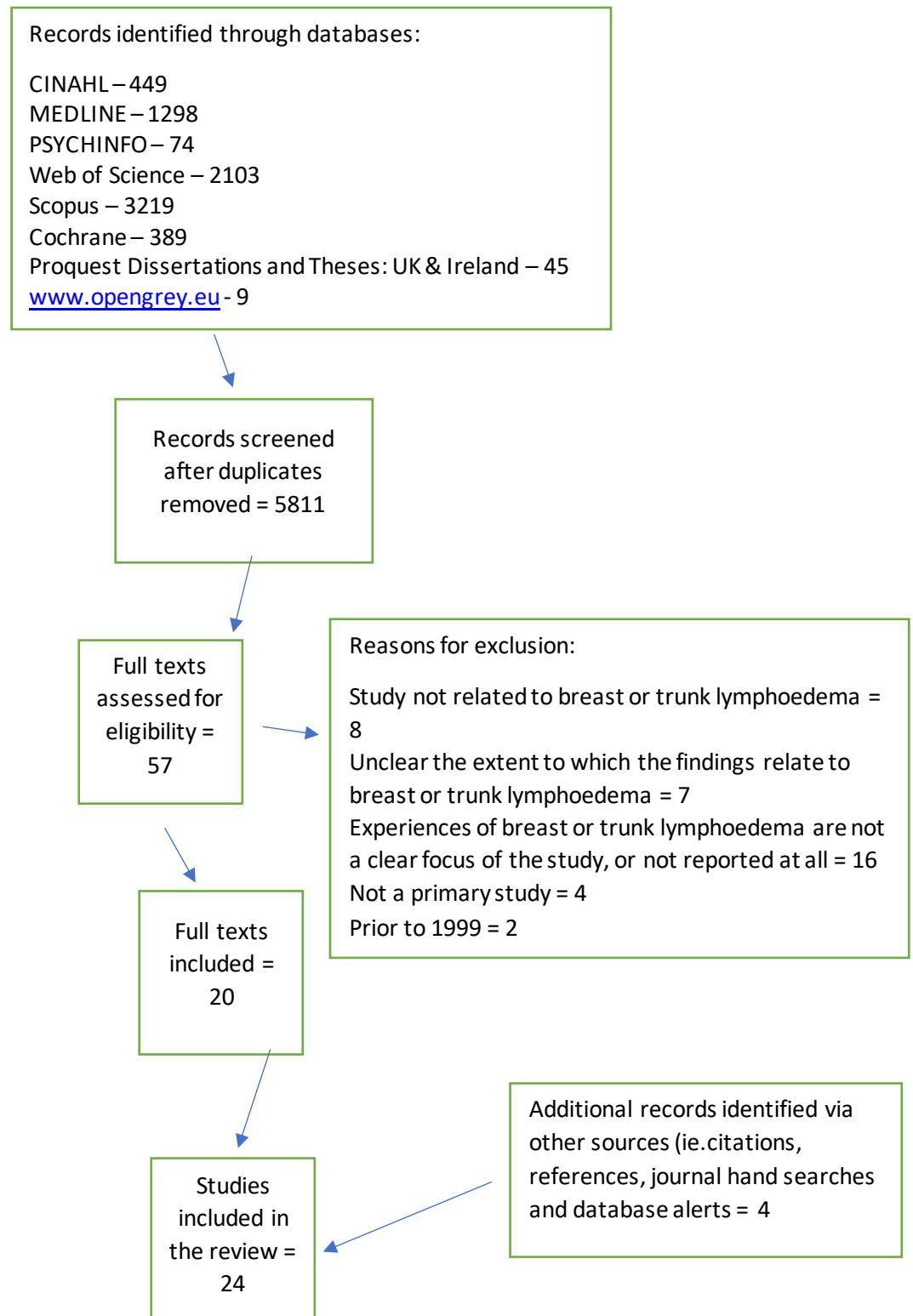
Finnerty (2010); Sierla (2013) - Centre for Evidence-Based Management CEBM critical appraisal of a survey checklist.

Hammond (2010) - Institute of Health Economics (IHE) checklist for case series

Probst (2021) – the COREQ was employed (as indicated in the PROSPERO submission) as well as the JBI checklist for qualitative research (which is a NICE recommendation).

Appendix 7:

PRISMA diagram representing results of the systematic search for the literature



Appendix 8:

Details of the articles included in the systematic literature review and outcome of quality assessment

Lead author and year	Study type	Brief description of aims	How are women's experiences measured?	Quality assessment (and tool if appropriate)
Adriaenssens 2012b	prospective, cross-sectional	to assess incidence & degree of BLE; to assess HRQoL; to determine correlations, including between degree of BLE and HRQoL	uses EORTC QLQ BR23; and a self-devised questionnaire to determine symptom impact	no checklist recommended by NICE/ SIGN; self-developed checklist used instead. Outcome: SOME CONCERNS
Collins 2018	feasibility RCT	to determine the feasibility of an RCT to evaluate the effectiveness of kinesiology tape & usual care vs usual care alone	Visual analogue scale for breast heaviness/fullness, discomfort and redness.	Self-developed checklist used. Outcome: SOME CONCERNS
Degnim 2012	prospective, longitudinal	to determine the frequency of BLE & to characterise its physical presentation, symptoms, clinical course and impact on QoL	breast heaviness, discomfort, redness, visible swelling, & associated distress were measured using 11-pt rating scales; the FACT-B was used to measure QoL	Self-developed checklist used. Outcome: SOME CONCERNS

Finnerty 2010	audit, including a questionnaire	to explore women's feelings and experiences of using kinesiology tape in the breast and truncal area & to establish whether measurable change could be detected with its use.	used a (presumably self-devised) questionnaire, with the option for patients to make comments	(NICE- recommended) CEBM critical appraisal of a survey checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS
Giactalone 2016	case study	to report a case of BLE successfully treated with supermicrosurgical lymphaticovenous anastomosis (LVA)	descriptive comments about the patient's experiences are reported indirectly by the authors	JB case study checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS
Goffman 2004	retrospective cross-sectional study	to assess risk for lymphoedema of the breast and arm in radiotherapy patients 'in an era of less extensive axillary surgery'.	details about symptoms and treatment outcomes derived from case notes - description only (ie no tools used)	Self-devised checklist used. Outcome: SOME CONCERNS
Gregorowitsch 2019	prospective, longitudinal pilot study	to evaluate whether the use of a compression vest reduces symptoms of breast/chest wall oedema in patients with breast cancer	EORTC QLQ - BR23 module questions 50 & 51 to determine breast/chest wall swelling and pain; HRQoL and pain assessed using the EORTC QLQ - C30 & BR23. The Brief Pain Inventory (BPI) used to	Self-devised checklist used. Outcome: SOME CONCERNS

			measure pain severity and pain interference with daily function.	
Haen 2012	cross-sectional, observational study	to demonstrate that measuring tissue dielectric constant (using the MoistureMeter-D) is an effective method to detect tissue water changes (arm and breast); to investigate the correlation between this method and arm volume & self assessment questionnaires (patient reports)	<ul style="list-style-type: none"> * self-report questionnaire of participants' experience of lymphoedema in the arm and breast * pain rated on an 11-point numerical scale * discomfort, heaviness and perception of increased size were measured on a 4 -point scale * skin changes to arm or breast (yes/no) * ratings of the success of treatment on an 11-point numerical scale *satisfaction with the lymphoedema clinic on an 11-point scale 	Self-devised checklist used. Outcome: SOME CONCERNS

Hammond 2010	case series	to report on the clinical outcomes, therapist observations & subjective impressions of patients with truncal and limb lymphoedema following in-clinic and home treatment including FT (a programmable pneumatic device)	the authors report that the five patients provided their subjective impressions of their experiences (of MLD and the FT system). The article provides detail of women's experiences of MLD and the FT system.	IHE case series checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS
Hansdorfer-Korzon 2016	experimental study: randomised to treatment or control	to determine the effect of compression therapy (corsets) in the prevention and treatment of truncal lymphoedema and the reduction of pain associated with breast cancer surgical treatment	a visual analogue scale is used to report levels of pain	RoB 2.0 completed Outcome: HIGH RISK in the absence of information about the reliability of measurements and blinding of assessors (domain 4)
Jacob 2019	case study	to describe a physical therapist intervention for a patient with signs and symptoms of secondary axillary web syndrome, breast swelling and seroma	provides a detailed description of the symptom experiences of the patient in the form of a tabulated descriptions of treatment sessions; 10-point visual analogue	JBIC case study checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS

		which presented seven months after surgery and RT for breast cancer	scale for breast pain & arm pain	
Jahr 2008	experimental ('pilot') study: randomised to treatment or control	to evaluate swelling & pain and functional limitations (reduction of RoM of shoulder & cervical spine) of patients with secondary BLE; and to assess the additional therapeutic benefit of Deep Oscillation when combined with MLD	VAS (10 points) each for pain, swelling and the effectiveness of lymphoedema treatment	RoB 2.0 completed: outcome = HIGH RISK OF BIAS due to potential for the patient (and clinician) to have been influenced by knowledge of the intervention - placebo effect a possibility acknowledged by the authors. This study is referred to by the authors as a pilot study and they appeared to have examined whether treatment effects/outcomes are consistent with expectations; however there is no suggestion of moving onto a full RCT, indicating that this study was treated as such.
Johansson 2019	randomised controlled pilot study	to investigate whether BLE can be treated by compression 'at an early	A 100 mm horizontal VAS to measure	Own checklist used as well as RoB 2.0 tool (as unclear whether the RoB

		stage'; to investigate whether there is an association between BLE and oedema in the upper arm or lateral thorax	tightness, heaviness and pain; patient reports of discomfort from the compression bras are also recorded	tool can be used with a pilot RCT). Outcome with RoB 2.0: SOME CONCERNS
Kilbreath 2020	RCT	to establish the safety, feasibility and acceptability of an exercise programme to reduce breast lymphoedema	uses EORTC BR23 for breast symptoms; and LSIDS for symptom intensity and distress, where breast or chest wall were asked about rather than the arm	RoB 2.0 used. participants are aware of assignment; potential for high risk with outcome measurement - validated measure for arm lymphoedema used to for breast measures & acknowledged difficulties with physical measurements (aerobic fitness); also the PROMs scores could have been influenced by knowledge of the intervention received. Outcome: SOME CONCERNS
Linnitt 2007	case study within a discussion on managing breast oedema	to examine the issues surrounding breast oedema including the psychological impact and	provides a description of the impact of breast oedema and the patient's feelings	JBIC case study checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS

		the role of referral to a specialist centre for Rx.		
Petkov 2016	experimental study, randomised to treatment or control	deep oscillation therapy (breast and upper limb) was compared to standard lymph drainage to the upper limb	Total Life Quality Scale (numerical scores) including a VAS for pain (0-10)	RoB 2.0 tool used. Some concerns about the randomisation process; potential risk of bias due to deviations from the intended interventions; risk of bias in measurement of the outcome; risk of bias in the selection of the reported result - limited reporting of outcome measures. Outcome = HIGH RISK
Probst 2021	a participatory co-design methodology involving 5 workshops (2 for patient representatives & 1 for patient reps and HCPs)	to understand the patient experience of the radiotherapy pathway for breast cancer	workshop discussions were audio-recorded and analysed using framework analysis	JBIC checklist for qualitative studies was used. Outcome: LOW RISK/WELL-DESIGNED AND REPORTED STUDY
Ridner 2010	a 'quasi-experimental' (single group) pre-treatment, post-treatment uncontrolled study	to examine the potential efficacy of a pneumatic therapy device as a component of self-care for women with truncal lymphoedema following	Symptom burden/intensity and distress, and function assessed using LSIDS-AT and FASQ respectively (numerical scores). Also comments	Self-devised checklist used. Outcome: HIGH RISK

		treatment for breast cancer	about compliance and participants' responses to the equipment are documented.	
Scaglioni 2021 Switzerland	case report and literature review N =1	to report a case of breast lymphoedema which was successfully treated with LVA	a narrative provided which includes reference to patient distress and afterwards the improvement in her quality of life. The account of her surgery is accompanied by before, during and after photographs	<p> JBI case study checklist incorporated into self-devised checklist. Outcome: LOW RISK </p>
Sierla 2013	cross-sectional descriptive survey	to describe the presentation of BCRL, severity of swelling and discomfort, treatments used and their perceived effectiveness	electronic, validated questionnaire. Uses multiple choice questions with occasions to provide additional comments. A validated measure is used for determining the degree of swelling; rating scale also used for discomfort/other sensations; and a Likert-type scale for treatment effectiveness.	<p> NICE-recommended CEBM critical appraisal of a survey checklist incorporated into self-devised checklist. Outcome: SOME CONCERNS </p>

<p>Tan 2019</p> <p>USA</p>	a case report	to describe the initial findings and physical therapy management for a patient; case completed in accordance with CARE guidelines for reporting clinical case reports	reference to the patient's 'subjective remarks' made during history-taking; use of objective measures of BL but no patient-reported outcome measures; appeared to speak on behalf of the patient in describing empowerment and taking control - unclear if the patient herself talked this way The authors conclude that the patient "had a positive experience" although only objective measures of circumferential size, range of movement, strength and function were employed.	<p>JB case study checklist incorporated into self-devised checklist.</p> <p>Outcome: SOME CONCERNS</p>
Teguh 2016	pre-treatment, post-treatment design	to examine patient-reported outcome measures of women undergoing hyperbaric oxygen treatment (HBOT) after BCT (ie late	EORTC QLQ BR23 to measure the severity of breast symptoms of swelling, pain, oversensitivity and skin problems.	<p>Self-devised checklist used.</p> <p>Outcome: HIGH RISK</p>

		toxicity of all kinds including breast symptoms).	[The EORTC QLQ C30, the EQ-5D (health status) & the NRS pain scale were also used].	
Wennman-Larsen 2015	prospective cohort (one group) study	to examine the severity and development of breast and arm symptoms (separately) during the two years after surgery; to examine whether previously defined predictors of arm symptoms are associated with breast symptoms	EORTC QLQ BR23	Self-devised checklist used. Outcome: SOME CONCERNS
Young-Afat 2019	prospective cohort study	to evaluate the prevalence and determinants of breast oedema, and the association between breast oedema and patient-reported HR-QoL and breast pain	EORTC QLQ C30 and BR23: breast oedema measured by BR23 question 51 (four-point Likert scale) breast pain measured by BR23 question 50 (four-point Likert scale)	Self-devised checklist used. Outcome: LOW RISK/WELL-DESIGNED STUDY

Appendix 9:
Examples of the data extraction and quality assessment process

The content of this appendix was included for the purposes of the viva examination for this thesis and subsequently has been removed.

Appendix 10a: University ethics approval



RESEARCH ETHICS REVIEWER'S FEEDBACK FORM (SHUREC3)

Principal investigator: ULMAN, J
2017-8/HWB-HSC-01

Reference number:

Other investigators: PROBST, H

Title of project:

Investigating women's experiences of breast or trunk lymphoedema following treatment for breast cancer

In my judgement the application should be (tick one box):

- ☒ Approved
- ☐ Approved with attention to the items listed below (1). Please email the details of how the issues have been addressed to the FREC and provide confirmation from the supervisor that the issues have been addressed for student projects.
- ☐ Referred back to the applicant for a full resubmission to address all the conditions listed below (1)
- ☐ Not approved for the reasons listed below (2)

1. The following issues need to be addressed:

Reviewed indendently and decision agreed by the following:

Colette FEGAN

Robert APPLEYARD

30/08/2017

Appendix 10b – NHS Research Ethics Committee approval



Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

13 July 2018

Mrs Janet A Ulman
Doctoral student
Sheffield Hallam University
Chestnut Court
Collegiate Crescent
Sheffield S10 2BP

Dear Mrs Ulman

Study title: How do women describe their experiences of developing and living with breast (or trunk) lymphoedema after surgery and radiotherapy for breast cancer? A qualitative study using visual methods.

REC reference: [REDACTED]
IRAS project ID: 225878

Thank you for your letter of 12 July 2018, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster invitation]	Version 1.0	27 March 2018
Covering letter on headed paper [Invitation letter]	Version 1.0	13 March 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance certificate]		01 August 2017
Interview schedules or topic guides for participants [Interview prompts]	Version 1.0	27 March 2018
IRAS Application Form [IRAS_Form_10042018]		10 April 2018
IRAS Checklist XML [Checklist_12072018]		12 July 2018
Letters of invitation to participant [Invitation letter]	Version 1.0	13 March 2018
Other [Second consent form]	Version 1.0	20 July 2017
Other [Participant support sheet]	Version 1.0	21 July 2017
Other [PIC site confirmation letter]		26 February 2018
Other [Amendments to IRAS form]		27 March 2018
Other [Literature review]		29 November 2017
Other [Current GCP certificate]		20 February 2017
Other [Data management plan]		13 March 2018
Other [Employer's liability letter]		31 July 2017
Other [Professional indemnity letter]		31 July 2017
Other [Academic supervisor - CV - HP]	Not applicable	17 January 2017
Other [Academic supervisor - CV - LS]	Not applicable	13 April 2018
Other [Prompts and guidelines for taking photos]	Version 2.0	28 June 2018

A Research Ethics Committee established by the Health Research Authority

Other [Letter to REC following provisional opinion]		29 June 2018
Other [Protocol with amendments highlighted]	Version 2.0	28 June 2018
Other [Social media invitation]	Version 1.0	28 June 2018
Other [Letter in response to July REC comments]		12 July 2018
Participant consent form [Participant Consent Form]	Version 3.0	12 July 2018
Participant information sheet (PIS) [Participant Information Sheet]	Version 2	28 June 2018
Research protocol or project proposal [Study protocol]	Version 2	28 June 2018
Summary CV for Chief Investigator (CI) [Curriculum vitae]		08 March 2018
Summary CV for Chief Investigator (CI) [Curriculum vitae]		17 January 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart study process]	Version 1.0	28 June 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

[REDACTED] Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

[REDACTED]
pp [REDACTED]

[REDACTED]
Chair

Email: [REDACTED]

Enclosures: "After ethical review – guidance for researchers"

Copy to:

[REDACTED]

[REDACTED] Foundation Trust

Appendix 11: Amendment log

Sheffield Hallam University

Substantial and Non-Substantial Amendment Log

Study Title:	How do women describe their experiences of developing and living with breast (or trunk) lymphoedema after surgery and radiotherapy for breast cancer? A qualitative study using visual methods.
Chief Investigator:	Professor Heidi Probst; project undertaken by PhD student Janet Ulman
Sponsor Internal Reference:	Research proposal number: 2017-8/HWB-HSC-01
Other reference numbers:	IRAS Project ID: 225878
Amendment details (reference number; type of amendment; date of submission; amendment category; details of amendment and outcome):	<p>Sponsor Amendment Reference Number 1, submitted 05.11.18</p> <p>Non-substantial; amendment category C; approved 08.11.18</p> <p>Details: a reminder letter to potential participants identified through the PIC.</p>
Amendment details (reference number; type of amendment; date of submission; amendment category; details of amendment and outcome):	<p>Sponsor Amendment Reference Number 2, submitted 16.01.19</p> <p>Substantial Non-CTIMP; approved 30.01.19</p> <p>Details: List of proposed organisations or individuals to widen recruitment, including attempts to access participants from BME communities.</p> <p>Includes changed wording of an invitation to the study via social media postings, in order to minimise breaches of confidentiality for potential participants.</p>

<p>Amendment details (reference number type of amendment; date of submission; amendment category; details of amendment and outcome):</p>	<p>Sponsor Amendment Reference Number 3, submitted 13.04.21</p> <p>Non-substantial: 3 amendments</p> <ol style="list-style-type: none"> 1. Participants will be e-mailed a further time with an invitation to provide their feedback on the draft analysis from the entire dataset; 2. Invitation via e-mail will be sent to the Lymphoedema Support Network (a charitable organisation) to provide feedback on the draft analysis. This is not part of the data collection process which has already been completed. 3. Due to COVID restrictions and an extension on my PhD scholarship granted by the university, the end date for analysis is 31.07.21 with an estimated completion of thesis write up as 30.10.21.
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Appendices 12-15: Study Information Pack:

Appendix 12 – Covering letter

Appendix 13 – Participant Information Sheet

Appendix 14 – Prompts and guidelines for photographs

Appendix 15 – Participant consent form



Dear

Thank you for contacting me about my research study which aims to investigate women's experiences of developing and living with breast or trunk lymphoedema after treatment for breast cancer.

Included with this letter you will find:

- A Participant Information Sheet
- Prompts and guidelines for selecting images of your experiences
- A Participant Consent Form (*for signing when we meet together, if you decide to take part*)

Please take time to read the information carefully. If you would like any more information, or if think that you would like to take part in the study, you can contact me on XXXXXXXX. Alternatively, you can e-mail me at janet.ulman@shu.ac.uk.

Yours sincerely

Janet Ulman

PhD student Sheffield Hallam University



Participant Information Sheet

Women's experiences of developing breast (or trunk) lymphoedema following surgery or radiotherapy for breast cancer

You are invited to take part in this research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read this information carefully. You can discuss it with others and ask the researcher (details below) if you have any questions. Take some time to decide if you want to take part.

The University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of public tasks that are in the public interest. A full statement of your rights can be found at <https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notices/privacy-notice-for-research>. However, all University research is reviewed to ensure that participants are treated appropriately and their rights are respected. This study was approved by the University the NHS research ethics committees. Further information can be obtained at <https://www.shu.ac.uk/research/ethics-integrity-and-practice>.

Thank you for reading this.

1. What is the purpose of the study?

We know that some women develop lymphoedema (swelling) in their breast or trunk after surgery or radiotherapy for breast cancer; however, we know very little about women's experiences of this condition and how it affects their lives.

The purpose of the study is to increase understanding of women's experiences of breast or trunk lymphoedema. Women who participate will be invited to take or select photographs that help to show or represent their experiences of breast or trunk lymphoedema. These photographs will be used by participants during an individual interview with the researcher.

The knowledge gained from the study could help to improve services through educating healthcare professionals and improving the information and support that is given to patients diagnosed with breast cancer.

2. *Why have I been invited to take part?*

You have been invited to take part because you are a woman who has developed breast or trunk lymphoedema after surgery or radiotherapy for breast cancer, and so have some experience of the condition.

3. *Do I have to take part?*

It is your decision whether or not to take part. It will not affect any further treatment or support you are offered for your breast or trunk lymphoedema. If you do decide to take part, you will be given a copy of this Information Sheet to keep and you will be asked to read and show your agreement on a consent form. You can still withdraw at any time; you do not have to give a reason. Any information already collected will remain anonymous, including anonymised quotes which may be used in publications, talks or exhibitions.

4. *What will happen to me if I take part?*

You will be asked to meet with the researcher on one or two occasions, either at [name of recruitment site], in your own home, or at another location of your choice where we will be undisturbed.

On the first occasion, you will have an opportunity to ask any questions you might have about the study. If you agree to take part, you will be asked to read and sign a consent form. Some basic information will then be collected from you, such as your age and how long ago you received treatment for breast cancer. [Note: If you would prefer this meeting can take place over the telephone, in which case the consent form will be signed when you meet with the researcher for your interview].

The researcher will then explore with you the type of photographs (if any) you may want to take or select to represent or convey aspects of your experience of breast or trunk lymphoedema. If you choose to take or select photographs, they will be used in your interview with the researcher (which will take place a few weeks later). Photographs have been found to be useful in other studies, where they have helped participants to express what it is like to live with a health condition.

You might choose any or all of the following:

- photographs that you take yourself (using a disposable camera provided to you by the researcher);
- photographs or pictures that you already have (for instance, pictures from magazines, pictures on your phone, or pictures in family albums);
- photographs provided by the researcher (which you will be able to have at home with you to look at and select)

In the case of photographs that you take yourself:

You will be given some guidelines about taking photographs, including the advice not to include images of children or other people.

Approximately 2-3 weeks later you will meet with the researcher for an audio-taped interview with any photographs that you have taken or selected. If you have used a disposable camera provided to you, the photographs will have been developed by the researcher prior to the interview.

During your interview, you will be able to talk about the meaning of your photographs. The interview is expected to last between 30 and 60 minutes, but no longer than 90 minutes. The researcher will take a digital photograph of each of the photographs used in your interview, so that there is a digital record of all of the photographs.

Please note: If you would like to take part in the study but would prefer not to use photographs in your interview, you are just as welcome to participate.

The audio-recording of your interview will be sent securely to an external company to be transcribed. A few weeks after your interview, you will be contacted again and asked if you would like to read the transcript of your interview and say whether you think that it is an acceptable record.

A few weeks or months later, you will be invited to offer your opinion:

- upon the researcher's draft analysis of your interviews and photographs; and
- upon the overall analysis of all the information from the study.

The researcher intends to invite all the study participants, other women with breast or trunk lymphoedema, and select healthcare professionals working in the field of breast or trunk lymphoedema, to comment upon the researcher's draft analysis of all of the interviews/photographs. For this stage, you will not be identifiable from the interview transcripts or the photographs, ie you will remain anonymous.

The intention is to share the findings of the study in several ways, such as in an exhibition, in a conference poster or presentation, in an academic journal article, with breast cancer and lymphoedema organisations and in teaching materials. You will be asked whether or not you agree to any of your images (if you selected any) being used in any of these ways; and if so, you will be invited to choose which images you consent to being used in the ways you specify. You will be able to remain anonymous, but you can also choose to be identified in any quotes/photographs used (for instance by using your first name).

5. What are the possible disadvantages and risks of taking part?

It is possible that you will find it upsetting to talk about some aspects of your breast or trunk lymphoedema experience. The researcher will provide you with contact details of services that can provide you with support, ie someone to talk to. You will be able to contact them yourself, or the researcher can make contact for you.

6. What are the possible benefits of taking part?

It might be rewarding to have the opportunity to talk in detail about your experiences of breast or trunk lymphoedema to someone who is listening carefully. The knowledge gained from your participation could help healthcare professionals understand your experiences better and thus help future women who have been diagnosed with breast cancer.

7. What if something goes wrong?

If you have any complaints about the study, in the first instance you can contact the researcher or her supervisor. If you feel that your complaint has not been handled satisfactorily, you can contact Sheffield Hallam University. See point 12 below for further details.

8. Will my taking part in the study be kept confidential?

Any information collected about you during the course of the study will be kept strictly confidential.

Information stored electronically (such as personal information, photographs, audio files and transcripts of the interview tapes) will be secured on an encrypted USB stick and backed up on a password-protected secure computer drive maintained by Sheffield Hallam University.

Any quotes or photographs used in reports, publications, presentations, websites or exhibitions will maintain your anonymity (so that details that would make you recognisable will be removed) unless you choose and consent to being identified. If you choose to remain anonymous, a pseudonym will be used instead of your real first name and any identifying features in photographs will be digitally altered.

After the study, information collected from you (that is, the transcript from the audio-taped interview and – if you consent - your selected photographs) will be stored in anonymous form in Sheffield Hallam University's research archive for a minimum of ten years, after which it will be destroyed. It is preserved in this way

so that other researchers can have access to it, either to better understand the current study, or to build upon it in future research.

9. What will happen to the results of the research study?

It is envisaged that one or more exhibitions will be organised which will display anonymised photographs and interview quotes from the study (unless you choose and consent to being identified).

The study findings will also be used in presentations (at conferences, at breast cancer groups and at lymphoedema groups, for instance); on websites and in newsletters; and published in academic journals.

10. Who is organising and funding the research?

The researcher is a doctoral student on a Vice-Chancellor scholarship awarded by Sheffield Hallam University.

11. Who has ethically reviewed the study?

The study has received ethical approval from the Health and Social Care research ethics sub-committee of Sheffield Hallam University and the appropriate Research Ethics Committee for the NHS.

12. Further information and contact details:

If you have any further questions, concerns or wish to make a complaint, in the first instance please contact the researcher, Janet Ulman, on XXXXXXXX or at janet.ulman@shu.ac.uk; her supervisor, Professor Heidi Probst, can be contacted on XXXXX or at h.probst@shu.ac.uk.

If you still have any complaints or concerns that have not been addressed satisfactorily, you can contact Nikki Jordan-Mahy, head of the Faculty Research Ethics Committee on XXXXX or at scinj@exchange.ac.uk.

You should contact the Data Protection Officer if:

- you have a query about how your data is used by the University
- you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately)
- you would like to complain about how the University has used your personal data

DPO@shu.ac.uk

Postal address: Sheffield Hallam University, Howard Street, Sheffield S1 1WBT
Telephone: 0114 225 5555

You should contact the Head of Research Ethics (Professor Ann Macaskill) if

- you have concerns with how the research was undertaken or how you were treated

a.macaskill@shu.ac.uk



Prompts and guidelines for images of your experiences of developing and living with breast or trunk lymphoedema

[to accompany the Participant Information Sheet]

Here are some questions to consider that might help you when you are creating or choosing photographs to represent your experiences of breast or trunk lymphoedema. You don't have to use them!

1. What was it like to develop breast or trunk lymphoedema? What it is like to live with it?

Can you think of any way to express any aspect of this in a photograph?

2. Think of a typical day, from getting up in the morning to going to bed at night. Have you had to change the way you carry out any everyday activities or the way you live your life because of your breast or trunk lymphoedema?

Can you take or find any photographs of objects, places or situations that show examples of this?

3. Can you take or find any photos that remind you of a particular occasion connected to having breast or trunk lymphoedema?

4. Could you represent in a photograph any physical changes you have experienced from developing breast or trunk lymphoedema?

5. Can you photograph how living with breast or trunk lymphoedema has made you feel?

6. What do you want other people to know about living with breast lymphoedema?

Remember:

1. Your photographs don't have to show something literally - the image might stand in for something else.

2. Your photographs are not expected to speak for themselves! You will have the opportunity to talk about the meaning of your images with the researcher during your interview.

Important – taking photographs for the study

1. Please remember that there could be restrictions on taking photographs in some locations, such as within clinics or hospital settings. If in doubt, please ask permission.
2. Please do not take photographs with children or any other people in them.
3. If you take any photographs of yourself, they will be anonymised (digitally altered) before they are shared with the research team at the University and the wider 'research team' (that is, the participants in the study, a small group of women treated for breast cancer, and lymphoedema specialists attached to two lymphoedema services).

Please turn over:

4. At the end of the study, you will be invited to choose any of your photographs that you would like to be displayed publicly (for instance, in an exhibition, in presentations or in journal articles).

If you appear in any of your photographs, you can choose whether you would like to be identified (by your first name and by your image), or whether you would prefer to remain anonymous (using a pseudonym and photographs in which you have been digitally altered, if you appear in any of them).

Appendix 15: Participant Consent Form

IRAS Project ID 225878



Participant Consent Form

Investigating women's experiences of breast or trunk lymphoedema following treatment for breast cancer

Name of Researcher: Janet Ulman

Participant Identification Number for this project:

Please initial box:

1. I confirm that I have read and understand the information sheet dated 28.06.18 explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. Any information already collected will remain anonymous, including anonymised quotes which may be used in publications, talks or exhibitions. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that my responses will be kept strictly confidential unless I share information with the researcher that requires her to disclose information to an appropriate professional (such as my GP) to ensure my, or someone else's, welfare. ☐
4. I understand that relevant sections of my data collected during the study may be looked at by individuals from Sheffield Hallam University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

Appendix 16: Reminder letter to potential participants



*Alongside logos for the
Participant Identification
Centre and the recruiting
lymphoedema service*

Date:

Re: Study investigating women's experiences of developing breast (or trunk)
lymphoedema following surgery or radiotherapy for breast cancer

Dear

Recently you were sent an information pack about the above study.

You may have decided not to take part in the study, in which case you need do nothing at all.

However you may still be considering taking part. If you are still considering whether to participate in the study, this letter is a reminder that **you do not need to use photographs to take part in the study**. It would be just as valuable to the study if you chose to be interviewed about your experiences without using photographs.

If you would like to speak to the researcher Janet Ulman to find out more about what participating in this study would involve, she would be pleased to hear from you. Janet can be contacted on XXXXXXX or at janet.ulman@shu.ac.uk. In addition [*name and job title of contact at recruitment site*] on [*telephone number*] can also be contacted if you would like to talk over taking part in the research.

Yours sincerely

Name and address of the recruiting lymphoedema specialist

Appendix 17:

The set of researcher-found photographs: written description and rationale for selecting them

The photographs were obtained from websites that declared that the images were free to use; the main website from which the images were sourced was Pixabay. A small number of images were taken by me.

I selected them in an unstructured way, having no plan regarding the number of pictures I would select or the type of images they would be.

Whilst they were intended to be open to interpretation, and to allow participants to use each image in either a literal or a metaphorical sense, I did however aim to include images that could be (broadly) interpreted as 'positive' or 'negative' and to include images of people, objects, and the environment. It could be said that there are more images that could be construed as negative, however, and my justification for this is that by its very nature, I'm investigating a subject that it a negative feature of women's lives. Hence it can be argued that there is a need for more negative images to access women's experiences of BTL.

I acknowledge that these choices are merely my own responses and interpretations, and therefore representative of only one perspective. But I believe that there is likely to be some commonality between my responses and those of my participants, as fellow human beings and perhaps more specifically as women.

Multi-coloured balloon

Broadly a 'positive' image. Aimed to enable participants to think about it in terms of colour and of the connotations associated with a hot air balloon, for instance.

Blank jigsaw with missing piece

I was drawn to this image for its potential to be interpreted in many ways. I expect it to be used in a metaphorical rather than a literal sense, though of course the image of a jigsaw may trigger a specific memory linking a participant's experience of breast lymphoedema with a jigsaw.

Women sitting around a table smiling, looking at photographs.

When I chose this image, I believed that the women were playing a card game, ie I thought that they were 'playing'. On closer inspection, however, one group member is laying out photographs, and a pen and notepad is lying on the table which may imply a work task rather than play. I do think that on glancing at this image, the overall

impression is of a group of women who appear relaxed together; and I'm assuming that this is the tone that participants will take from the image.

I selected it to enable participants to talk about any of a range of subjects relating to friendship, family, leisure, laughter, relaxation.

Footprints in the sand.

I was drawn to this image for its potential to elicit responses at the abstract/metaphorical level as much as its ability to represent being on the sand. I'm conscious that it could be construed as a rather clichéd image – there is a well-known poem often engraved into gifts about not being alone – but I believe that the images of footprints, the sand, and the edge of the sea seem to hold many possibilities for eliciting stories from participants.

An open notebook of blank paper and a pencil.

This image seems to have both literal and metaphorical possibilities. When I look at some of the images such as this one, I find that I imagine the ways in which participants may use them. For instance, I see this as possibly construed more literally as the participant's story yet to be told; or it could relate to a hospital appointment where there was a lack of information, for instance. The latter idea stems from an experience told to me by my own mother during her obtaining a diagnosis of lung cancer.

Sharing a cup of tea with a friend or trusted person.

I anticipate that this image will give participants an opportunity to consider aspects of their experiences of developing/living with breast/trunk lymphoedema that relate to being supported, or leisure/relaxation. However on further inspection I see that the woman in the image is wearing quite a loose top and so participants may be prompted to talk about their clothing choices, if their breast/trunk lymphoedema required them to wear looser clothing.

Older woman with her hand on her head.

I selected this image for its representation of three aspects: - an older woman; a woman from an Asian background; and the feelings that her posture seemed to represent (such as being tired). I note that the vast majority of images that are freely available represent younger, white people.

Rocks across a river.

I'm aware that images of water have longed been used in a metaphorical sense. I selected this image for its potential to convey or elicit obstacles/difficulties as well as opportunities.

Rusty car.

My expectation is that – in the context of this research study – this image would be employed to represent thoughts or feelings. However participants may use this in other abstract or more literal ways.

Young girl walking down an empty road.

This image could give participants an opportunity to talk about aspects of their experiences in terms of a journey. It was also selected for its positioning of the woman with her back to the camera; and the writing on the road sign is in a foreign language. Thus, I anticipate that this image could have a number of metaphorical meanings.

Cactus.

I believe that there are both literal and metaphorical associations with this image which may engage participants.

I chose this image having no knowledge about the physical sensations associated with having breast or trunk lymphoedema, but I imagined that this could be used to represent physical feelings of prickliness, if this is relevant to any participants; or at least it could trigger a discussion about what other physical sensations are experienced instead.

It could also be used to represent a person's attitude, either the participant's or someone that they have encountered.

A bridge.

This may be taken literally or metaphorically by participants. Women in the study may respond to the apparent tone of the image (which may be said to be peaceful) or the time of year it seems to portray (summer).

Rollercoaster.

Once again, this may be taken literally, or used in its common usage as a way to describe life's 'ups and downs'.

Sunglasses reflecting sunshine

These may act as a trigger to discuss some aspect of experience relating to summer/sunshine/a holiday; or I thought that it could be used in a more abstract way to explore ideas relating to dark glasses, reflection, glare and so on.

Group of carved wooden figures

I hope that this image can be seen in multiple ways: characters acting in a wooden way; the focus on the character who has raised his hand to his mouth as he shouts something in order to be heard; the androgynous nature of the characters who all have no hair.

Hot coals

Once again (as with the cactus image), I included this image in an attempt to elicit detail about the physical sensation of breast lymphoedema – although a participant may or may not be able to relate specifically to the sensation of heat.

This image may also be taken literally to elicit a memory or story connected to a coal fire.

Cat.

The intention in selecting this image was to provide an opportunity for participants to consider cats literally (such as having a pet); or to promote responses that may be triggered by elements of the image, such as the cat staring into the camera.

Garden gate

This felt like an archetypal image of a gateway to somewhere. The fact that it is a garden gate may be said to give it additional connotations of having the potential to lead into a garden which may be 'secret'. Thus, this image seems to offer up metaphorical as well as literal possibilities.

Wing mirror on a speeding car

This image struck me as clearly representing speed, which could be used by participants in multiple ways.

A bowl of cherries

This is in acknowledgement to the well-known saying/song 'Life is just a bowl of cherries'. I feel it has the potential to elicit responses from participants about attitudes, as well as providing an opportunity to be taken literally.

Two-way sign

There is no subtlety in my selection of this image, which I feel clearly represents a choice about which direction to take. I do acknowledge that it is possible participants may view it in a different way.

Stained glass window

I took this image myself in the cathedral in Palma, Mallorca. In a similar vein to the multi-coloured balloon, I feel it has the potential to engage participants through its colours and light; but it also provides an opportunity to consider religion.

Foggy steps

I included this image to denote *uphill*, either to describe something as a struggle or challenging, or to support the idea of achievement through climbing. The fogginess may give participants a prompt about a lack of clarity or being unable to see something.

Woman with arms outstretched, smiling

I have made the assumption that this image portrays feelings of joy or happiness. She seems to be on or next to the sea, which is open to interpretation.

Head partially submerged in water

I anticipate that this image may be taken literally – to support discussions about going swimming and what this could mean to a participant – or metaphorically to denote a number of perspectives, such as swimming against the tide, keeping afloat, or drowning.

'Love' spelled out in the sand

The word is self-explanatory and may allow participants an opening to describe what this means in relation to their experiences. However, it is written in the sand next to an approaching wave and could therefore also be seen as temporary.

Three dice landing on a chequered board

My immediate thought on selecting this image was its opportunity to open a discussion about chance ('decided on the roll of the dice') and perhaps whether participants felt that their experiences were out of their control; and if so, whether they attributed the cause of their breast lymphoedema to chance or whether they held beliefs about some other cause.

A pile of tablet blister packs

My sense is that this could be taken literally to be about medication, or more generally about healthcare experiences.

Golden sunlight through trees onto a road

I believe that this could be construed as quite a positive image, evoking metaphors relating to *golden, light, seeing clearly* and so on. Alternatively, it could trigger a memory about being in the countryside that may relate in some way to participants' experiences.

Woman holding child closely

This image may give participants an opportunity to talk about children and grandchildren generally, as well as specific issues such as whether such close contact causes discomfort.

Metal springs on old bike seat

I imagine that this image could be used to describe a range of feelings, physical or psychological: phrases that came to mind included 'having a spring in one's step' and 'losing one's bounce'. It's probably not clear from the image but it belongs to the seat of an old bicycle, which may have significance for some participants.

Sailing boat on still water

I selected this image for its apparent stillness. I think that it could provide opportunities for participants to make a range of literal or figurative associations including with water, being afloat, or being on holiday.

Icicle

This image could prompt participants to talk about an event or a person; it could relate to the actual temperature/season, a physical feeling, or a description of someone's attitude or behaviour.

Sunflower

As for icicle, this image may prompt discussion of an event or a person: I anticipate that it could be related to summertime/heat, a mood, or a description of someone's attitude or behaviour.

Girl with head down, sitting on a barrier.

There seems to be more than one potential focus for this image. The girl's posture may resonate for participants as it could indicate sadness or reflection, for example; or the barrier may be used as a prompt for discussion.

Slice of chocolate cake on a plate.

I anticipate that this could be related to pleasure, enjoyment, comfort or sharing time with friends; however it could also relate to issues such as body shape, appetite, diets, or changed activities.

Open country gate.

This image could have a number of literal or metaphorical meanings. The gate is free-standing, unattached to a fence, and appears old and neglected. The image could be construed as rather desolate. It may stand for ideas around being neglected, or freedom, or desolation; or just as an image of the countryside.

Woman in bikini in shallow water.

In choosing this image, I am making an assumption that women may have a response to wearing swimwear/going swimming when they have breast lymphoedema. This image may provide a prompt for some participants to discuss this.

A flock of geese in flight.

This image may provide a prompt to consider thoughts about being part of a group; or of flying (literally, in a plane for instance, or figuratively).

Girl with red tape across her mouth.

I believe that this image gives a clear message about being silenced. Whilst it's perhaps not very subtle, I think that it's valuable to include such an image in the context of a study which is informed by the 'Silences Framework', in which breast lymphoedema is understood to be largely silenced in practice and absent in the academic literature.

Woman celebrating.

The woman in this image appears to be at a party or celebration and seems joyful. There may be some significant associations for some participants with these themes. The tones of the image make the woman's skin colour ambiguous, so her ethnic origin is open to interpretation: this is important to me as I wanted to include some images of women that were not White.

Buddha statue.

I anticipate that this image could allow for a range of associations such as with meditation, religion, and mindfulness. It may also act as a literal prompt about a holiday in the Far East.

Bed with downturned open book on the cover.

I chose this image due to its possibilities to be linked to tiredness/fatigue, sleep or the activity of reading. In particular, however, I hope that it presents - in a non-threatening way - the option for participants to talk about the impact that their breast lymphoedema may have had upon their feelings about sex and their sexual relationships.

A duck with ducklings.

I anticipate that this image is most likely to be used in the sense of representing family, thereby offering participants a prompt to discuss the impact of their breast lymphoedema upon family relationships, socially, psychologically (ways in which their feelings may have changed, for instance) or physically (eg. having abandoned hugging family members due to the discomfort).

Entrance to dark tunnel.

My personal response to this image is as a figurative representation of entering the unseen/unknown, and so conveying uncertainty. My assumption is that this is a fairly universal response, and I anticipate that the theme of uncertainty may be relevant to some participants.

Statues of large red masks, displayed on grass.

I feel that this image could enable participants to talk about any feelings about 'wearing a mask' rather than displaying their real feelings to others.

Tea lights burning in a church.

I have included this image for its clear religious associations. Alternatively, participants may use the image in relation to the themes of light or of burning, for instance.

Rain dripping down a windowpane.

This image may be taken literally, allowing participants to recall a significant occasion on which it was raining; or it could be used to express feelings, for instance. In addition, the image through the window pane is blurred and this could be taken figuratively by participants to explore something that's unclear.

Large wire hearts decorated with padlocks.

I selected this image for its potential for layers of meaning. Initially I was drawn to it because I thought that the hearts could be considered attractive to look at, and that they could represent the obvious association with love. However, on closer inspection there are some potential alternative associations: the hearts are decorated with dozens of small padlocks, which could denote being locked up; and they are displayed in snow, allowing for associations with the theme of coldness.

Forest with hazy light.

I was drawn to this image for its fairy tale-like quality. I feel that there is the potential for several associations including being lost, being hunted, and being unable to see the wood for the trees.

Barbed wire fence.

I was struck by some impressions that may be formed by this image, including the idea of being imprisoned (or the opposite: being kept out); and the idea of barbed wire as having potential to cause pain and physical damage.

Plain closed door in a room with bold wallpaper.

The primary reason for selecting this image was for the possibilities associated with a door being closed (figuratively or literally), although participants may find a different focus.

Seeds blowing off a dandelion head.

My assumption is that participants will associate this image with telling the time, although I do realise that this may not be everyone's childhood experience. So it was included for its potential to raise the theme of time. However, the image could provide alternative representations such as the idea of vulnerability (the seeds being so easily carried away by the breeze).

Four walking figures in shadow, seen only from the waist down.

For me, this image evoked some feelings of unease and potential threat, as there are so few cues to the motivations of the figures and the scene is in darkness and otherwise apparently deserted (there is empty seating in the image). I have included the image as I felt it might prompt discussion of any uncomfortable or difficult feelings.

Mountain top against blue sky.

This feels like quite a hopeful image, one of achievement (reaching the top) and exhilaration. It is included as I wanted some 'positive' emotions represented, particularly as it could give participants an opportunity to describe how they have overcome any difficulties, and the resources (personal or other) that they found to achieve this.

A large, unblinking eye.

This is included for its figurative potential. For instance, it could be linked to ideas about being watched or looked at; about seeing (understanding); or about having a revelation ('the scales falling from your eyes').

Older couple with young children.

The image appears to represent two grandparents, each with a grandchild on their knee. It felt important to represent older people amongst the images; and I felt that it could elicit discussion about family. Additionally I have heard anecdotal evidence that women who develop breast lymphoedema are sometimes unable to hug their grandchildren due to the discomfort, and I felt that this image could enable participants to disclose this.

Row of taps, one leaking.

In the context of this study, my personal response to this image was to associate it with the (trapped) fluid that is lymphoedema. Some participants may relate to this image in this way to talk about how their lymphoedema developed and how it feels physically.

Golden treasure.

I see this image as clearly containing metaphors. The findings from my pilot study demonstrated that some women may find 'treasure' in the form of hidden resources and developing talents as a consequence of having treatment for breast cancer and its side effects. I hope that this image may prompt some participants to explore this.

Appendix 18:
An example of a participant's I-Poem

Zoe

I was having my radiotherapy

I thought well I'll get a photo of myself

I signed a form at some point to say that I was aware that I could get lymphoedema

I've read 30% different things but, I just didn't take it in, I really didn't

I thought I was just having radiation which was bad enough

I didn't realise there would be any other side effects.

I must have signed a form but to be honest, you feel like you're on a conveyor belt

I did go

I went to see the, what do you call him? The Oncologist was it

I can't remember, anyway,

I took my friend to write everything down

I'm so glad

I got a book in front of me and a pen

I think they play it down, they say oh well it's very, very rare

I tend to sleep either on my back or my right side

When I went to bed it was then that you felt it

I was taking ibuprofen every night, which apparently can cause you to retain fluid

I went to the Moving Forward

I went and as you can see you get another great wodge of stuff

I asked the Nurse because my breast was feeling very hard and lumpy

I don't know, I never had a lump anyway

I asked the Nurse and she had a look at and said no, this is just scar tissue

I thought, well I'm not very happy about that

I asked her to have a look at it and she said oh yes that looks like and feels like lymphoedema

I said to my husband, ooh what does this look like to you?

I said to him just touch that and he said ooh it's horrible

I knew it wasn't a cancerous lump .. they were usually much smaller ... aren't they?

I was waiting and waiting for this referral

I ended up emailing

I thought this is ridiculous

I had literally gone straight after I'd seen her

I'd come back, phoned up, asked for an appointment and seen somebody the next day

I made a formal complaint

Eventually I got this which was called 'final answer'

I don't know that it did any good

I think what he had done was ring the Hospice and spoke to somebody ... who then went on holiday.

I said no, that says palliative care, I don't think I need that

I don't know

I had seen in the book which said if you develop lymphoedema and it is diagnosed and treated early ...

I'm trying to think when it would be.

I didn't go to Moving Forward straight away because I had enough last year

I had this hardness but every time I spoke to anybody they said it would be the radiotherapy

I did mention lymphoedema, they said we very rarely get any cases of that

I honestly can't remember

I tried not to think about it

I think it was always a bit hard

I just thought this (was) part of it

I wear underwire bras anyway

I don't know if I told you this before

I just had this funny feeling

I looked in the mirror

I thought well that's all in the same place

I've had thickening there in the past

I didn't really pay a lot of attention to it

I do three deep breaths from my chest

I do three deep breaths from my stomach

I put this under my arm and I do this

I do this about 45 times

I do that religiously every morning

I was doing it twice a day

I was doing morning and evening

I went back after a week and she said I could cry, the difference

I couldn't really see much difference

I couldn't really see a difference, but she said I can
I knew nothing, you can see there was a big chart on the wall
I didn't know really what it was
I saw this chair and I thought my god
I knew nothing about the lymph drainage system
I'm not quite sure

I couldn't say it was a swelling really, it was more like this hardness
I felt like there was an insect crawling under my skin
I didn't bother
I had already got the scar there from the DCIS
I thought when I go back ...
I thought when I get back I'll ring up
I thought well I'll go and ask him about this

I had a meeting with this other doctor
I took my friend with me for support
I was just so stressed about the whole thing and I said no
I've just kind of left it
I'd hate to make a huge fuss and it closed down
I was on the patient participation group
I left before this
I felt I was wading through treacle

I was telling him about what had happened
I said, look it's done, he'll probably never do it again

I said I complained about the health service in the past and it's just caused me a lot of stress

I as a patient could have told them quite a lot if they'd wanted to listen

I've been involved a lot with health service issues as a carer

I had a lot of battles, so I'm sort of aware of how the health service works or doesn't work

I'll show you if you want, so many people have seen my boobs

I said to the doctor because he said do you mind?

I said, listen I said I fling my bra off for anybody

I didn't know, when I had the DCIS, they didn't need to take anything from under my arm

I'll show you

I've got that skin that they love

I think the information is totally unrealistic

I'm out in the garden, what if I get a cut and dirt in it?

I just don't, I just think sod it.

I don't know

I have no idea

I don't know

I went back the next time she said have you got your bra on?

I said what do you mean?

I had been massaging it, it had obviously got it all back into shape

I started massaging

I don't feel any hardness there now

I do it every morning after I've had a shower, that's my routine

I don't do it at night now

I did at first, when I first saw her

I can't remember when I last didn't do it because it's just there

I was a bit worried about flying but it seemed to be okay

I seemed to be okay

I've tried everything ... garlic, you name it

When I'm 80 I'll appreciate that

I think we had taken him a couple of times

I got diagnosed

I was saying oh for God's sake

I said please, just finish work early or come back and take me

I told him, but he had it in his throat I think it was

I think it's different, people have different techniques

I would think maybe 40 years ago it was just something you lived with

I think probably if you've something like a leg that's swelling, you can see that

I can't say that's it's a big change to my life

I think if it was a more serious case and I had to wear compression garments or something

I forgot to tell you, when I first went to the hospice ... it was this huge bra thing

I said no. It was just awful

I bought myself

I actually got a couple in Poundland

I bought the largest size which was just about right
I'm an F cup and it needed to have some support
I took one look at it
I thought no, it's very hard to buy a pretty bra anyway
I thought that's a real passion killer isn't it?
I just decided not to
I've got a couple of sports bras that I wore
I did wear them during the day at first, but they just stretch don't they, the sheer weight?
I couldn't go without a bra at all
I would have felt really self-conscious
I went to the, there's a shop
I went back to get this bra and it was fine. £80
I realised it was very, very similar to the ones I had been wearing
I stuck with them
I didn't bother with that
I just buy it off the peg really
I know that it will fit me and work
I know they do have specialist ones, but I've never tried
I've gone to John Lewis in the past
I know that Marks and Spencer's do bras ... don't they?
I think I've talked enough.

Appendix 19:

An example of Step 4 using The Listening Guide

Research question: What are women's experiences of developing/living with breast lymphoedema?

How do they make sense of them? What aspects of their lives do they describe?

Context

Zoe (a pseudonym) was interviewed in her own home. My diary notes that "I was conscious before arriving that this participant lived in a relatively wealthy area. Her willingness to generate photographs and display them during the interview on her iPad also spoke of someone educated and having resources."

I also note attempts to promote a more equal relationship with her by sharing some details about myself, including my age. My diary also suggests that I felt I had been able to gain a rapport with her, including her sharing some very personal information about her experience as a carer after the recorder had been switched off at the end of the interview.

The story

Zoe reports that she had had no lymph nodes removed when she was diagnosed with a non-cancerous ductal carcinoma in situ (DCIS) several years earlier. However on this occasion some nodes were removed to "make sure it hadn't spread because it actually was cancer." She was repeatedly told that there would be side effects to her radiotherapy treatment, although she does not recall signing a form acknowledging that she may develop lymphoedema. Moreover, when she attended a 'Moving Forward' course (run in partnership between Breast Cancer Care [*as it was known*] and NHS hospitals) she discovered that none of the other women attending could recall this either. She admits that she did not take in the information, although it suggested that the likelihood of developing lymphoedema was small. Difficulty absorbing the information resulted from her feeling "like you're on a conveyor belt", suggesting that she felt swept along by the process. Not only was her head "too full of information" but she admitted that "your brain is thinking of all these other worst-case scenarios" which may have distracted her from details about possible treatment side effects. For her appointment with her oncologist, she took a friend with her who wrote everything down to ensure that she had all of the information.

Zoe's first symptom was "like there was an insect crawling under my skin." However, she did not act on it immediately, deciding to address it when she was due to go back for her final mammogram. She describes the pain that she later experienced from her breast during the evenings and night-time which she managed using a soft pillow (her teddy bear) and Ibuprofen medication. The pain worsened when she removed her bra and her breasts were unsupported - it was "awful" - although she subsequently discovered that Ibuprofen could cause fluid retention and so exacerbated her condition. Meanwhile her breasts appeared markedly different, and this is demonstrated in Zoe's photographic image of an orange and one of her husband's socks filled with objects to appear as 'droopy'. Later on, she would be provided by the nurse at the lymphoedema clinic with some padding for her bra because of the degree of breast tissue that had been removed during surgery.

Her sense is that healthcare professionals view lymphoedema as a rare side effect - "oh we don't get many cases" - and she perceives them to "play it down". When she attended the Moving Forward course she was given a large amount of information in the form of a thick booklet, supplemented by a series of talks. She also met other women who already had lymphoedema "but they knew they had it" as their swelling was more obvious than "this hardness and strange feeling" that Zoe felt in her breast. Thus she positioned herself as not as bad as other women, for whom "it was a lot worse."

It was during this course that she took the opportunity to ask speakers about her condition, which she experienced as a "very hard and lumpy" breast ... like there were stones in it". She was dismayed by the first nurse she approached who looked at her breast and suggested that the problem was scar tissue which could be resolved by further surgery. However the lymphoedema nurse specialist recognised that it "looks like and feels like lymphoedema" and advised her to obtain a GP referral to the lymphoedema clinic.

Although Zoe acted on this advice immediately, after waiting a month she enquired and learned that the lymphoedema service had not received a referral for her. She made a complaint to the GP practice but did not pursue it, partly because of her fear that it would contribute to the GP practice closing and due to her past experiences of complaining which had been negative. However, she felt that she was essentially silenced: the letter she received in response was headed 'final answer' - "there was no opportunity for me to argue with it". The letter stated that "this condition would not have been made worse" by the delay in making the referral, even though this is contrary to lymphoedema advice in the patient literature she has obtained. At the same time, there seems to be some admission of a failure to act since the locum GP that Zoe had seen had reportedly "really been made to think about it".

The GP practice's insistence that there would be no negative consequences caused by the delay was perceived by Zoe suspicious and as an attempt to 'cover themselves.'

Her lack of confidence in the GP was also evident when she reports that she felt she had to advise the GP during her consultation on the appropriate referral form. The consequence was that Zoe felt helpless to do anything: "there wasn't much I could do."

Conversely, the lymphoedema nurse specialist was "very nice, very kind" and able to empower Zoe to manage her breast lymphoedema herself by teaching her some "simple" and "effective" exercises. During her interview it was evident that Zoe had been taught to understand the theory behind the self-management techniques. Prior to this, Zoe had no knowledge about the lymphatic system. She was shocked by the large chair used for treatment, which she learned was necessary as some patients are large and only "just fit in this chair."

The lymphoedema nurse intended to contact Zoe's GP to highlight the importance of lymphoedema, highlighting the years of unnecessary pain endured by some people. Zoe viewed her as an advocate, a "warrior" on behalf of people who have lymphoedema.

Initially Zoe was offered a support bra which she declined as it was "just awful," describing it as "a real passion killer." Instead, she was able to source her own support bras to wear at night from a cheap nationwide store; and sports bras which, whilst "not very pretty", were an improvement over "these huge garments." She also obtained a suitable bra from an independent shop that "didn't look abnormal"; however, it turned out to be expensive and she reverted to using a cheaper, similar high-street version. In fact, she has not needed to seek out specialist bras as she has found 'off the peg' styles that provide a good fit and support.

After only one week of self-management, the lymphoedema nurse specialist was impressed with the change in Zoe's breast; this contrasted with Zoe herself, who "couldn't really see much difference." The massage was effective in returning her breast to its normal shape, although Zoe was unable to explain this: "it was very strange."

Initially Zoe undertook the exercises twice a day; however now she does them "religiously" every morning. She appears to have incorporated the massage into her daily routine with ease: "it's just there."

She feels that lymphoedema prevention advice is "totally unrealistic" and indicated that she wants to continue with activities that she enjoys: "I just think sod it." Although she has had some concerns about going on holiday, she seems to have been "okay." Overall, Zoe feels that her breast lymphoedema does not affect her significantly.

Whilst she believes that there is more recognition of lymphoedema because of the existence of lymphoedema clinics, clearly her personal experience has been lacking: "certainly the GP surgery didn't seem to take it very seriously." She suggested that breast lymphoedema may be particularly challenging for healthcare professionals to

identify due to its anatomical location, as opposed to an affected lower limb which is more visible.

Contrapuntal voices: not knowing and knowing; ignored

There is a disparity between Zoe's initial lack of awareness about the possibility of lymphoedema as a side effect of her treatment and the information that she is reported to have been given: "apparently I signed a form at some point ..." The assumption from healthcare professionals therefore appears to be that patients have been made aware that lymphoedema may develop, at the same time predicting it to be an unlikely side effect. Hence, patients such as Zoe are assumed to have knowledge about potential side effects even though many may have difficulty absorbing the information.

This assumption that women are being presented with useful information carries over into the Moving Forward group which Zoe attended, where she was given "another great wodge of stuff" and attended a series of talks. In fact, the information that she needed, relating to her "hard and lumpy" breast symptoms, was difficult to obtain and in fact was misunderstood by the first nurse speaker that she approached.

Zoe's bodily knowledge prompted her to think that there was a problem: "it just felt wrong," "this hardness and strange feeling," "like there was an insect crawling under my skin." She shows some ambivalence about her knowledge of what may be happening to her. For instance, in the following excerpt Zoe begins by presenting herself as knowledgeable; however, by the end of the sentence she is less sure: "I knew it wasn't a cancerous lump because they were usually much smaller, *I think, aren't they* (my emphasis)?"

She had had a sense that she may have developed breast lymphoedema, but this was dismissed by healthcare professionals. So Zoe herself had accurate knowledge of her condition which was disbelieved by healthcare staff. Meanwhile she is unclear whether any particular event triggered her lymphoedema, such as her scar imploding after a long-haul flight.

Zoe has had a difficult relationship with the health service in terms of being taken seriously about the knowledge that she has herself or requires of healthcare practitioners. She learned that it was important for lymphoedema to be diagnosed and treated early; however, her GP practice, in response to her complaint for failing to refer her for treatment, denied this by claiming that "you will suffer no adverse effects." Thus, she is provided with contradictory information from different healthcare sources, leading to her lack of confidence in the GP practice. Moreover, Zoe's desire for knowledge and understanding in the context of her having had to complain to the health service in the past had had a negative outcome: "it's just

caused me a lot of stress and (I) got no answers." Zoe's own expert knowledge as a patient went unheard by the GP practice during her time on a patient group at the practice: "I as a patient could have told them quite a lot if they'd wanted to listen."

Zoe's introduction to the lymph system and lymphoedema "was quite a shock" when she was shown the huge chair in clinic required to accommodate patients with extensive lymphoedema and a poster displaying the lymphatic system.

During her interview, Zoe is able to demonstrate her knowledge of self-management drainage techniques, both practical and theoretical elements. She has clearly been using the techniques successfully as the lymphoedema specialist observes an immediate difference. However, for Zoe the process is more mysterious as she "couldn't really see a difference" herself.

She understands the risk factors for exacerbating her breast lymphoedema but at the same time uses that knowledge against her own priorities for enjoyable activities, regarding the prevention advice as "totally unrealistic," although she admitted that she "was a bit worried about flying." She has gained knowledge of the type of support bras that are suitable for her and relatively inexpensive: "I know that it will fit me and work" although she also knows of specialist bras.

Zoe's perception is that - like herself - "these days people are recognising it more" as a consequence of the way services are provided: "we have hospices and things." She recognises that healthcare professionals may have particular difficulty recognising breast lymphoedema as opposed to say lymphoedema in a limb due to its position in the body, instead dismissing the symptoms as the effects of surgery or radiotherapy.

Themes

Changing breast

Zoe talks of and describes the physicality of her breast symptoms. Her first symptom was feeling "like there was an insect crawling under my skin." Her photographic image of an orange and her husband's sock filled with objects to create a "big droopy" breast demonstrates the strong difference in how her breasts looked and felt.

Her lymphoedema was experienced as "very hard and lumpy ... like there were stones in it." She used marble eggs to represent how her breast felt 'rock hard'. Her bodily knowledge was of something that "just felt wrong" although she was unable to name it. Previously, her "nice and flat" surgical scar had "suddenly kind of imploded" and she is uncertain whether this was connected to lymphoedema.

Her breast has been repeatedly under the medical gaze and she reflects on how she has had to display her breasts to so many professionals that she is used to it, joking that she will "fling my bra off for anybody."

Can you tell me what is happening?

Zoe's symptoms of lymphoedema appear to have been part of a series of "things going on in your breast" at the time of her breast cancer and treatment. She has some difficulty distinguishing her breast hardness as a symptom of lymphoedema as she thinks that "it was always a bit hard." Hence she had not paid it much attention. Nevertheless there are a number of occasions when Zoe is seen to have approached others for their opinion on what is happening to her breast, including nurses who had been speakers on the 'Moving Forward' course and her husband ("what does this look like to you?"). However she reports that "every time I spoke to anybody they said it would be the radiotherapy" that had caused the hardness in her breast.

Information barriers

Not only does she not recall being told about lymphoedema as a potential side effect of her treatment for breast cancer, but her experience is shared by other women who attended the 'Moving Forward' group. Difficulty absorbing the information resulted from her feeling "like you're on a conveyor belt", suggesting that she felt swept along by the process. Not only was her head "too full of information" but she admitted that "your brain is thinking of all these other worst case scenarios" which may have distracted her from details about possible treatment side effects. For her appointment with her oncologist she took a friend with her who wrote everything down to ensure that she had all of the information.

In addition, her sense is that healthcare professionals view lymphoedema as a rare side effect - "oh we don't get many cases" - and she perceives them to "play it down". Whilst she believes that there is more recognition of lymphoedema as a consequence of the existence of clinics, clearly her personal experience has been lacking: "certainly the GP surgery didn't seem to take it very seriously." Her lack of confidence in her own GP was evident when she reports that she felt she had to advise the GP during her consultation on the appropriate referral form. The lymphoedema nurse intended to contact Zoe's GP to highlight the importance of lymphoedema, highlighting the years of unnecessary pain endured by some people. Zoe viewed her as an advocate, a "warrior" on behalf of people who have lymphoedema.

Zoe suggested that breast lymphoedema may be particularly challenging for healthcare professionals to identify due to its anatomical location, as opposed to an affected lower limb which is more visible.

Finding the right bra

Initially Zoe was offered a support bra which she declined as it was "just awful," describing it as "a real passion killer." Instead, she was able to source her own support bras to wear at night from a cheap nationwide store; and sports bras which, whilst "not very pretty", were an improvement over "these huge garments." She also obtained a suitable bra from an independent shop that "didn't look abnormal"; however it turned out to be expensive and she reverted to using a cheaper, similar high-street version. In fact she has not needed to seek out specialist bras as she has found 'off the peg' styles that provide a good fit and support.

Gaining understanding

The lymphoedema nurse specialist was "very nice, very kind" and able to empower Zoe to manage her breast lymphoedema herself by teaching her some "simple" and "effective" exercises. During her interview it was evident that Zoe had been taught to understand the theory behind the self-management techniques. Prior to this, Zoe had no knowledge about the lymphatic system.

Lifestyle adjustments

Initially Zoe undertook the exercises twice a day; however now she does them "religiously" every morning. She appears to have incorporated the massage into her daily routine with ease: "it's just there."

She feels that lymphoedema prevention advice is "totally unrealistic" and indicated that she wants to continue with activities that she enjoys: "I just think sod it." Although she has had some concerns about going on holiday, she seems to have been "okay." Overall, Zoe feels that her breast lymphoedema does not affect her significantly.

On being silenced

Zoe did in fact have some indication that her symptoms could be lymphoedema; however, the breast care nurses were dismissive: "they said we very rarely get any cases of that."

Not only is Zoe's breast lymphoedema initially misdiagnosed, but her GP also fails to make a referral to the lymphoedema service even though Zoe made an immediate approach after the diagnosis by the lymphoedema nurse. When she complained, she received a 'final answer' which was interpreted as her having no right to reply,

essentially silencing her by the GP practice's response. The letter attempts to exonerate the GP by stating that "this condition would not have been made worse" by the delay in diagnosis, which is untrue and implies that Zoe's complaint was unnecessary.

Zoe's experiences are set in a context of her previous experiences as a carer for her former husband, during which time she conveyed a sense of being misunderstood and her views disregarded by health services: "I had a lot of battles." At the same time, she evidently has some appreciation of and concern about the fragility of existing services, choosing not to pursue her complaint in part because of her fear that it could contribute to the GP practice shutting down. She is evidently someone who has made an effort to contribute to the quality of primary care services, being a member of a patient participation group. But she had left the group as she had felt unheard: "whereas I as a patient could have told them quite a lot if they'd wanted to listen."

Appendix 20:

Letter inviting participants to feed back on their individual themes

TSF analysis phase 2

Hello *first name*,

I hope that you are keeping well. I wrote to you approximately three months ago about my research study which is investigating women's experiences of developing and living with breast or trunk lymphoedema after treatment for breast cancer. Some time ago you kindly took part in an interview with me.

I am writing to you again to ask whether you would be prepared to take a look and comment on the themes that I've developed from your interview?

In due course, I will share with you the overall themes that emerged from the study as a whole. But at this stage it would be valuable to know whether you think that I've captured what you told me, or whether you think that any of the themes should be changed, added or removed. If you are interested in doing this, I will send you two things:

1. a copy of the transcript from your interview with me. This has been anonymised and so please be prepared for the fact that your name and any other identifying features will have been changed or removed!
2. a list of the themes developed from your interview, together with a short description of each theme.

In order to maintain confidentiality, I'd like to send this information in an encrypted form which means that you will need a password to unlock it. If you are willing to go ahead, I will contact you by phone to give you the password.

Of course it is perfectly fine if you don't want to do any of this. In any case, I'd be happy to keep you updated with progress about about the study.

I look forward to hearing your decision. If you'd prefer to speak to me by telephone, you can call me on my mobile phone 07593 554560 (please leave a message and I'll return your call).

With all good wishes,

Janet Ulman
PhD student
Health Research Institute
Sheffield Hallam University

e-mail: janet.ulman@shu.ac.uk

Appendix 21:

An example of feedback received on individual participant themes

Zoe

Zoe's feedback, reflecting some corrections to the factual content of her story, is incorporated in the themes below **in red**:

Changing breast

Zoe talks of and describes the physicality of her breast symptoms **after surgery**. Her first symptom was feeling "like there was an insect crawling under my skin." Her photographic image of an orange and her husband's sock filled with objects to create a "big droopy" breast demonstrates the strong difference in how her breasts looked and felt.

Her lymphoedema was experienced as "very hard and lumpy ... like there were stones in it." She used marble eggs to represent how her breast felt 'rock hard'. Her bodily knowledge **of her initial symptoms** was of something that "just felt wrong" although she was unable to name it. **Later, a long time after her second surgery**, her "nice and flat" surgical scar had "suddenly kind of imploded" and she is uncertain whether this was connected to lymphoedema.

Her breast has been repeatedly under the medical gaze and she reflects on how she has had to display her breasts to so many professionals that she is used to it, joking that she will "fling my bra off for anybody."

Can you tell me what is happening?

Zoe's symptoms of lymphoedema appear to have been part of a series of "things going on in your breast" at the time of her breast cancer and treatment. She has some difficulty distinguishing her breast hardness as a symptom of lymphoedema as she thinks that "it was always a bit hard." Hence she had not paid it much attention. Nevertheless there are a number of occasions when Zoe is seen to have approached others for their opinion on what is happening to her breast, including nurses who had been speakers on the 'Moving Forward' course. **The specialist breast care nurse who was the first nurse speaker on the course believed that Zoe did not have lymphoedema; however the second nurse speaker, the lymphoedema manager at the hospice, stated that it was in fact breast lymphoedema. Zoe also approached her husband to ask him what the imploded scar looked like ("what does this look like to you?") to which he replied "the Grand Canyon".** But she reports that each time she

approached a clinician, they told her that the hardness in her breast would have been caused by radiotherapy.

Information barriers

Not only does she not recall being told about lymphoedema as a potential side effect of her treatment for breast cancer, her experience is shared by other women who attended the 'Moving Forward' group. Difficulty absorbing the information resulted from her feeling "like you're on a conveyor belt", suggesting that she felt swept along by the process. Not only was her head "too full of information" but she admitted that "your brain is thinking of all these other worst case scenarios" which may have distracted her from details about possible treatment side effects. For her appointment with her oncologist she took a friend with her who wrote everything down to ensure that she had all of the information.

In addition, her sense is that healthcare professionals view lymphoedema as a rare side effect - "oh we don't get many cases" - and she perceives them to "play it down". Whilst she believes that there is more recognition of lymphoedema as a consequence of the existence of clinics, clearly her personal experience has been lacking: "certainly the GP surgery didn't seem to take it very seriously." The lymphoedema nurse intended to contact Zoe's GP to highlight the importance of lymphoedema, highlighting the years of unnecessary pain endured by some people. Zoe viewed her as an advocate, a "warrior" on behalf of people who have lymphoedema.

Zoe suggested that breast lymphoedema may be particularly challenging for healthcare professionals to identify due to its anatomical location, as opposed to an affected lower limb which is more visible.

Finding the right bra

Initially Zoe was offered a support bra which she declined as it was "just awful," describing it as "a real passion killer." Instead, she was able to source her own support bras to wear at night from a cheap nationwide store; and sports bras which, whilst "not very pretty", were an improvement over "these huge garments." She also obtained a suitable bra from an independent shop that "didn't look abnormal"; however it turned out to be expensive and she reverted to using a cheaper, similar high-street version. In fact she has not needed to seek out specialist bras as she has found 'off the peg' styles that provide a good fit and support.

Gaining understanding

The lymphoedema nurse specialist was "very nice, very kind" and able to empower Zoe to manage her breast lymphoedema herself by teaching her some "simple" and "effective" exercises. During her interview it was evident that Rebecca had been taught to understand the theory behind the self-management techniques. Prior to this, Zoe had no knowledge about the lymphatic system.

Lifestyle adjustments

Initially Zoe undertook the exercises twice a day; however now she does them "religiously" every morning. She appears to have incorporated the massage into her daily routine with ease: "it's just there."

She feels that lymphoedema prevention advice is "totally unrealistic" and indicated that she wants to continue with activities that she enjoys: "I just think sod it." Although she has had some concerns about going on holiday, she seems to have been "okay." Overall, Zoe feels that her breast lymphoedema does not affect her significantly.

On being silenced

Zoe did in fact have some indication that her symptoms could be lymphoedema; however the breast care nurses were dismissive: "they said we very rarely get any cases of that."

Not only is Zoe's breast lymphoedema initially misdiagnosed, her GP also fails to make a referral to the lymphoedema service even though Zoe made an immediate approach after the diagnosis by the lymphoedema nurse. **The nurse had explained that the referral to the lymphoedema service was required to come from her GP. In fact she saw a registrar who was in training at the practice who, although he agreed to find out how to make a referral, did not do this.** When she complained **after several weeks had passed**, she received a 'final answer' which was interpreted as her having no right to reply, essentially silencing her by the GP practice's response. The letter attempts to exonerate the GP by stating that "this condition would not have been made worse" by the delay in diagnosis, which is untrue and implies that Zoe's complaint was unnecessary.

Zoe's experiences are set in a context of her previous experiences as a carer for her former husband, during which time she conveyed a sense of being misunderstood and her views disregarded by health services: "I had a lot of battles." At the same time, she evidently has some appreciation of and concern about the fragility of existing services, choosing not to pursue her complaint in part because of her fear that it could contribute to the GP practice shutting down. She is evidently someone who has made

an effort to contribute to the quality of primary care services, being a member of a patient participation group. But she had left the group as she had felt unheard: "whereas I as a patient could have told them quite a lot if they'd wanted to listen."

Zoe's e-mail feedback:

This is good! Here are my comments:

In the first para, you describe the first symptoms then go onto the photo of the orange etc and to me, it's not clear that you're saying this was AFTER the surgery etc.

Para2, "her bodily knowledge ... refers to the initial symptoms then the bit about the scar imploding which took place well after this second surgery.

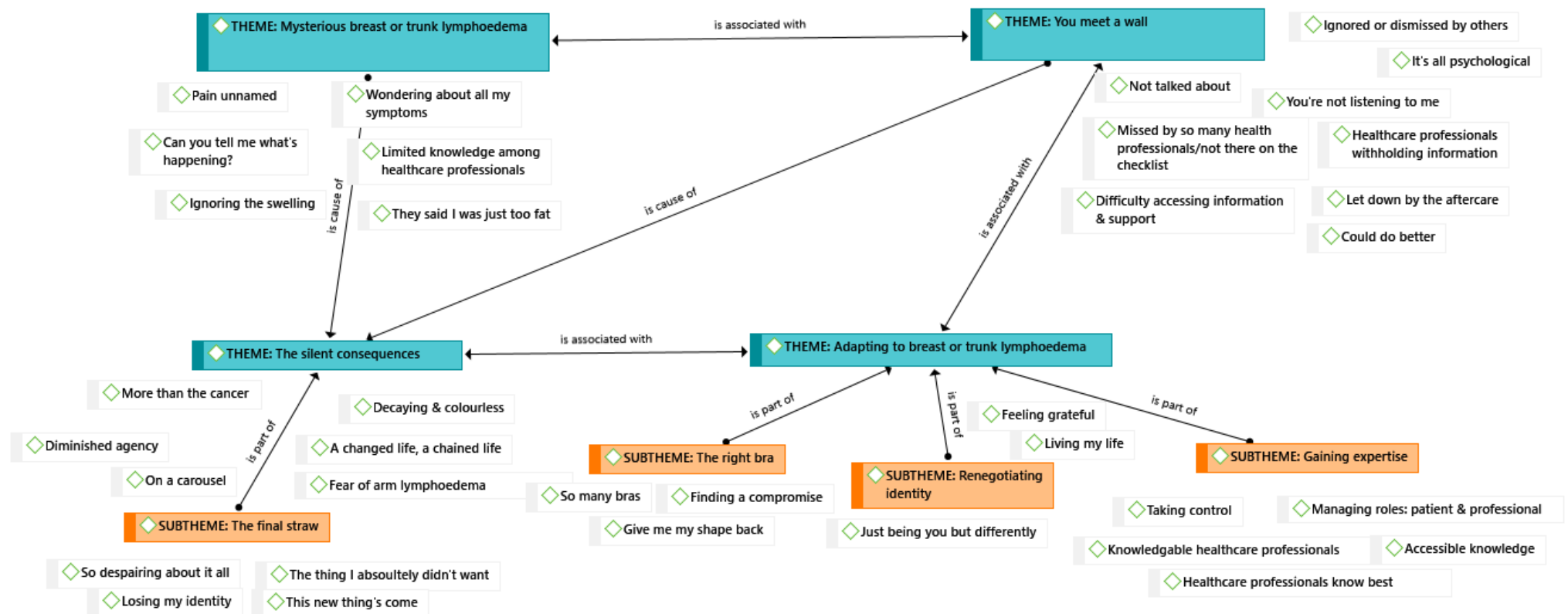
Can you tell me

I don't think I asked Andy about the hardness, I asked him what the imploded scar looked like and he said The Grand Canyon! the bit where you say "including nurses who had been speakers ..." This is wrong. The first nurse speaker (specialist breast care nurse) said it wasn't lympho, the second, who was the Lympho Manager at the Hospice, said it was.

On being silenced

I think you need to state that the Lympho nurse said that referral HAD to come from my GP. I saw a registrar who was in training at the practice for three months. He didn't know how to refer but promised he would find out and do it but didn't. THEN I complained as weeks had gone by.

Appendix 22: Visual network showing relationship between overarching themes (alongside individual themes supporting each overarching theme)



Appendix 23:

Draft 1 findings (overall themes) provided to the *collective voices* (the wider network) – followed by **feedback**.

TSF analysis phase 3

Women's experiences of developing and living with breast, chest or trunk lymphoedema after treatment for breast cancer

Note: in this document the term 'breast lymphoedema' also includes chest and trunk lymphoedema.

The following themes were developed from interview data from fourteen women:

1. THEME: Mysterious breast lymphoedema

2. THEME: You meet a wall

3. THEME: The silent consequences

3.1. SUBTHEME: The final straw

4. THEME: Adapting to breast lymphoedema

4.1. SUBTHEME: The right bra

4.2. SUBTHEME: Renegotiating identity

4.3. SUBTHEME: Gaining expertise

Explanation of themes

1. THEME: Mysterious breast lymphoedema

Many women spoke about their bafflement, unease or discomfort at developing breast, chest or trunk symptoms. In general they could not recall being told about breast lymphoedema as a possible side effect of their treatment for breast cancer. It was common to hear stories of women enduring breast symptoms such as sharp pains, redness, hardness, heaviness and severe swelling for many months or more. For one woman, her pain was so great that she asked for her breast to be surgically removed. Some women felt that once their treatment had ended there were no opportunities to discuss these unfamiliar symptoms with anyone from the healthcare team. Other women spoke of their concerns being repeatedly dismissed or misdiagnosed by health professionals. The lack of awareness of breast lymphoedema amongst some healthcare professionals simply worsened some women's anxiety, particularly if women speculated that their symptoms were a sign of cancer recurrence. However this was not everyone's experience and on occasion breast lymphoedema was correctly diagnosed immediately.

Once diagnosed, some women speculated on the possible triggers of their breast lymphoedema, recognising that it is a condition which is still not well understood.

2. THEME: You meet a wall

Sadly, having their concerns ignored or dismissed by healthcare professionals was a common experience amongst women who participated. One woman commented that she was made to feel 'like I was making it up and it's all psychological'. For one participant, a delay in diagnosis meant that she endured symptoms for two years before she could be treated; whilst another participant with trunk lymphoedema was told that she was 'just too fat.'

In spite of this, participants frequently complimented the care and support that they received from health professionals and one pointed out that she was not criticising health professionals for repeatedly missing her breast lymphoedema. She theorised that it was simply 'not there on the checklist' of issues for them to consider.

On the whole it was felt that lymphoedema services did not appear to be accorded high priority and this was reflected in one participant's belief that they can be 'a bit of a battle' to access. Delays in accessing the local lymphoedema service were either due to some misunderstandings about the referral pathway or a long waiting list. In contrast, once they accessed the service women tended to speak very favourably about the expertise and success of the lymphoedema staff in treating their breast lymphoedema.

3. THEME: The silent consequences

There was an acknowledgement that breast lymphoedema was a life-long condition, potentially made worse by any delay in diagnosis. The impact on one participant's life was "massive ... my whole life ... from the moment I wake up, it's just different." This was reflected by one woman's drawing of a ball and chain which represented the weight of living with breast and trunk lymphoedema that she is "dragging around." It referred to her need to incorporate daily self-massage exercises into her busy family life and to manage the risk of developing cellulitis. Like many other participants, she also lived with the fear of developing lymphoedema in her arm.

Thus, breast lymphoedema was perceived as life-changing and in some ways "as much as ... if not more than the cancer." A sense of feeling trapped on a constant round of hospital and clinic appointments from which there is no escape was echoed by another participant. Images of being on conveyor belt or being unable to step off a carousel were described.

Fatigue was one of the silent consequences believed to be caused by breast lymphoedema, which had an impact upon work and social life. Breast lymphoedema was seen as "an unseen thing .. an unseen ailment" which is therefore "totally ignored."

3.1. SUBTHEME: The final straw

The emotional consequences for women of developing breast lymphoedema were considerable. Some participants expressed strong reactions against developing lymphoedema and this was sometimes expressed in a willingness to pay significant amounts of money for any promising new treatments.

Feelings of despair were expressed and of feeling misunderstood and disconnected from friends and family.

For some women the compression garments they were provided with were uncomfortable and affected their feelings of femininity: one woman described her appearance as "totally flat chested ... as though I'd been bound."

One woman spoke of feeling judged and scolded by the lymphoedema specialists for not adhering to some of their advice.

4. THEME: Adapting to breast lymphoedema

All participants have been required to adapt their lives in order to manage their breast lymphoedema. Although some reported the *silent consequences* (see above), descriptions of managing it successfully were also provided.

4.1. SUBTHEME: The right bra

A major issue for women was the trial-and-error process of finding a comfortable and supportive bra that met the needs of having breast lymphoedema but also met other needs such as allowing women to regain their breast shape or to take part in physical activity. Often this resulted in repeated purchases of bras because they quickly became unsuitable due to breast size changes; or they were contrary to the advice of the lymphoedema service. Images shared by participants included a large pile of redundant bras; and a before-after image displaying a beautiful item of lingerie previously worn next to a rather beige and clinical-looking supportive bra which now needed to be worn by the participant.

4.2. SUBTHEME: Renegotiating identity

Women shared descriptions of their changing breast size, shape and texture. Humour was used by several participants during their accounts. Often women's treated breast changed from being larger than the untreated one (due to swelling) to becoming smaller once the swelling had subsided (because areas of the breast had been surgically removed). There was mention of losing identity, of adapting to 'just being you but differently' and of finding a compromise with clothing.

4.3. SUBTHEME: Gaining expertise

Universally, women became proficient in managing their breast lymphoedema, in part due to the skilful way that they were taught by the lymphoedema specialists. One participant noted that knowledge and understanding increases 'exponentially when you're in the situation', commenting on how much learning occurs through living with a condition. Accounts from participants demonstrate how they have tackled problems such as finding garments which provide suitable compression and support to prevent pain and discomfort but also give them a feminine shape or enable them to pursue enjoyed activities.

Questions posed to the network:

1. *In your opinion, do any of the themes reflect the experiences of women who you have treated for/spoken with about breast lymphoedema?*
2. *Are there any themes that you feel may contradict the experiences of women who you have treated for/spoken with about breast lymphoedema?*
3. *Do you have any other thoughts or comments about the themes?*

OR

1. *Do any of the themes reflect you own experiences of developing and living with lymphoedema?*
2. *Are there any themes that contradict your own experiences?*
3. *Do you have any other thoughts or comments about the themes?*

Feedback:

Advisory group member 1:

I think having looked at the themes you have identified there are some that I can identify with and others personally haven't affected me.

Theme 1 certainly is one I can identify with as I can't recall ever being told about breast lymphoedema and there certainly wasn't anywhere to discuss it, I rang to talk to the specialist nurse and was told as it was over a year so I couldn't even ask for advice from them.

Theme 2 certainly my own doctor didn't really know about it even though the lymphoedema service is at my GP's and found I had to push to be referred, once referred I knew I wasn't imagining things which is what you feel when nobody knows what you are talking about.

Theme 4 adapting to it and knowing how to manage it helped me to continue to move on.

Theme 4.1 I had already taken advice about the correct bra and this was reaffirmed when I was seen at the lymphoedema service.

Theme 4.3 as above knowledge provides proficiency in managing the lymphoedema, the nurses give you the knowledge to be your own expert of the condition, and make sure you know all about it and how to deal with things if you should need help.

I hope these comments help.

Continued good wishes for your study on an important and very often overlooked part of the condition and treatment.

Advisory group member 2:

I have read all of your comments and what an informative summary you have written.

ALL of the points you have covered I have experienced.

I would add that 7 years on I still have the lymphoedema and feel there needs more information on support and help. I feel after the 5 years all clear you are forgotten.

Hope this helps.

Advisory group member 3:

Feedback via a Zoom call

Note: Advisory group member 3 has extensive experience in talking to (medical) students about her cancer experience. She has arm lymphoedema and she had all her surrounding lymph nodes removed during her treatment.

She noted the difficulty in accessing the lymphoedema service in her city. **This supports one aspect of the theme** *You meet a wall*. In the time she has used the service there has only been either one or two lymphoedema nurse specialists for the entire service. She waited nine months from her first referral. In addition, it is not located in the centre of the city and so geographically is not easy for some patients to reach.

Her reason for accessing the service is that she was no longer eligible to see the breast care nurse (who had lymphoedema training) as the nurse only dealt with severe cases of lymphoedema and her lymphoedema was not severe and she was self-managing. However, she proactively asked to be referred to the lymphoedema service where was provided with compression sleeves. She has maintenance sleeves from them.

In other ways, her experiences **do NOT support the theme** *You meet a wall*. For instance, she believes that her symptoms were taken seriously.

Similarly, **the theme** *Mysterious breast lymphoedema* **does not reflect her experiences** as she was warned from the beginning of her treatment of the possibility of lymphoedema.

She commented that she ought to wear her compression sleeve every day although she doesn't, suggesting that she has found a compromise to suit her lifestyle. **This supports the theme** *Adapting to breast lymphoedema*.

In fact, she **does also lend some support to the subtheme** *The right bra*. She notes that her consultant had told her that she needed to wear a supportive bra, which now makes her wonder if she did in fact have some mild lymphoedema in her breast as well as arm lymphoedema. However due to her different breast shapes she had difficulty in

finding a supportive bra and was upset that M&S in the city centre were unable to accommodate her. Although the store promotes a bra service and products for women who have had breast cancer, she was told that she would need to go to (another) branch which she did not want to do.

In support of the theme *Gaining expertise*, she had approached her GP for antibiotics for her holiday. She remarked that the GP had not known about this precaution but was happy to be guided by her, ie to accept her expertise about her condition. She presumed that he looked up the evidence for this afterwards.

Possibly also **in support of the theme *Gaining expertise*** is her decision to wear a compression sleeve because she witnessed a woman who opted not to wear them, and she realised that she did not want her arms to look the same.

The importance of correct knowledge and information was highlighted in her example of a GP providing incorrect massage for a colleague's lymphoedema. This **links to the code *Limited knowledge amongst healthcare professionals***. She suggested that healthcare professionals need improved awareness of lymphoedema.

The issue of individual preference was discussed: she commented that she needed to know everything but accepts that some people don't want to. She gave an example of worrying about some symptoms because she had not been told about them (eg a feeling of electric shocks in her breast) until she asked about them. At the same time, she accepts that it can be upsetting at the beginning to be told about potential side effects.

We spoke about the significance of being an expert in your own body and seeking help for your individual needs.

We also spoke about the significance of a person's mental attitude and how that may be more important than the type of lymphoedema experienced.

Her experiences **do not match the theme *The silent consequences***, although she admits that she did not want lymphoedema and was irritated by the sleeve. She knew it was for life and that it was "another thing", suggesting some acceptance **akin to the theme *Renegotiating identity***; she commented on an attitude of being grateful for being alive.

Feedback from lymphoedema service:

Feedback via a Zoom call

Theme: Mysterious breast lymphoedema

This response was not uncommon at all - "hear it all the time". Saddened that it still happens. The nurses are keen to know what they can do and view this research as leverage.

Arm lymphoedema has become more talked about. Saddened that people wait so long. Perceived to be a gap between surgery and seeing an oncologist - no-one to call on in between. Have been educating HCPs for the last 17 years, yet last week district nurses had poor understanding of the lymph system.

Although a referral may be for arm lymphoedema, at assessment (questions and examination) breast or chest lymphoedema are detected. A high percentage are identified this way. Breast swelling may be seen by patients as a treatment side effect; it's also personal to discuss - an intimate body part.

Also, the arm is visible/people tend not to show their breast to others.

Patients don't take in all the information provided at the point of cancer diagnosis. She stressed the importance of being consistent with information and of people knowing where to go.

If dismissed as a side effect, how do you move from a position of being unsure to believing that it is lymphoedema?

Both the lymphoedema specialists being interviewed here teach on a Moving Forward group (attended by patients sometime after their cancer treatment) - many referrals for the LE service stem from this.

She would rather talk to someone at risk than at the point when it is a severe, complicated condition.

They would never see a referral as a waste of time - always able to give some advice (even if it turns out not to be lymphoedema).

Theme: You meet a wall

Discussed the extent to which the pandemic would affect the findings. There has been no access to LE services (in their local area). They have offered a scaled-back service but have tried to support patients. Staff have been redeployed from the clinic; in other clinics across the country the response has varied.

Patients will not be presenting at GPs, so the referrals will be late, presenting with later stages of LE. Huge impact. There is a whole year of people to be seen, plus this next years' list. Needs reflecting in the write-up.

They have always done such a holistic, thorough assessment, so providing advice remotely is difficult: we've done our best but it's not good enough in our eyes

The findings make her sad, and then the pandemic effects as well.

Already thinking, how can we use this (research)?

Theme: The silent consequences

Surprised at the fear of the arm; patients seen more concerned about the breast.

The arm is always the lesser consequence - perhaps it's our interpretation?

Pain from the breast more than the arm. More difficult to manage.

Sexuality as well.

Both agreed with the sentiment that LE was bigger than the cancer.

Re fatigue: is it a consequence of cancer treatments?

Lots of people attending with cellulitis (or they think it is and it's not) - surprised not mentioned at all. Treatment moves the lymph around the body and so the body is having to work harder.

Less of a cycle of clinic appointments now as patients are self-managing earlier due to COVID. The nurses haven't been needed as much as they anticipated. [Video calls on WhatsApp - different dynamic, they think they're talking to a friend].

Expectations are different. In the pandemic, people have to self-care, to rely on SLD rather than as an addition to MLD.

There may be those who haven't been self-managing.

Subtheme: the final straw

Feedback:

Paying for treatments - didn't expect it in relation to the breast (rather than legs or arm). I acknowledge that this may have related to arm lymphoedema rather than their chest or trunk (*post-meeting check: this seems to relate to arm lymphoedema rather than BL*). JU acknowledged women's difficulty in separating body parts for discussion about feelings etc.

Re. compliance - they ask patients about barriers, tell them that it's up to us (nurses) to give you the toolbox, then you make your own decisions. Psychological preparedness. Some people attend the clinic on advice, not because they want to.

Framed it as an invitation to be part of the treatment plan.

If they are not on board at the time, give them the information and ask them to come back when they are.

Feeling scolded wouldn't happen because they were with you and wouldn't feel like that, if you were part of the care plan, they wouldn't think you were judging.

But some patients comment that 'you're going to tell me off' and respond, no, but I'd rather you were honest. Ways of dealing with barriers include matching an arm sleeve with an aerobics outfit; making compromises to fit in with lifestyle and jobs. The importance of knowing the barriers and knowing where patients are in their journey.

Misinformation on sites: the lymphoedema service provides information on the best websites - although by then patients are already in the service so they don't have the information initially.

Wants to focus on patients who are at-risk, prior to developing lymphoedema.

Theme: Adapting to breast lymphoedema

Subthemes: The right bra/Renegotiating identity/Gaining expertise

They are not wrong about finding the right bra.

Good to hear that they felt proficient.

They need to be our advocates.

Both lymphoedema specialists believed that education needs to be high on the priority list.

A patient invited them to talk - provided a talk to five women at a GP surgery. We are approachable.

The expertise that you have and the level of service that you provide is significant - but the challenge is changing circumstances beyond that, extending that.

We like to hear what we're not doing - that's how you grow. We can learn so much from patients, hearing what they have gone through. It's positive.

Made some notes (for action).

Research is the evidence to take to the powers-that-be; more force, a catalyst

Both specialists felt that breast lymphoedema is just not there.

Feedback from Lymphoedema Support Network (LSN):

1. *In your opinion, do any of the themes reflect your experiences/the experiences of any women you know who have developed breast (or trunk or chest wall) lymphoedema after treatment for breast cancer?*

The themes are very familiar with our experiences, delays in acknowledgement of condition, lack of knowledge and empathy from cancer teams and non specialist HCP

challenges getting referral. Frustrations with compression and bras, changes in body image and the final straw thoughts.

2. *Are there any themes that you feel may contradict your experiences/the experiences of any women you know who have developed breast (or trunk or chest wall) lymphoedema after treatment for breast cancer?*

None that are obvious.

3. *Do you have any other thoughts or comments about the themes?*

A couple of themes that we hear which are maybe not reflected in your work, the feeling that the individual has somehow brought this on themselves or caused it by not following advice a sort of guilt if you were, when in actual fact we do not yet know why one woman may develop lymphoedema and another who has had less invasive or the same treatment.

Not being believed when they present early as we would suggest they do.

The fact that the size of the swelling has no equivalence in terms of impact for some a small swelling is devastating for others a large swelling not much of a problem.

TSF analysis phase 5

Document shared with participants, accompanied by the questions:

- 1. Can you tell me if you recognise yourself in any of the themes?*
- 2. Do you feel that there is anything important about your experience of breast, chest wall or trunk lymphoedema that is missing from these overall findings?*

The following themes were developed from interviews with fourteen women:

2. THEME: Mysterious breast (or trunk or chest wall) lymphoedema

Many women spoke about their bafflement, unease, or discomfort at developing breast, chest wall or trunk symptoms. In general, they could not recall being told about breast (or trunk or chest wall) lymphoedema as a possible side effect of their treatment for breast cancer. It was common to hear stories of women enduring breast symptoms such as sharp pains, redness, hardness, heaviness, and severe swelling for many months or more. For one woman, her pain was so great that she asked for her breast to be surgically removed. Some women felt that once their treatment had ended there were no opportunities to discuss these unfamiliar symptoms with anyone from the healthcare team.

The lack of awareness of breast lymphoedema amongst some healthcare professionals simply worsened some women's anxiety, particularly if women speculated that their symptoms were a sign of cancer recurrence. However, this was not everyone's experience and on occasion breast lymphoedema was correctly diagnosed immediately.

Once diagnosed, some women speculated on the possible triggers of their breast lymphoedema, recognising that it is a condition which is still not well understood.

2. THEME: You meet a wall

Sadly, having their concerns ignored or dismissed by healthcare professionals was a common experience amongst women who participated. One woman commented that she was made to feel 'like I was making it up and it's all psychological'. It was evident

that some healthcare professionals lacked awareness about breast lymphoedema. For one participant, a delay in diagnosis meant that she endured symptoms for two years before she could be treated; whilst another participant with trunk lymphoedema was told that she was 'just too fat.'

Despite this, participants frequently complimented the care and support that they received from healthcare professionals, and one pointed out that she was not criticising them for repeatedly missing her breast lymphoedema. She theorised that it was simply 'not there on the checklist' of issues for them to consider.

Overall, it was felt that lymphoedema services did not appear to be given high priority and this was reflected in one participant's belief that they can be 'a bit of a battle' to access. Delays in accessing the local lymphoedema service were common, either due to some misunderstandings about the referral pathway or a long waiting list. In contrast, once they accessed the service women tended to speak very favourably about the expertise and success of the lymphoedema staff in treating their breast lymphoedema.

3. THEME: The silent consequences

There was an acknowledgement that breast lymphoedema was a life-long condition, potentially made worse by any delay in diagnosis. For some women it was perceived as life-changing and in some ways had more of an impact than the cancer. The impact on one participant's life was "massive ... my whole life ... from the moment I wake up, it's just different." This was reflected by a drawing of a ball and chain which represented the weight of living with breast lymphoedema that she is "dragging around." It referred to her need to incorporate daily self-massage exercises into her busy family life and to manage the risk of developing cellulitis. Many participants also feared developing lymphoedema in their arm.

Thus, breast lymphoedema was perceived as life-changing and in some ways "as much as ... if not more than the cancer." A sense of feeling trapped on a constant round of hospital and clinic appointments from which there is no escape was echoed by some women, using images of being on conveyor belt or being unable to step off a carousel.

Fatigue was one of the silent consequences believed to be caused by breast lymphoedema, which had an impact upon work and social life. Breast lymphoedema was also seen as "an unseen thing .. an unseen ailment" which is therefore "totally ignored."

3.1. SUBTHEME: The final straw

The emotional consequences for some women of developing breast lymphoedema were considerable. Participants expressed feelings of despair and feeling

misunderstood and disconnected from friends and family. One spoke of feeling judged and scolded by the lymphoedema specialists for not adhering to some of their advice.

For some women, the compression garments they were provided with were uncomfortable and affected their feelings of femininity: one woman described her appearance as "totally flat chested ... as though I'd been bound."

4. THEME: Adapting to breast lymphoedema

Participants have been required to adapt their lives to manage their breast, chest wall or trunk lymphoedema and many provided descriptions of managing it successfully.

4.1. SUBTHEME: The right bra

A major issue for women was the trial-and-error process of finding a comfortable and supportive bra that met the needs of having breast lymphoedema but also met other needs, such as allowing women to regain their breast shape or to take part in physical activity. Often this resulted in repeated purchases of bras because they quickly became unsuitable due to breast size changes; or they were contrary to the advice of the lymphoedema service. Images shared by participants included a large pile of redundant bras; and a before-after image displaying a beautiful item of lingerie previously worn next to a rather beige and clinical-looking supportive bra which now needed to be worn by the participant. However, many women had been able to find suitable bras from specialist shops or chain stores, including bras which catered for fluctuating chest wall swelling.

4.2. SUBTHEME: Renegotiating identity

Women shared descriptions of their changing breast size, shape, and texture. Humour was used by several participants during their accounts. Often women's treated breast changed from being larger than the untreated one (due to swelling) to becoming smaller once the swelling had subsided (because areas of the breast had been surgically removed). There was mention of losing identity, of adapting to 'just being you but differently' and of finding a compromise with clothing.

4.3. SUBTHEME: Gaining expertise

Universally, women became proficient in managing their breast lymphoedema, in part due to the skilful way that they were taught by the lymphoedema specialists. One participant noted that knowledge and understanding increases 'exponentially when you're in the situation', commenting on how much learning occurs through living with a condition. Accounts from participants demonstrate how they have tackled problems

such as finding garments which provide suitable compression and support to prevent pain and discomfort but also give them a feminine shape or enable them to pursue enjoyed activities.

Feedback:

Twelve participants provided feedback on the proposed overall themes, either by e-mail or during a phone call. One did not respond to two e-mails, and I did not pursue it any further. The other participant who did not respond had earlier shown some ambivalence to providing feedback on her individual themes, due to the potential undoing of the perceived benefits from taking part in her interview. When she did not respond to this invitation, in a phone call relating to consent to using her photographs I suggested to her that she need not provide feedback but thanked her for her significant contribution, effectively giving her permission not to engage further; she appeared to readily accept this arrangement.

Tilly:

Tilly felt that they were 'very recognisable'.

She commented that her right breast is 'a lot bigger' than her left breast, such that below her right breast is painful as it is so full that it is bursting out of the bra; whilst her left breast does not fill the left cup (she sometimes uses tissues or foam to pad it out).

She puts up with it: she is 'happy to be here and alive'.

In response to the suggestion of a bespoke bra, she admitted that she had considered what this would be like, if she had the means to buy one. However, she felt that it would be 'noticeable' in her clothing and that she would 'look like a freak'.

She reflected that she is unsure about women's experiences of arm lymphoedema. She has swelling near her armpit for which she does exercises every day although she didn't appear to have sought guidance from LE specialists for these.

Her sense was that there were people 'a lot worse' than her.

Zoe:

I've read the themes and don't recognise myself in them but it seems a long time ago and I can't even remember the significance of the bowl of eggs!

The only thing I feel is missing is the mention of radiotherapy as I was later told that 30% of women (at least) go on to develop it and that "you were told this when you signed the consent form" I have no recollection of being told. I know you touch on this in the first sentence but I thought that there would be much more swelling etc than I actually got, so didn't identify with the word lymphodema.

Catherine:

-For question 1- I recognise myself in Theme 1- I did not know there was such a thing as treatment for lymphoedema of the breast as the doctor at my first year post surgery never mentioned this when I told him of the difference in size of my two breasts and now I realize that this may have been because he was not aware of the service.

Theme 2- I was lucky my referral happened quickly and I had no problem with getting regular treatment sessions.

Theme 3 - I was self conscious when my breast sizes were different what I could wear and getting bras to fit. Now I feel better that 3 years down the line my breast seem to be of equal size and the problem seems to have resolved and be managed by wearing sports bras daily and a comfy bra at night , a small price to pay if it resolves the problem.

I did not think I could comment on the other themes and I don't think any other important things are missing from your summary. I hope this information is helpful.

Helen:

I think the theme you have written is very good and accurate that some women have experienced. It will be very good to have a paper on this subject for future ladies to read and learn what can happen, as there were nothing when I developed lymphoedema.

Ladies in the future can read what may happen if they developed this condition, then they may not be as worried when different things happen to them and what to expect.

I'm sure many ladies would appreciate what you have done.

Jackie:

That all reads well.

Well done.

Samantha:

Thanks for sharing this and thanks so much for undertaking this important research.

1. *Can you tell me if you recognise yourself in any of the themes?* - Yes completely in all of them
2. *Do you feel that there is anything important about your experience of breast, chest wall or trunk lymphoedema that is missing from these overall findings?* - No, captured it brilliantly, thank you.

Alice:

To answer your questions, yes I can recognise my thoughts and experiences in the themes.

- I agree that I don't recall being told about breast Lymphoedema as being a side effect.
- I agree that there isn't the opportunity for following up with the breast team and I had a mistrust of GP awareness, knowledge and signposting abilities to relevant services.
- I think I was aware the radiotherapy caused my breast lymphoedema but had not known that before. I have since gone on to develop lymphoedema in my arm and this was from an insect bite on holiday.... I kicked myself for not covering myself in insect repellent that night!!
- Yes I agree that breast lymphoedema is a low priority in many contexts.. access to service has a long waiting list and the team is very short-staffed. Since the start of the pandemic, I am not longer supported by the service...
- Yes, I feel judged for not being able to juggle family life and maintaining self-massage.
- I feel lymphoedema is seen as insignificant. Especially with family and friends. I feel the expectation is you should be happy to be alive and should just learn to live with any lifelong side effects!!
- And bra... yes I hate the bra situation... still now I struggle!!

In answer to your 2nd question, no I don't think anything is missing... I think your themes are really good.

Joanna:

It's interesting to read your findings and see how many experiences are similar as well as some things I didn't undergo. Themes 1, 3 and 4 definitely resonate with me.

Leah:

1. Yes I do recognise myself in 4.1 subtheme - The Right Bra. It relates to one of the photographs of what was my best bra, and a picture of a sad face .
2. I don't feel there is anything missing about my experience. In fact I believe you have covered everything very well, and I imagine you have had positive feedback from the other women too.

Charlotte:

Interesting to read your report. As it is mainly about breast lymphoedema I assume this is most common.

I think I was the person who was told they were just fat!

I had it in my arm first and then it appeared on my trunc down the same side. I have not been able to get any treatment for it at the moment so I am trying to find someone who can give my lymph nodes the correct massage.

Sarah:

My assessment of how I think the themes link to me below

Theme 1 – I recognise in respect of the speculation re possible triggers

Theme 2 – I presented to the GP with lymphoedema in my arm, I suggested to him that having had breast cancer and the resulting treatment that that was what it was likely to be and after considering other possibilities he agreed and referred me immediately to the lymphoedema service which I access without too much delay. I would concur that I recognise how good the treatment was.

Theme 3 – absolutely recognise

Theme 3.1 – not so much

Theme 4 – recognise

Theme 4.1 – don't recognise

Theme 4.2 – recognise compromise with clothing but because of the mastectomy rather than lymphoedema

Theme 4.3 – recognise re managing the condition

I'm not suggesting the themes I don't fully recognise aren't valid, just that they don't correlate with my own experience.

Lisa:

I think I can see my experiences in a number of the themes;

Theme 1

I certainly have found a lack of awareness of Lymphoedema in healthcare professionals which makes it tricky to get information and advice.

Theme 2

Delay in diagnosis which had to be pushed quite hard for and being told that it was my fault for not doing the exercises properly all added to a feeling of despair and rejection. I agree that very little resource seems to be aimed at researching and alleviating lymphoedema.

Theme 3

I agree that the life long nature of lymphoedema is overwhelming at first as you have just dealt with a life threatening condition only to have it followed by a life long one which is poorly understood and makes a massive difference to the way you can live your post cancer life.

Theme 3.1

My experience was of being told it was my fault, which would be hurtful if it was but when it wasn't it was very difficult to stand up to. You are quite vulnerable at this stage, however well clued up you are and being chastised for something you haven't done is hurtful.

Theme 4

I think that when you take control of your Lymphoedema yourself, things do improve as you are becoming aware of how to help yourself and you become knowledgeable about what works for you and what doesn't which is a huge step on the path to acceptance. Prescription pressure garments are sure not to win any awards for beauty and I have found that I have to really check every detail when receiving new garments as 8 out of 10 times they would be wrong at first; either wrong colour, wrong in that details were missed off such as soft linings in delicate places or only one set instead of the two ordered would arrive necessitating a return visit to the GP or Pharmacy and another 10-14 day wait.

In terms of anything missing, I don't see any acknowledgement of fears about the future for people with Lymphoedema. I think my biggest fear is what happens when I am too old or frail to put on my own garments? This worries me greatly.

Thanks for the feedback and please feel free to contact me anytime you think that I can be useful.

It has been good to take part. Something that I didn't highlight was the fact that 8 times out of 10 my prescription is wrongly fulfilled and although that is only an annoyance to me in that I have to deal with it, some people may not even realise they have been sent the wrong thing and may in fact be receiving garments that actually cause harm rather than help their situation. I have thought of sending in an Adverse Incident Report to the MHRA but haven't done so but it is an issue when the company, Juzo, so regularly fails to fulfil a prescription properly. It has improved slightly now but my prescription hasn't changed since 2017 so they have had a long time to get it right and other people may have prescriptions that change regularly and may always receive the wrong thing without knowing they have.

Appendix 25:

Data management plans, as documented in IRAS application:

Two sets of photographs developed from participants' disposable camera will be brought to the interview. One set will be given to the participant to keep; the other set will be used as the focus of discussion during the interview. Afterwards, the researcher will photograph the set of photos using a digital camera, so that there is a digital record. Until the analysis has been completed, the photographs will be stored in a locked cabinet in a locked room on University premises; or initially in a fireproof, locked box in the researcher's own home (if the interview takes place at the end of the day, for instance).

Audio-recordings of the interviews will be made on a digital recorder; a back-up recording will be made using a second audio recorder. The latter will be deleted immediately after it has been verified that the first digital recorder has successfully recorded the interview. The audio-recordings will be uploaded to the University's secure drive as soon after the interview as is practically possible and deleted from the recording device. Until that time, the audio-recorder will be stored in a locked cabinet in a locked office on University premises, or in a locked, fireproof box in the researcher's home. Transfer of audio files to a professional transcription service will use encryption.

Interview transcripts (MS Word documents) will be stored in a folder on the University's secure network drive, as will all digital photographs taken at the interviews, given the possibility that some may contain identifying features. They will be coded so that they can be linked with the relevant section of the associated interview transcript. The digital photographs will be uploaded directly onto the University secure network drive from the digital camera's memory card. The memory card will be destroyed at the end of the study.

Data analysis files, including theme development and memos (created in a password-protected project within ATLAS.ti software for data analysis) will be stored on an ongoing basis during the study on the hard drive of the researcher's password-protected laptop provided by the University, and on the University's secure network drive.

It is intended that on completion of the study all underpinning research data will be registered in the Sheffield Hallam University Research Data Archive (SHURDA), in line with the University's guidelines. The University network is secure and backed up every evening. However participants will be able to opt to exclude their photographs from the archive; and although efforts will be made to store the interview transcripts in the archive, this decision will need to be reviewed dependent upon whether the data would be likely to reveal the identity of the participant. In preparation for storage in the archive, non-digital data (the field notes notebook) will be scanned so that it can be saved and stored digitally along with the other data from the study; the research diary will be exported from 'PebblePad' software for archive storage. The SHURDA will keep the data for a minimum of ten years.

In view of the fact that participants may choose to be involved in dissemination activities after the end of the study, participants' personal details will be kept securely for up to 12 months after the study ending, on the University's secure drive and on an encrypted, password-protected USB stick.

Appendix 26: Photograph Reproduction Consent Form

IRAS Project ID 225878



Photograph Reproduction Consent Form

To be completed with participants at a meeting subsequent to the research interview

Investigating women's experiences of breast or trunk lymphoedema following treatment for breast cancer

Name of Researcher: Janet Ulman

Participant Identification Number for this project:

Thank you for participating in an interview with me for my study.

For your interview, you had taken or selected some photographs to help describe your experiences of breast or trunk lymphoedema. I kept a digital copy of these photographs.

I also explained my intention to share the findings of the study with others including health professionals, cancer support groups and academics (such as through an exhibition, presentations, publications and teaching materials).

It is your choice whether any of the photographs are shared in this way. Your name will not be used (unless you specifically tell me that you would like to be identified this way, in which case your first name will be used).

If you appear in any of the photographs that you choose to be shared but you do not want to be identified in them, the researcher will digitally alter the photographs (eg. by blurring the image) to keep your anonymity.

Please read the statements on the next page and decide whether and how you consent for the photographs to be shared. Please sign one of the three boxes:

Please tick ONE of the following three boxes:

1. If you give consent for the photographs to be shared (please indicate where you give consent for them to appear):

1. I give consent for my photographs to be reproduced (in electronic or print form) in the following (please tick all that apply):

- a) Reports and journal articles ☐
- b) Verbal presentations ☐
- c) Conference posters ☐
- d) Exhibitions ☐
- e) Teaching materials ☐

2. a) I understand that my real first name will NOT be used with the photographs & any accompanying interview quotes; a pseudonym will be used instead.

(Please tick if you agree with this:)

☐

OR:

b) I wish for my real first name to be used with the photographs & any accompanying interview quotes.

(Please tick if you agree with this:)

☐

3. I do/do not (please delete as appropriate) wish to be identified in any photographs I appear in.

2. If you give consent to share some but not all of the photographs (please state which - the photographs are numbered) - please indicate where you give consent for your selection to appear:

1. If you would like to give permission for some, but not all, of your photos to be reproduced, please list the numbers of the photos you give permission to be used:

I give consent for the following photographs (please number):

.....

to be reproduced (in electronic or print form) in the following (please tick all that apply):

- | | |
|---------------------------------|--------------------------|
| a) Reports and journal articles | <input type="checkbox"/> |
| b) Verbal presentations | <input type="checkbox"/> |
| c) Conference posters | <input type="checkbox"/> |
| d) Exhibitions | <input type="checkbox"/> |
| e) Teaching materials | <input type="checkbox"/> |

2. a) I understand that my real first name will NOT be used with the photographs and any accompanying interview quotes; a pseudonym will be used instead.

(Please tick if you agree with this:)

☐

OR:

b) I wish for my real first name to be used with the photographs and any accompanying interview quotes.

(Please tick if you agree with this:)

☐

3. I do/do not (please delete as appropriate) wish to be identified in any photographs I appear in.

3. If you do not wish the photographs to be used outside of the research team².

a: (The research team includes the researcher, her supervisors and the wider community of individuals/organisations relating to breast or trunk lymphoedema, who will be invited to comment upon the draft analysis of the anonymised interview transcripts/photographs).

I do not wish any of the photographs arising from the study to be reproduced for any purpose.

(Please tick if you agree with this:)

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

To be signed and dated in presence of the participant

Thank you for participating in the study.

If you have any questions about this form or about the study, please contact Janet Ulman on 07593 554560 or at janet.ulman@shu.ac.uk.

Copies to:

Participant

Project site file

(Adapted from: Wiles et al (2008) ESRC National Centre for Research Methods Review Paper *Visual Ethics: Ethical Issues in Visual Research* National Centre for Research Methods NCRM/011)

Appendix 27:

Correspondence regarding intellectual property advice

From: [Walsh, James](#)
To: [Lisman, Janet](#)
Cc: [Probst, Heidi](#); [Hall, Matthew R](#)
Subject: RE: Some advice on intellectual property
Date: 18 February 2021 14:27:44

Dear Janet,

I have consulted RIS Legal Services and also RIS's resident ethics adviser concerning your enquiry.

As you are already aware, copyright in the images created by the participants in your research vests in them (i.e. they own the copyright). For a party to legitimately reproduce images whose copyright is owned by someone else, they must obtain permission from the copyright owner to use the copyright (i.e. a licence), or they must become the copyright owner (i.e. assignment of ownership).

In the case of the consent form that you used in your research, there is nothing in the wording that could reasonably be regarded as having the effect of transferring ownership of copyright from the participants to you/SHU. Rather, the wording is clear that permission is being sought for reproduction of the images for specified purposes. Consequently and notwithstanding the fact that the consent form bears little resemblance to copyright licenses used in other contexts, it is, in effect, a licence. RIS Legal Services was not overly concerned about the lack of contractual formality/detail in the permission. In summary, I do not see any reason to be concerned that copyright ownership might inadvertently be transferred to SHU, thereby depriving participants of all of their rights in respect of the images.

On the matter of whether or not the permissions that may be granted by the consent form include permission for you to use the images in your thesis, I think that you may reasonably regard consent for "reports and journal articles" and for "verbal presentations" to cover the thesis itself and your viva, respectively. With regard ownership of copyright in your thesis as a whole, that would normally vest in the student creator unless there is agreement to the contrary. For PhDs fully funded by SHU, it is common for the institution to put in place an agreement, at the outset, assigning arising IP to SHU. I am not sure whether this applies in your case, but you might wish to consult any relevant agreements that you have signed. Photographs whose copyright is owned by research participants and that are carried within your thesis remain owned by the original copyright owner, but may be regarded as being reproduced under the permission obtained by the consent form (i.e. you are using them under licence). Your thesis will be a copyright work in its own right that has embedded within it the copyright work of third parties, used under licence.

While there are options that we could pursue to make the situation concerning use of the images more legally robust, there is probably very little to be gained in doing so, considering the investment of time that would be required and also the scope for causing confusion among the study participants (i.e. presenting them with documents more complex than the ones already used).

I hope that this helps and let me know if you have additional questions.

Best regards.

Appendix 28:
Extract of Step 1 using the Listening Guide

Sandra

<p>Q: Thank-you very much, lovely. So, Sandra so I guess the purpose of my speaking to you now is really, I'd be really interested to hear about anything and everything really that you'd be prepared to share with me about your experiences of developing and living with or however you might term it really, with breast lymphoedema, so anything at all.</p> <p>F: Yes. Mm hm. Right so that's where I go blank.</p> <p>Q: Oh okay, so well, you could start at the beginning perhaps about when you first thought that something was going on, that would be perhaps a good place would it?</p> <p>F: With the lymphoedema</p> <p>Q: Yes, yes</p> <p>F: or after the diagnosis?</p> <p>Q: no right at the beginning I'd be really interested to know when you first sort of suspected that something might be going on.</p> <p>F: Yes, well after the first diagnosis what five, seven years passed by after the chemo and the radiotherapy and everything I was triple negative, found to be triple negative so they couldn't give me anything again like Tamoxin to prevent the cancer coming back so I was kind of just, yes you finish treatment and that was it.</p> <p>Q: Yes.</p> <p>*****</p> <p>F: So, it was arranged for me to go and see plastic surgeon guy at the (name of clinic) again, and he wouldn't recommend it because I'd already had the two lots of cancer on that one, he didn't recommend reconstruction on that side, but he suggested maybe something can be done to reduce the one on the right side (laughs)</p> <p>Q: Okay, a different take altogether.</p>	<p><i>I am acknowledging her previous reaction to using the phrase 'living with' and how it didn't resonate for her.</i></p> <p><i>This style of introduction hasn't worked for Sandra - it is clearly too open-ended for her.</i></p> <p><i>I make a more tangible suggestion for where she could start her story.</i></p> <p><i>I wonder if I've misunderstood her here - is she referring to her diagnosis of breast cancer rather than breast lymphoedema?</i></p> <p>Seven years after her first episode of breast cancer, Sandra was on holiday in Spain when she had bleeding from her nipple. It was the same breast and so her reaction was 'oh God ... it has come back'</p> <p>.....</p> <p>However the plastic surgeon whom she saw would not recommend the surgery due to her having had breast cancer twice in the left breast. Instead, he suggested that her right breast was reduced.</p>
---	--

<p>F: A different take, so anyway he wrote then to (national lymphoedema specialist) and suggested that they did liposuction to get rid of the fluid</p> <p>Q: Right</p> <p>F: on the right one. Anyway and he discussed it with his whole team and what have you, but then (national lymphoedema specialist) said no, he did not think that it was going to be (laughs), you know liposuction was going to be the thing for this particular one</p> <p>Q: Oh</p> <p>F: So yes so I mean we tried (laughs)</p> <p>Q: You did!</p> <p>F: Nothing actually ever did happen, so I'm just used to now having one large and one small (laughs)</p>	<p>The plastic surgeon approached the national lymphoedema specialist with the suggestion of liposuction. However in consultation with the team, the conclusion was that this was not an appropriate approach.</p> <p><i>I can't tell how Sandra actually feels about this meeting a dead end.</i></p> <p>Subsequently no further action was taken and Sandra is 'just used to now having one large and one small' breast.</p>
---	--

Appendix 29:
Dissemination opportunities relating to the study

2018

CAnceR Experience conference, Sheffield

Poster presentation entitled 'Capturing women's experiences of developing and living with breast or trunk lymphoedema following treatment for breast cancer'

2019

Three-minute thesis competition, Sheffield Hallam University (Finalist and commended)

2020

Invited speaker at the UK Imaging and Oncology Congress: Pathways and Communication. Presentation entitled 'Listening to women's unheard experiences of developing & living with breast or trunk lymphoedema after treatment for breast cancer'

2021

Breast Cancer Now have agreed to facilitate methods for disseminating the findings, including the publication of a report about the findings on the organisation's website.

2021

Oral presentation at British Lymphology Society virtual conference entitled 'Understanding women's experiences of breast (or chest wall or trunk) lymphoedema after treatment for breast cancer: a qualitative study' (see slides below).

Reflection:

Not only did the presentation provide an opportunity for participants' voices to be heard, but members of the audience acted as members of the 'wider network' in relation to The Silences Framework and provided further feedback on the findings. Comments included:

"... really powerful presentation and definitely echoing the stories we have from women locally unfortunately."

"Absolutely spot on Janet Ulman, from the way women with BCRL are treated. The silence surrounding women's experience, and the dehumanising () of being unable to by (sic) matching underwear and the strait jacket bras. So few women feel they can talk about BCRL and we need to change this."

"I am a lymphoedema CNS... Your research echoes so closely the words and feelings of many of the clients I see. It was fantastic to hear your insights and to know that your work will help people to understand the huge impact of breast and chest wall oedema"

"... Such empathetic and enlightened insight into the lived experiences of lymphoedema. I look forward to reading more."

"Heart-breaking but needs to be heard ..."

"Janet we are currently developing an MDT approach to early Breast Oedema identification and would love to link up with you."

"I really enjoyed your presentation today and found it really beneficial to my practice."

"Janet we are currently developing an MDT approach to early Breast Oedema identification would love to link up with you" (Vice Chair, BLS Scientific Committee)

Extract from article in the Winter 2021 edition of LymphLine, the newsletter of the Lymphoedema Support Network:

"There was a particularly interesting presentation by Janet Ulman looking at women's experiences of breast/chest wall or trunk lymphoedema after breast cancer treatment, which was insightful and moving."

Slide 1

Understanding women's experiences of breast (or chest wall or trunk) lymphoedema after treatment for breast cancer: a qualitative study

Janet Ulman
PhD student
Sheffield Hallam University

THE #BLS2021 CONFERENCE

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BREAST CANCER NOW The research & care charity

Slide 2




Image: Alexas_Fotos /Source – Pixabay

Professor Heidi Probst
Sheffield Hallam University

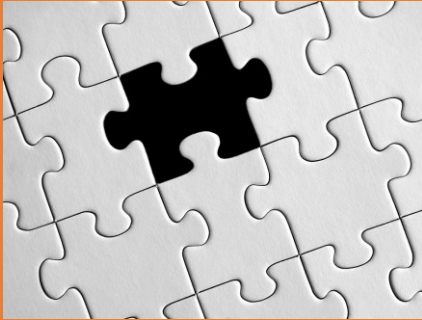
Professor Laura Serrant
Health Education England

Associate Professor Margaret Dunham
Edinburgh Napier University

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Slide 3



Source: Pixabay

Why this study?

Breast (or trunk or chest wall) lymphoedema

Incidence: up to 90% ¹

Silence surrounding women's experiences

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BREAST CANCER NOW The research community

1 Verbelen et al 2014

Slide 4




Image: Anemone123/Source – Pixabay

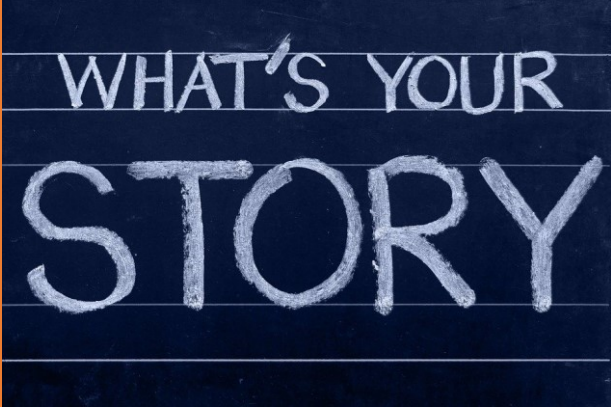
Voice-centred relational method (VCRM)

- The Listening Guide
I-Poem

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BREAST CANCER NOW The research community

Slide 5



Source: Pixabay

14 women participated

Location of lymphoedema:

- Breast only = 7
- Breast and armpit = 1
- Breast, armpit, arm, back and hand = 1
- Breast, trunk and arm = 2
- Trunk and arm = 1
- Chest wall and arm = 1
- At mastectomy scar, armpit and arm = 1


2 telephone interviews

10 used images; 1 used drawings

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BREAST CANCER NOW The research. The reality.

Slide 6



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Theme:
Mysterious breast,
trunk or chest wall
lymphoedema

"I could only explain it to them as if I desperately needed to feed a baby ... I mean they literally were different sizes and it was massive, it was hard."

- Jackie

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BREAST CANCER NOW The research. The reality.

Slide 7



Reproduced with permission

Theme: Mysterious breast lymphoedema

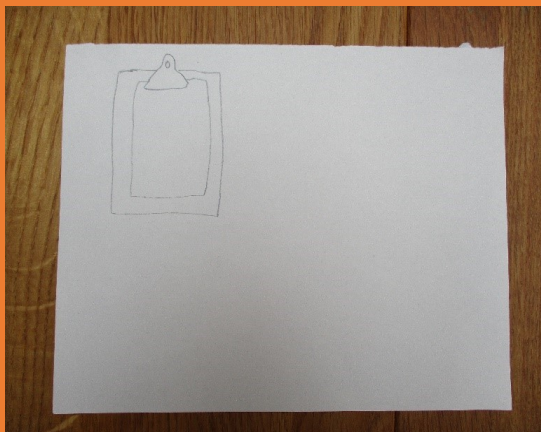
*"it's blurry, it's droopy,
there's no definition and
sometimes there's no
definition to how I feel
..."*

- Leah

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Slide 8



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Theme: You meet a wall

*" the clipboard represents the
fact that- and this isn't a blame
of professionals, but that they're
so focused on their job and what
they are seeing me for that so
many missed the diagnosis of my
lymphoedema ...*

*everyone is so focused on their
little bit"*

- Samantha

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Slide 9

*I just kind of thought, come on, you missed this
I'm not going to ... put in a complaint
I'm not angry at you, but
I would have expected you to apologise ... just say ... I'm sorry I missed
that
I wasn't going to go on about my chest anymore
I don't expect doctors to get it right all the time
I'm very grateful my breast cancer has been found early*

*I'm not a person in the eyes of so many of the professionals
I'm just a problem ... to be fixed medically*


**Theme: You meet
a wall**

I-Poem extract - Samantha

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BREAST CANCER NOW The research is our priority

Slide 10



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**Theme: You meet a
wall**

*"... it's just that wanting to shout so,
okay, so breast lymphoedema is a big
thing, it has a massive impact on
people's lives. Do you all know about
it? Are you thinking about it? Because I
think they're not. I don't think they
know much about it."*

(Samantha)

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BREAST CANCER NOW The research is our priority

Slide 11

*I went to my doctor at one time
I was going away on holiday
I went to the doctor and asked her for the antibiotics and
she was most horrible
I was telling her that I needed them, to go on holiday
I wanted them and I said 'but no, it's in the form'
I've got the leaflet
I didn't take it with me so
I couldn't show her... the recommendation*

*I never went back to her after that.. it really made me
feel so small, so awful*

I-Poem extract

Theme: You meet a wall

Sandra

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BREAST CANCER NOW The research is here to stay

Slide 12



Source: Pixabay

**Theme:
The silent consequences**

*"That just says it all, you know, it's
despair isn't it?"*

- Sharon

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BREAST CANCER NOW The research is here to stay

Slide 13



Source: Pixabay

Theme:
The silent consequences

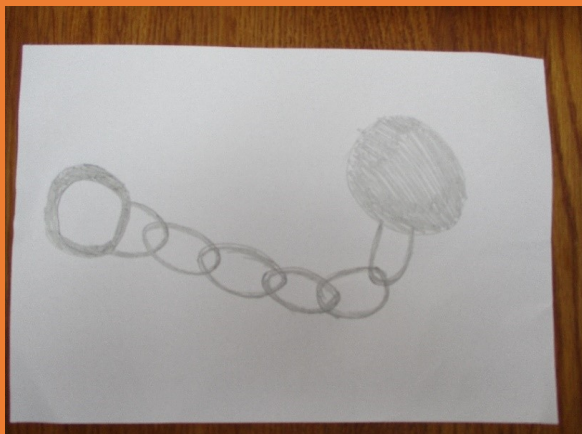
*"to other people I probably
look the exact same"*

- Catherine

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Slide 14



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Theme:
The silent consequences

*"my whole life ... from the
moment I wake up, it's just
different"*

- Samantha

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Slide 15



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Theme:
The silent consequences

"you can't get off... that's how it still feels"

*"I think with the lymphoedema coming,
you realise that it's now never going to
end"*

- Sarah

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Slide 16



Image: Janet Ulman

Subtheme:
The final straw

*"what's it come to, I've got
through cancer, radiotherapy
and now I'm reduced to
looking like a man"*

- Tilly

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NOW

Slide 17



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Theme:

Adapting to breast, trunk or chest wall lymphoedema

Subtheme: The right bra

*"that's just what life is like when
your breasts are continually
changing sizes and you're
forever buying different bras"*

- Joanna

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Slide 18

Goodbye beauty

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*" this horrible
thing ... this like
whitey beigey
thing with no
seams in."*

- Leah

Subtheme:
The right bra

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Slide 19

<p>Implications for practice:</p> <p>Information about breast, chest wall and trunk lymphoedema</p> <hr/>	<p>Improved awareness and understanding amongst healthcare professionals</p> <p>Access to information for patients</p> <p>Sheffield Hallam University College of Health, Wellbeing and Life Sciences</p> <p>BREAST CANCER NOW <small>The research is here early</small></p>
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Slide 20

<p>Implications for practice:</p> <p>Service improvements</p> <hr/>	<p>Development of self-assessment tools</p> <p>Improved access to assessment and treatment of breast, trunk and chest wall lymphoedema</p> <p>Sheffield Hallam University College of Health, Wellbeing and Life Sciences</p> <p>BREAST CANCER NOW <small>The research is here early</small></p>
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Slide 21

With thanks to:

Members of the study advisory group

The lymphoedema nurse specialists at the recruiting clinic, and the service development & information lead at the local cancer support centre, for their help and support

Breast Cancer Now for helping to ensure that the findings reach other women who have breast cancer

All the women who participated, for their generosity in sharing their stories with me

Thank you for listening

With thanks

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BREAST CANCER NOW The research is now charity

Slide 22

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Suggested reading

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