

## INTRODUCTION

Approximately 58,000 women are diagnosed with breast cancer annually in the UK (Breast Cancer Care, 2015). Due to improvements in the diagnosis and treatment of breast cancer, survival rates have steadily improved with 85% of women now surviving breast cancer more than 5 years (Breast Cancer Care, 2015). As survival rates improve, the long-term effects of breast cancer treatment are receiving increasing attention (Department of Health and Macmillan, 2013). Complications from breast cancer treatment include impairments of the upper limb, which can have significant adverse effects on function and quality of life (Ahmed et al., 2008; Levangie and Drouin J, 2009; Thomas-MacLean et al., 2009). These impairments include restricted movement, altered movement patterns, pain, weakness, axillary web syndrome (AWS) and lymphoedema,

To date, the main focus in the literature has been the prevention and treatment of lymphoedema, which is currently estimated to affect 20% of breast cancer patients (Hayes et al., 2012; National Health Service, 2017). In comparison, restricted movement and pain of the shoulder, arm and chest wall caused by axillary web syndrome (AWS) and myofascial impairments have been reported as being more prevalent but have received comparatively less research or clinical attention. Historically, these upper limb movement impairments (ULMI) have been considered to be largely self-limiting (Lacomba et al., 2009; Leidenius et al., 2003; Moskovitz et al., 2001), However, more recently, research has shown that ULMI can affect up to 50% of patients 6 years' post-surgery (De Groef et al., 2015). Living with on-going ULMI has been shown to have significant psychological, social and financial impacts (Martins da Silva and Rezende, 2014; Nesvold et al., 2011; Rosedale and Fu, 2010). Provision of pre- and post-treatment unsupervised exercise advice is insufficient to prevent the development of ULMI (Dylke and Kilbreath, 2015; National Institute for Health and Care Excellence, 2017) and the need for more effective post-treatment

intervention has become paramount (Stout et al., 2012; Westrup, Lash, Thwin, and Silliman, 2006).

In view of the increasing recognition of ULMI as significant complications of breast cancer treatment, an increase in referral to physiotherapy for the management of ULMI has been anticipated (Schmitz et al., 2012a). Guidelines recently issued in the UK by the National Institute for Health and Care Excellence (2017) recommend the referral of patients with on-going reduced arm and shoulder mobility after breast cancer treatment to physiotherapy. Physiotherapy treatment encompasses a number of interventions that can be broadly divided into prescriptive therapeutic exercises and manual interventions, such as soft tissue and joint mobilisation (De Groef et al., 2015). A growing body of evidence supports the effectiveness of physiotherapy for ULMI. Evidence for manual treatments is currently based on professional opinion drawing from recommendations provided by small RCTs, retrospective studies and case studies (Black et al., 2014; Cho et al., 2016; Fourie and Robb, 2009; Marshall-McKenna et al., 2014; Yeung, McPhail, and Kuys, 2015). A larger body of evidence drawing from a number of high quality studies informs physiotherapy-instructed exercise intervention (McNeeley et al., 2010; Tatham et al., 2013).

Although breast cancer rehabilitation guidelines exist they do not include specific guidance on the assessment and management of AWS and myofascial impairments (Harris, Schmitz, Campbell, and McNeely, 2012; National Cancer Rehabilitation Advisory Board, 2012). Furthermore, evidence supporting the benefits of manual therapies for the relief of ULMI is provided by low quality studies that have a high risk of bias and there is some concern regarding the potential for adverse effects (Yeung, McPhail, and Kuys, 2015). In the UK there remains significant variation in post-treatment pathways for women after breast cancer treatment regarding ULMI and the provision of physiotherapy care. Owing to a lack of specialist service provision in the

UK, care is often provided in different healthcare contexts by non-specialist physiotherapists as part of a generic caseload along with specialist physiotherapists (Hunt, 2014 and 2016b).

In light of the limited research into physiotherapy management of ULMI, this study aimed to explore experiences of physiotherapists involved in the management of people with ULMI following breast cancer treatment to gain insights into factors that may improve our understanding of this relatively new and under-researched area of practice and help inform directions of future research and professional education.

## METHOD

This exploratory study used a hermeneutic phenomenological approach aligned with the philosophy of Heidegger (1962). In this study, hermeneutic phenomenology is concerned with understanding the meaning (and associated underlying beliefs and attitudes) of people's experiences through analysis of participants' accounts of their experiences, which were gained through the use of semi-structured interviews. Hermeneutic phenomenology recognises that people make sense of the world in which they are located through their interactions with others and the world around them (Petty, Thomson, and Stew, 2012). In addition, context, space and time are understood to have an important and fluid influence on meaning and understanding (McConnell-Henry, Chapman, and Francis, 2011).

Hermeneutic phenomenology adopts an ideographic approach, allowing participants to tell their stories in their own words and not in relation to any predefined hypotheses or prior assumptions (Nicholls, 2009). This conveys a sense of 'being there' and allows a deeper engagement with the phenomenon. Researchers are recognised as active participants in the research process through their engagement in the dynamic and iterative processes of reflexivity and the hermeneutic circle.

Reflexivity acknowledges the researchers' own values and assumptions and aims to make these explicit within the generation and analysis of data (McConnell-Henry, Chapman, and Francis, 2009). The hermeneutic circle is underpinned by reflexivity and refers to the iterative process of comparison between the parts of the text and the whole of the text to gain understanding (Smith, Flowers, and Larkin, 2009).

### Participants

This study purposefully recruited physiotherapists from different healthcare contexts whose regular practice involves treating people with ULMI (see Table 1). The inclusion criteria were deliberately broad to maximise participant involvement in the study regardless of clinical speciality, work setting and number of years of experience. The study was advertised through the Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC) and three interactive Chartered Society of Physiotherapy online networks (iCSP). Nine responses were received and six physiotherapists were recruited having met the inclusion/exclusion criteria and being geographically accessible for interviews. Smaller samples support a hermeneutic phenomenological approach, allowing similarities and differences between participants' experiences to be examined while also providing a rich, in-depth analysis of individual experience so that participants retain a defined identity rather than being subsumed into anonymity within a larger whole (Robinson and Smith, 2010; Smith, Flowers, and Larkin, 2009).

### Data generation

The data were generated through face-to-face, in-depth semi-structured interviews undertaken by the first author. The interview guide and technique was developed and refined through input from service users and piloting processes (see [Figure 1](#)). The interviews were conducted and digitally recorded between December 2014 and February 2015. Examples of lived-through situations were elicited to help participants

offer accounts of their experiences rather than theoretical views or viewpoints (Van Manen, 1997). Probing questions were utilised as relevant during each unfolding interview to explore the research interest of their experiences with treating people with ULMI. A flexible approach aimed to enable unexpected aspects of experience to emerge and to avoid constraining potential insights (Smith, Flowers, and Larkin, 2009).

Interview times and locations were arranged according to participants' convenience; three interviews were conducted in participants' homes, two in a quiet public area and one in a private workplace. The interviews lasted between 45 and 70 minutes. Notes were taken to record reflections on the interview and any observations such as non-verbal communication and contextual factors that might influence interpretation of the transcript. This strategy aimed to support as complete an account as possible of the meanings expressed in the interview as well as the reflexivity and transparency of the interviewer's role in co-creating the interview data generated.

### Data analysis

All interviews were transcribed verbatim and participants were given pseudonyms to maintain anonymity. The Interpretative Phenomenological Analysis (IPA) method was used to analyse the data (Smith, Flowers, and Larkin, 2009). IPA uses an inductive, iterative and flexible process of analysis consistent with the hermeneutic phenomenological approach (Smith, Flowers, and Larkin, 2009). This analysis involves using a constant process of reflection based on the hermeneutic circle (Smith, Flowers, and Larkin, 2009), while maintaining an ideographic commitment to the data. The IPA method extends through four stages of analysis as shown in Figure 2. An example of development of a master theme from the raw data is presented in Figure 3.

## Rigour

To ensure rigour of the process, each stage of the analysis was documented to ensure transparency of the analysis method, development of the themes and to provide a clear audit trail from the original raw data to the final master themes (Smith, Flowers, and Larkin, 2009). Verbatim examples from the interviews are provided to evidence the findings, ensuring that the interpretations remain grounded in the data. Throughout the research process a reflexive diary was maintained to record and make explicit the researchers' thoughts, questions and observations. Regular discussions were held within the research team during the stages of analysis to enhance reflexivity and to challenge and refine interpretation.

## FINDINGS

The findings of this study focus on the participants' shared meanings of their experiences of providing treatment for people with ULMI following breast cancer treatment. We identified four master themes that represent these: (1) Lack of confidence related to treatment of ULMI (2) Development of confidence through experience (3) Perceived impact of physiotherapy on patients' quality of life (4) Practice challenges.

### Lack of confidence related to treatment of ULMI

A common experience expressed was a lack of confidence and sense of unease in treating ULMI in breast cancer patients. One issue concerned a perceived uneasiness within the physiotherapy profession in general regarding the use of manual therapeutic techniques on people with cancer:

*"in our training we're told if anyone's got cancer, don't go near them, don't do this, don't do that...so therefore people back away" (Sally)*

The participants understood the basis of this unease was a fear of causing lymphoedema or spreading cancerous cells, which was something they had also experienced personally:

*“everyone gets freaked out with the diagnosis of cancer. It’s like...can’t do manual therapy, can’t do acupuncture...you might dislodge something and then stimulate it up the lymphatics and spread it everywhere” (Becky)*

*“I just kind of tiptoed my way in and felt my way and just recorded everything neurotically” (Jo)*

*“I’m cautious when I start to stretch the cording” (Michelle)*

They perceived that this unease caused many physiotherapists to be fearful of treating ULMI and described encountering this unease within the physiotherapy profession:

*“physios are scared to death” (Sally)*

*“I will go first and feel the scar tissue around the mastectomy area...I will look at that and treat it if it needs be but others might not...because...I think physios are a bit fearful” (Jo)*

*“they are a bit nervous about treating patients with cancer, that’s what I often find” (Alex)*

The participants also talked of a lack of knowledge amongst other physiotherapists about ULMI, such as cording (AWS), which they themselves experienced initially:

*“this patient’s got cording, it’s like... “Oh, what’s that?” (Becky)*

Emerging from the participants’ accounts was a sense that the lack of evidence and guidelines to support decision-making for physiotherapeutic interventions, particularly manual interventions, left them vulnerable:

*“I felt kind of very on my own and quite alone with it really” (Jo)*

*“because there is so little evidence...you are kind of going in a bit blind...we need to sort of protect ourselves really that we are being safe” (Becky)*

### Development of confidence through experience

This theme describes the participants' accounts of becoming more experienced in treating ULMI, reflecting increasing levels of self-confidence in the safety and effectiveness of their practice. Their accounts reveal how the knowledge developed through experiences of seeing positive transformations of patients' symptoms, movement and function as a result of their treatment enables them to manage the uncertainties surrounding clinical decision-making more easily:

*"it definitely comes with experience because... you go...I'm a reasonable clinician, I know that I'm not going to do anything wrong by doing this particular technique"*  
(Becky)

*"it's [manual therapy] one of those things that doesn't have a lot of research and because it works... that's sort of the way that we've been working"* (Pippa)

*"you get results so you're confident in your own ability to get the outcomes that you need without any ill effect for the person"* (Michelle)

The participants' practice confidence had been particularly strengthened by their experiences of seeing significant and unexpected improvements in movement and pain through the application of connective tissue release in patients who had lived with ULMI for many years. This challenged not only their assumptions about the potential for recovery but also the patient's expectations, with the experience being felt profoundly by both:

*"just by releasing that scar or the cording you significantly change someone's quality of life and that shocked me, and it shocked me that you could do it so quickly...it can make such a difference that far down the line [15 years], and I'm still finding it now, people who've had surgery a long time ago, who don't think that we can change it, and are shocked"* (Sally)

This increasing confidence in practice was also based on their increasing reassurance and confidence in the effectiveness of the knowledge and



understanding they possessed, which was viewed in terms of the therapist's ability to alleviate patients' fears and gain their trust:

*"when people say to me at the end of an assessment where I've done very little, I feel so much better already just goes to show how much just talking to someone, but I think talking to someone with the knowledge...I don't think you could have somebody who could just talk. It couldn't be someone that people could just offload and just tell. You have to know what you're talking about"* (Sally)

The participants' accounts also displayed increased certainty in the effectiveness of their assessment skills, which had been strengthened by their experience of seeing a difference in the confidence of patients who had previously been assessed by therapists who were unaware of how to manage ULMI:

*"some of them have been to see other people...but having an understanding about the fascia, the scar tissue and mobilising that...they'll just say "...nobody's ever managed to work on that...nobody's made that kind of difference"* (Jo)

Greater confidence in the ability to provide reassurance and manage the emotional aspects of having difficult conversations with patients was revealed through accounts of becoming more experienced in treating ULMI. Areas of difficulty included asking patients about their history of cancer and their feelings and emotions, as well as discussing psychological input or concerns regarding suspected recurrence requiring oncological review:

*"I suppose earlier on you're, you don't know quite what to ask or how much detail to go into because you don't want to upset somebody... I feel better at talking to them about things that are upsetting them or worrying them so...if somebody brings up a difficult topic, it doesn't worry me so much"* (Michelle)

*"if you are concerned about something, you have to come out with it straight and talk to them properly about it rather than, when I was afraid to do it, it came out wrong"* (Sally)

### Perceived impact of physiotherapy on patients' quality of life

The improvement of breast cancer patients' quality of life as a result of physiotherapy treatment was felt to be deeply important to the participants. The participants viewed the effects of physiotherapy to be greater than simply improving or restoring physical movement and function because achieving this allowed people to return to meaningful activities, enabling them to re-engage with life as the person they were before their illness:

*"when you see them talk differently about themselves, you know they've changed their story of how they perceive themselves and you've helped them facilitate it"*  
(Jo)

Untreated ULMI was perceived to have significant negative psychological effects for those people affected, often acting as a constant reminder of the person's cancer history, making it difficult for them to move on with their lives:

*"the restriction made, rather than her being able to...put the past behind her...you could see in her demeanour that this was playing on her mind more than...just the physical attributes of what the problem was"* (Michelle)

Being able to alleviate longstanding AWS and scar or soft tissue tightness through the application of manual soft tissue techniques was perceived to alleviate patients' fears and anxieties:

*"she said "I'm feeling so different about my body. You've helped me not to be fearful of it"* (Jo)

*"suddenly to have one treatment session that removes it is quite a nice feeling for them because they're then thinking "Oh. This is nothing to worry about"* (Sally)

This was perceived to be particularly significant when treatment involved the mastectomy scar, as this helped women start to engage and become more confident with their new body image:

*“it is part of beginning to get patients to come to terms with their new body image as so many patients I see early post op are too scared to look at their surgery”  
(Alex)*

*“often by touching that area...you’re giving that patient permission to touch that area and not to be afraid of that area and actually to relax a bit more about it because people do have a huge fear about touching, looking at it” (Jo)*

Emerging from the participants’ talk was a strong conviction that physiotherapists are in a unique position to be able to identify and address movement impairments and functional deficits, making it possible for them to help people resume activities that are meaningful to them:

*“I got that better and got her back to doing yoga, which is what she really loves doing” (Jo)*

*“being able to offer people...solutions to something that they believe they’ve got to put up with because they’re told by other clinicians, “I’m really sorry, there’s nothing we can do”, is great...because you ...being able to offer that hope” (Sally)*

Guidance and support with exercise was felt to be important for empowering people to overcome their fears and anxieties. Exercise groups were valued for the opportunity they gave people to meet others and build friendships:

*“over the course of the 8 weeks, came out of her shell and...you could tell...from a confidence point of view, she’d improved... she’s kind of got a little friendship group now. So before, there was always just her and her husband and she was quite reliant on him” (Pippa)*

### Practice challenges

The participants perceived that people living with and beyond breast cancer often have a poor quality of life after their treatment and are unable to lead a life that is meaningful to them. This was accompanied by a sense of frustration that people often suffer unnecessarily owing to a general lack of recognition of ULMI and

awareness of the benefits of physiotherapy, which deny them effective treatment.

Throughout many descriptions there was an underlying passion to help these people; the participants often felt driven to make a difference:

*“I just really care about these people...I always felt that they needed more than they were getting. That they had a tough enough journey as it was and as a physio, what can I do to really help them?” (Jo)*

*“why go through this cancer treatment if you aren’t able to move on, whether it be physically, psychologically or whatever. It’s about quality of life afterwards, isn’t it? Great, treat the cancer, that’s really important but they need to get back to a life that’s meaningful for them and that’s where I think physiotherapy has such a big part to play” (Alex)*

The participants perceived **a general lack of knowledge** amongst health professionals about AWS (cording). Sally told of seeing patients with cording who had been misdiagnosed with lymphoedema and how this significantly affected those people emotionally:

*“if somebody doesn’t understand what that cording is, they tell them it’s lymphoedema...They are scared to death that they’ve got this lymphoedema” (Sally)*

A general lack of knowledge and understanding about ULMI amongst health professionals was perceived, shaped by the participants’ encounters with patients who were distressed as a result of previous care by someone who lacked specialist knowledge:

*“she didn’t feel confident that the physiotherapist understood what all her issues were ... they couldn’t really explain to her why the situation was...she was quite tearful, she was quite emotional” (Alex)*

The participants described how a lack of knowledge and understanding about ULMI amongst health professionals could prevent people from returning to exercise or previous activities:

*“the feedback I had from ladies when I said about doing exercises was “What if I bring my cancer back?”, “What if I do more damage?” and if you’ve got someone that can’t allay those fears...they don’t do it, so then things get worse and worse...then things deteriorate until they get to a point where they end up with a frozen shoulder” (Sally)*

The participants described a lack of recognition of ULMI by healthcare professionals, which left people at risk of suffering unnecessarily with ULMI by restricting their ability to become informed about ULMI as well as their ability to access physiotherapeutic care:

*“it’s quite common when I see people...that the afterwards has not been explained to them very well, or even at all...for the most part they...tend to think that they’re always going to have a movement restriction and that pain is a normal outcome of having had surgery” (Michelle)*

A sense of frustration also emerged in the participants’ experiences. In particular, those working outside a specialist integrated breast service perceived a common lack of recognition of ULMI from other healthcare professionals involved in breast cancer care:

*“I do think she’d sort of been brushed off by the surgeons a bit...you know, just get on with it...it’s the usual story, “we’ve treated your cancer, you should be pleased...don’t worry about the fact that you can’t move your arm and you’re quite young” (Alex)*

*“patients will often say “I need physiotherapy” and their healthcare professionals will say “No you don’t”, and I’ve had that a lot and that’s really difficult” (Sally)*

## DISCUSSION

This study was undertaken to explore physiotherapists’ experiences of treating ULMI to gain a deeper understanding and new insights into the ways in which management

of ULMI is meaningful to them. Based on the analysis, four master themes were identified: (1) Lack of confidence related to treatment of ULMI (2) Development of confidence through experience (3) Perceived impact of physiotherapy on patients' quality of life (4) Practice challenges.

The physiotherapists spoke about lived-through situations of managing ULMI that occurred at different stages of their overall experience including their first or early exposure to ULMI as well as more recent experiences. The study found a number of significant characteristics across the physiotherapists' experiences. These concern emotional aspects associated with treating ULMI, the significance of experiential learning for building confidence in clinical decision-making and barriers to physiotherapy care. These findings were not independent but interrelated as experiences of management and increasing clinical experience with ULMI were described by participants.

Across the experiences feelings of uneasiness were expressed. Fear of causing harm was a prominent feeling among the participants, particularly when they described lived-through situations associated with less experience of managing ULMI. This concern was related to the lack of evidence to support the long-term safety of manual therapy for cancer-related impairments as well as the lack of specific treatment guidelines for ULMI (Harris, Schmitz, Campbell, and McNeely, 2012; Yeung, McPhail, and Kuys, 2015). Concern regarding the safety of manual therapy within the cancer patient population is understandable since metastasis is the main cause of cancer death (Weigelt, Peterse, and van't Veer, 2005) and lymphoedema is irreversible (Davies and Desborough, 2008). Evidence now suggests that a highly complex integrated process involving genetic mutation and stromal response is responsible for causing metastasis (Jin and Mu, 2015; Weigelt, Peterse, and van't Veer, 2005). Fears that mechanical forces produced by the application of manual

therapy techniques may cause metastasis are therefore ill-founded. However, a prevalence of questions on numerous websites and online forums regarding the safety of massage in cancer patients suggests this knowledge is not well known (Cancer Council NSW, 2015).

Fear of causing harm to patients has been identified in the medical literature (Pugh, Obadina, and Aidoo, 2009; Smith, 1986), however, to our knowledge, this has not been raised in the physiotherapy literature. Feelings of anxiety regarding decision-making have been found in novice physiotherapists working in acute cardiorespiratory settings as well as in extended scope physiotherapists assessing patients with low back pain (Langridge, Roberts, and Pope, 2015; Smith, Higgs, and Ellis, 2010). Our findings also suggest that working in areas of practice **that are perceived to involve** a higher likelihood of significant negative consequences of inadequate decision-making and intervention may carry a significant emotional toll compared to other areas of physiotherapy practice.

In this study, fear of causing harm was closely related to a similar, but distinct emotion, of feeling vulnerable, which was particularly associated with less experience in managing ULMI. Feeling vulnerable appeared to be linked with a perception that manual treatment of cancer-related impairments was considered to be outside traditional physiotherapy practice and discourse. Leading specialist cancer physiotherapists in England have identified a general lack of leadership and understanding of cancer rehabilitation among the NHS workforce (Hunt, 2016a). These findings of fear and vulnerability in practice indicate a need to ensure that assessment and treatment of cancer-related impairments are included in **undergraduate and continuing education programmes, research initiatives and professional discourse**. This is particularly important to support physiotherapists

treating people with ULMI in non-cancer specialist settings, such as community rehabilitation, general musculoskeletal outpatients and women's health services.

Participants' experiences included the difficulty of managing emotions during consultations and when having difficult conversations, such as when patients relate their cancer journey, personal impacts, fears and worries, and when the need arose for specialist review relating to suspected recurrence. This difficulty appeared more pronounced during early experiences of treating ULMI and appeared to be associated with a lack of certainty around the adequacy of their knowledge and their ability to manage patients' emotions as well as their own. Anxiety about upsetting patients appeared to be one of the most commonly experienced emotions by the participants, mirroring similar findings among paediatric practitioners when holding difficult conversations (Martin Jr et al., 2015).

Managing difficult conversations and emotional aspects or processes in treatment situations have not been well addressed in the physiotherapy literature or the health literature in general (Gard and Gyllensten, 2004; Martin Jr et al., 2015). Effective emotion management is gaining increasing recognition for its importance in effective patient care, clinical outcomes and preservation of clinician well-being (Luff et al., 2016). Training to improve emotional well-being and develop resilience to burnout is currently available to specialist cancer physiotherapists (Macmillan Cancer Support, 2017). However, those working in non-specialist cancer settings may not be aware of or have access. Given the anticipation that people living with and beyond breast cancer will be increasingly treated in generic settings, there may be an increased likelihood of physiotherapists encountering emotionally challenging conversations compared to more established areas of physiotherapy practice. It is therefore important to recognise the need to prepare and support the ability of physiotherapists



in generic settings to manage their emotional well-being effectively in this area of practice.

Although the participants spoke of having to find their own way with regards to treating ULMI, accounts of decision-making and action revealed a unified approach to clinical practice as described in other studies (Black et al., 2014; Fourie and Robb, 2009; Glaessel, Kirchberger, Stucki, and Cieza, 2011). The participants commonly experienced significant improvements in range of movement, function and pain being gained by patients following soft tissue treatment for AWS and/or scar/soft tissue tightness. Consistent with previous research, connective tissue dysfunction was understood to have an important role in on-going ULMI, affecting areas distant to treatment sites via the fascial network (Binkley et al., 2012; Fourie and Robb, 2009; Fourie, 2008; Glaessel, Kirchberger, Stucki, and Cieza, 2011). There were several accounts of experiences of dramatic gains in range of movement and resolution of AWS and scar/soft tissue tightness following manual therapy against what might be typically expected with longstanding musculoskeletal problems, still yet to be explained fully in physiological terms. There were also experiences of improvements in lymphoedema symptoms following soft tissue treatment for scar/soft tissue tightness and AWS. The role and risk of manual interventions for ULMI in relation to lymphoedema also remains to be determined. AWS and scar/soft tissue tightness are gaining recognition as risk factors for the development and perpetuation of lymphoedema (Lymphoedema Framework, 2006; Royal College of Nursing, 2011). Cho et al. (2016) and Lacomba et al. (2010) found that early physiotherapy, including manual therapy techniques to mobilise AWS and scar and soft tissue, is effective at reducing the risk of developing lymphoedema. However, there remains significant uncertainty and limited research to guide management when the problems co-exist. The findings of this study indicate the value in further research in this area.

Practice confidence about the value of physiotherapy intervention was interrelated with increasing exposure to ULMI-related symptoms that persisted or recurred outside the self-limiting recovery period proposed by some researchers (Lacomba et al., 2009; Leidenius, Leppänen, Krogerus, and von Smitten, 2003; Moskovitz et al., 2001). Participants' experiences support the evidence that ULMI may not always recover spontaneously and can have important negative implications for breast cancer survivors' quality of life (Collins, Nash, Round, and Newman, 2004; Levangie and Drouin, 2009; Levangie, Santasier, Stout, and Pfalzer, 2011). Implicit in the physiotherapists' experiences of managing ULMI was a sense that gaining physical improvements had a significant positive effect on patients' well-being, reflecting quantitative studies evaluating quality of life (Cho et al., 2016; da Luz et al., 2017; Duarte, Aguiar, Faria, and Bernardo, 2017). Persistent ULMI prevented patients from forgetting about their cancer diagnosis. These findings are supported by studies of breast cancer survivor experiences (Collins, Nash, Round, and Newman, 2004; Rosedale and Fu 2010). Persistent ULMI was also seen to increase patient distress about cancer recurrence and the risk of developing lymphoedema. Fear of cancer recurrence and lymphoedema has been reported as a significant cause of on-going psychological distress (Binkley et al., 2012; Rosedale and Fu, 2010).

Awareness and sensitivity to patients' underlying emotions, in particular the negative psychosocial effects of living with ULMI was felt to be important. The participants acknowledged that successful treatment needs to consider and address these effects at both a cognitive level (the depth of knowledge required to provide information, reassurance and effective physical assessment and treatment) as well as at an emotional level (recognising, understanding and responding to patients' thoughts and feelings) (Gard and Gyllensten, 2004). The importance of specialist disease and treatment knowledge was highlighted through accounts of witnessing the effect of uninformed or conflicting advice on patient confidence. Specialist disease and

treatment knowledge have been identified as an important issue by physiotherapists for minimising patient uncertainty and anxiety (Glaessel, Kirchberger, Stucki, and Cieza, 2011) and may contribute to better outcomes (Collins, Nash, Round, and Newman, 2004). Women treated for breast cancer have expressed greater confidence in specialist breast cancer physiotherapy care than non-specialist physiotherapy care (Collins, Nash, Round, and Newman, 2004; Lattanzi et al., 2010; Pidlyskyj, Roddam, Rawlinson, and Selfe, 2014); revealing how being cared for by a physiotherapist experienced in breast cancer care is significant for the sense of reassurance and understanding they impart through their knowledge and understanding of the medical and treatment aspects of breast cancer and its psychoemotional effects (Lattanzi et al., 2010; Pidlyskyj, Roddam, Rawlinson, and Selfe, 2014). This highlights the importance of resources to support specialist knowledge for physiotherapists new to this area of clinical practice or in non-specialist services.

The role of touch during the application of manual therapy was recognised as a valuable way of expressing their care, compassion and reassurance to patients (Gallace and Spence, 2010; Hertenstein, Holmes, McCullough, and Keltner, 2009). This included manual treatment of the mastectomy area, which was perceived to be one of the most powerful ways that physiotherapy can help patients overcome their fears and improve their self-confidence. This is supported by the findings of Pidlyskyj, Roddam, Rawlinson and Selfe (2014) whose interviewees described how the physiotherapist's touch of that area helped them to engage with and accept their new body image.

Central to the participants' understanding of effective treatment was a commitment to empowering the patient, which included offering guidance and support to return to exercise or specific activities. Participants working in integrated specialist services

spoke of the value of supervised exercise groups for facilitating patient empowerment and self-confidence, and for opportunities to meet and develop friendships with other breast cancer survivors. Collins, Nash, Round and Newman (2004) also identified social interaction and patient education to be important benefits of a breast cancer exercise group. Hwang et al. (2008) found the physical and psychological benefits of participation in an exercise group to be superior to performing exercises at home. Exercise groups were also valued for their role in providing on-going support and information as well as ensuring compliance with exercise. Other studies have revealed how breast cancer survivors fear causing harm to their arm when exercising without supervision (Larsson et al., 2008; Sander et al., 2012).

In addition to the benefits of physiotherapy for ULMI, frustration about current after-care service provision and support for breast cancer patients was also voiced.

Participants working outside an integrated specialist breast service (where access to physiotherapy is controlled by other health professionals) were critical of commonly encountered surgical and medical attitudes towards ULMI and physiotherapy, which was perceived to often overlook the impact of ULMI and the role of physiotherapy intervention. The physiotherapists felt these attitudes dominated current models of after-care, resulting in inadequate information provision, a lack of referral to physiotherapy and a general lack of patient awareness of physiotherapy treatment for ULMI.

The lack of recognition of ULMI was perceived to deny or limit patient access to physiotherapy, leaving patients at risk of suffering unnecessarily with ULMI. This included the consequences of inadequate after-care information and support that was understood to foster patient anxiety about unknowingly causing harm to themselves, leading to reduced activity and function, and resulting in physical and

psychological dysfunction. These findings are supported by a number of studies that have identified an association between patient fear of causing harm and lifestyle modification, particularly avoidance of pre-morbid or new activities as well as a lack of adherence to post-treatment exercise advice (Binkley et al., 2012; Levangie, Santasier, Stout, and Pfalzer, 2011). Concerns about inadequate aftercare support are echoed across the research literature (Binkley et al., 2012; Campbell et al., 2012; Cheville, Troxell, Basford, and Kornblith, 2008; Harris et al., 2012; Schmitz et al., 2012a) and a lack of understanding about the role of physiotherapy in improving ULMI is identified as a barrier to its inclusion in breast cancer care (Cheville and Tchou, 2007; Harris, Schmitz, Campbell, and McNeely, 2012; Schmitz et al., 2012a). However, research suggests patients may not always report the impacts or late effects that they are experiencing, which may also be a reason for non-referral (Cooney, Galvin, and Stokes, 2015). This highlights the need for patient access to a range of information resources and the development of clinical assessment approaches to help elicit aspects of altered health and function. The development of stronger evidence about the effectiveness, safety and value of physiotherapy management of ULMI is an important factor in providing high quality care for people undergoing breast cancer treatment.

### LIMITATIONS

Due to the idiographic nature of hermeneutic phenomenology, this study involved a small sample but undertook an in-depth exploration of the experiences of six physiotherapists who treat ULMI. The sampling process aimed to recruit participants engaged in practice that was typical of contemporary physiotherapeutic care of ULMI, drawing on the concept of information power within the sample (Malterud, Seirisma, and Guassora, 2015). It is not the aim of hermeneutic phenomenology to achieve data saturation, a statistically representative sample or develop findings that are generalisable to all physiotherapists or contexts of treatment of ULMI (O'Reilly and

Parker, 2013). The findings aim to add insight into physiotherapy management of ULMI and readers may determine if the findings are relevant and transferable to informing clinical practice, future research and professional education. All the participants were female and the findings may not reflect the experiences of male physiotherapists, which would be an area for further research.

Adhering to the principles of hermeneutic phenomenology the interviews were participant-led, allowing for issues of importance to emerge. Given the participants' free choice over which aspects of their experience were expressed, their entire experience of treating ULMI may not be represented. The researchers also recognise that while there was no intention of the interviewer to influence the interview, there is always an inevitable effect and probing questions may have unintentionally steered the participants towards issues related to the interviewer's foreknowledge of the topic. The participants mostly referred to the impairments of AWS and scar/soft tissue tightness, therefore other forms of ULMI and other physiotherapeutic interventions such as exercise were not explored in detail. The participants spoke only of experiences involving the treatment of women with breast cancer, although it is recognised that breast cancer also occurs in men. The findings may resonate with the experiences of physiotherapists who manage ULMI in men and offer transferability to context-similar situations, while also highlighting an important area for future research.

## CONCLUSION

Physiotherapy is considered an important aspect of post-treatment care for complications following intervention for breast cancer, particularly upper limb movement impairments (ULMI). Although physiotherapy is recommended in post-care guidance, there has been only limited research and evidence to support clinical practice, along with limited understanding of pathophysiology and risks of harm

associated with treatment related to ULMI and its relationship to lymphoedema. From an in-depth exploration of clinical experiences of treating this population, we found that despite initial uncertainty and significant experiences of feeling unease, physiotherapists become increasingly confident in their practice and in the value and importance of physiotherapy involvement in breast cancer care with increasing experience of treating ULMI. This is underpinned by an understanding that effective treatment encompasses equal consideration of the physical, psychological, emotional and social elements of ULMI.

Our findings extend current understanding of physiotherapy management of ULMI, showing that practice confidence is affected by it being an area of practice that is less well known within and beyond the physiotherapy profession. Practice confidence is further affected by the lack of a robust evidence-base and specific treatment guidelines to support decision-making, particularly concerning manual interventions. Fear of causing harm and vulnerability in practice indicate a need for further research to advance understanding of the long-term effectiveness and safety of manual therapy for ULMI, which should employ sufficiently long follow-up times to capture potential adverse effects of physiotherapy intervention and incorporate outcome measures that capture the breadth of potential improvements in quality of life as well as physical changes. The importance of resources to support specialist knowledge for physiotherapists, including the psychosocial aspects of cancer-related conditions and management of emotions during consultations and difficult conversations has been highlighted, in addition to the need for the development and delivery of physiotherapy training and education in cancer care and rehabilitation in a broad range of healthcare contexts.

Finally, our findings support the problem of a lack of patient and health care professional awareness of ULMI and the potential role of physiotherapy in ULMI

management. They highlight the need for collaboration with different professional, organisational and public stakeholders to improve awareness and recognition of the benefits and role of physiotherapy in the management of ULMI in order to support its routine inclusion in breast cancer care pathways.

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