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### **Paper:**

Watts, T. & Davies, R. (2016). A qualitative national focus group study of the experience of living with lymphoedema and accessing local multiprofessional lymphoedema clinics. *Journal of Advanced Nursing*

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## **Aim**

To explore people's experiences of living with lymphoedema and to assess the impact of access to local lymphoedema clinics on their condition and thus their lives.

## **Background**

A chronic condition caused by reduced lymphatic function, lymphoedema leads to swelling, pain, mobility problems and risk of infections and can adversely affect quality of life. Lymphoedema is of international concern as its prevalence is projected to rise. Yet awareness of lymphoedema is limited, diagnostic delay common and access to specialist treatment restricted. The concept of local lymphoedema clinics is gaining support and the All Wales Lymphoedema Service was founded in 2011. However empirical investigation of local lymphoedema services remains limited.

## **Design**

A qualitative exploratory study consisting of focus group interviews in every Welsh lymphoedema clinic ( $n= 8$ ).

## **Methods**

A convenience sample of adults living with lymphoedema in Wales was recruited. Data were collected in digitally recorded focus groups during July and August 2013. Interviews were fully transcribed and analysed using a qualitative content approach.

## **Findings:**

Fifty-nine people participated in eight focus groups. Three main themes emerged from the analysis: Living with lymphoedema is a battle; delays in obtaining a correct diagnosis and the positive impact of lymphoedema clinics on participants' lives. Locally accessible clinics made meaningful differences to peoples' lymphoedema, engendered positive patient-reported outcomes and improved engagement with and adherence to lymphoedema self-management.

**Conclusions:**

Local specialist lymphoedema clinics can make a positive difference. They may be cost-effective and further investigation, including economic evaluation is necessary.

**KEY WORDS**

LYMPHOEDEMA; FOCUS GROUPS; QUALITATIVE RESEARCH; SELF-MANAGEMENT; SUPPORTIVE CARE; ADHERENCE; CHRONIC CONDITION; PRIMARY CARE CLINICS; NURSE; NURSING.

## **SUMMARY STATEMENT**

### **Why is this research needed?**

- As populations age the prevalence of lymphoedema, a progressive, enduring, disabling, frequently unrecognised condition with profound psychosocial and economic sequelae, is projected to increase.
- Little is known about the acceptability and efficacy of local specialist multiprofessional lymphoedema clinics from the standpoint of people living with lymphoedema.

### **What are the key findings?**

- Participants identified that across care settings, including oncology, practitioners' had insufficient awareness and understanding about lymphoedema in terms of impact, prevention, diagnosis and management.
- Participants' reports indicated that access to local specialist lymphoedema clinics and continuity of patient-centred, holistic care conferred physical, psychosocial and economic benefits.
- Although access to local specialist practitioners, including nurses, motivated many individuals to sustain their engagement in lymphoedema self-management some were unable to do this in the absence of on-going practical support.

### **How should the findings be used to influence policy/practice/research/education?**

- Policy makers should consider the potential of local lymphoedema clinics to ensure best outcomes for patients and promote effective use of healthcare resources by sustaining patient engagement in lymphoedema self-management.

- Further research should be commissioned and conducted to provide evidence of the clinical and cost-effectiveness of locally accessible multiprofessional lymphoedema clinics.
- Education providers should be aware that lymphoedema and its management has a place in pre-registration nurse education and for generalists and specialists in post-registration curricula.

## **INTRODUCTION**

Lymphoedema is a chronic condition caused by reduced lymphatic function (Taghian *et al.* 2014). It leads to swelling, pain, mobility problems, risk of infections and skin texture changes. Lymphoedema affects an estimated 140-250 million people worldwide (Greene *et al.* 2015). Many more are at risk; particularly in developing countries where mosquito transmitted lymphatic filariasis is endemic (Person *et al.* 2009). In the developed world lymphoedema prevalence will rise due to growing obesity, chronic illnesses and cancer juxtaposed against increasing life expectancy (Christensen *et al.* 2009, Office for National Statistics 2015). This will place pressure on nursing and healthcare systems and generate concern for policymakers.

Poor awareness and understanding amongst healthcare professionals and the public means lymphoedema is frequently unrecognised. People with non-cancer related lymphoedema remain relatively invisible, experiencing considerable diagnostic delay and difficulties accessing limited specialist services (Williams *et al.* 2004, Bogan *et al.* 2007, Sneddon 2008, Deng *et al.* 2015). Ultimately the care and support needs of many individuals may not be identified or appropriately and effectively met resulting in preventable complications and suffering (Sneddon 2008). This is because lymphoedema can be profoundly disabling, disfiguring and debilitating. Moreover, lymphoedema is connected with adverse psychological, emotional and socioeconomic sequelae which impair quality-of-life and well-being (McWayne & Heiney 2005, Person *et al.* 2009).

### **Background**

Lymphoedema arises as a consequence of an inherited or acquired anomalous lymphatic system and affects people of all ages (Sneddon 2008, Ridner 2009). It is characterised by

enduring regional swelling of either the head / neck, upper and lower limbs and genitalia (Gary 2007) and categorised as either primary or secondary. Primary lymphoedema is associated with lymphatic malformation as a consequence of congenital or genetic factors, for example, Milroy's Disease and Miegge's Disease (Ostergaard *et al.* 2011, Brouillard *et al.* 2014). Secondary lymphoedema is connected with lymphatics damaged by trauma, burns, cardiac and venous diseases, surgery, cancer treatments and parasitic infections (Preston *et al.* 2004, Wanchai *et al.* 2013). In developed countries cancer treatments are the leading cause of secondary lymphoedema (Rockson 2008, Saito *et al.* 2013, Brayton *et al.* 2014). Internationally, there is rising concern about the connection between chronic conditions, morbid obesity and lymphoedema (International Lymphoedema Framework 2012, Keast *et al.* 2014).

The incidence of lymphoedema varies in different illnesses (Park *et al.* 2008, Taghian *et al.* 2014). In terms of lymphoedema prevalence, Moffatt *et al.*'s (2003) frequently cited epidemiological study conducted in South-West London identified a prevalence rate of 1.33 per 1000 patients. Prevalence estimates of cancer related lymphoedema have been reported in several small international studies, often using retrospective single centre cohort and cross sectional designs (for example, Ryan *et al.* 2003a, Penha *et al.* 2011, Deng *et al.* 2012). It has been argued that little is known about the prevalence of primary lymphoedema and secondary lymphoedema unrelated to cancer (Rockson & Rivera 2008, Gethin *et al.* 2011). Nonetheless, there seems to be universal agreement that prevalence rates are probably underestimated (Rockson & Rivera 2008).

Lymphoedema may not be recognised or experienced as sufficiently problematical by some individuals to generate concern and thus report (Williams *et al.* 2005). Invariably however, failure to recognise, diagnose and report lymphoedema is a consequence of poor

awareness (Kwan *et al.* 2012, Keast *et al.* 2014, Civelek *et al.* 2015). For health professionals the situation may be compounded by the absence of a universally recognised and accepted definition of lymphoedema, unified measurement criteria and inadequate research attention (Paskett *et al.* 2007, Rockson & Rivera 2008, Brayton *et al.* 2014).

Deficient knowledge and understanding of the importance of prevention, early recognition and effective management conjoined with inequitable access to specialist services is of international concern (Stout *et al.* 2012, Keast *et al.* 2014). Failure to recognise lymphoedema and initiate appropriate, effective therapeutic interventions generates adverse outcomes in terms of suffering, disability, disfigurement and distress (Keast *et al.* 2014). Indeed, the profound, lasting, adverse physical, psychological, psychosocial and economic impact of lymphoedema on individuals' well-being, everyday functioning and health related quality-of-life is well documented (Ryan *et al.* 2003b, Williams *et al.* 2004, Franks *et al.* 2006, Towers *et al.* 2008, Symvoulakis *et al.* 2010, Dunberger *et al.* 2013, Okajima *et al.* 2013).

Lymphoedema's complex, enduring nature necessitates early detection, integrated, multiprofessional interventions and supported self-management. Accordingly the concept of locally accessible multiprofessional specialist lymphoedema services is gaining credence internationally (Park *et al.* 2008, Morgan *et al.* 2012). The Welsh Government has had devolved responsibility for health care and policy since 1999. The National Lymphoedema Service was founded in 2011 to provide local multiprofessional clinics across Wales. Eight clinics have been established. The following study was designed to explore people's views and experiences of these clinics given that exploring experience is a first step in generating a new body of knowledge. By reporting findings from this study this paper aims to fill a gap in extant literature.

## **THE STUDY**

### **Aim**

The aim of this research was to explore and describe peoples' views and experiences of the specialist lymphoedema clinics. Specifically we sought to address two research questions:

1. What is it like to live with lymphoedema in terms of its effect on quality of life and well-being?
2. In what ways has access to local lymphoedema clinics made a difference to their lives?

### **Design**

A qualitative exploratory study using focus groups (Kreuger & Casey 2008) was designed. Focus groups, an established form of focused collective discussion on a defined topic, issue or experience are ideal for examining individuals' experiences (Kitzinger, 1994, 2005). An expedient method of generating data from several people simultaneously, they are popular in nursing and health research (Reed & Payton 1997, McLafferty 2004). Skilled facilitation capitalises on participants' interactions and generates rich data which may not be obtained through individual interviews (Webb & Kevern 2001, Ryan *et al.* 2015). For this research, focus groups would provide a platform for participants with an element of common experience to reflect, listen to and share experiences in company and enable natural talk to emerge and flow in a supportive environment.

### **Participants**

Convenience sampling was used to recruit individuals attending eight local lymphoedema clinics in Wales who could share experiences of the clinic's impact on their lives. We hoped

to recruit at least 48 participants. Access was granted by each clinic's lead practitioner. Participants were recruited in 2013 by publicising the project in each clinic. Inclusion criteria were: adults living with lymphoedema; able to consent and proficient in the English language.

### **Ethical considerations**

Approval was granted by the University and relevant Health Board research ethics committees. All participants gave written informed consent prior to the focus group. At the start of each focus group ground rules regarding confidentiality were established. It was emphasised that all participants must respect confidentiality and not share information discussed or identify individuals involved outside of the group. All participants were assured they could withdraw from the study at any time without this affecting their care. None ended their participation or withdrew from the study.

### **Data collection**

Focus group interviews ( $n=8$ ) were conducted in every Welsh local lymphoedema clinic during July and August 2013. The decision to hold eight focus groups was pragmatic, influenced by timescales and the desire to cover all clinics in Wales. Each focus group was assigned a code, for example FGH. FG indicates the focus group whilst a letter indicates the clinic.

RD, an experienced focus group researcher not known to participants, facilitated all focus groups. These lasted approximately one hour, were digitally recorded and discussion aided by a loose interview guide derived from the literature and expert advice (Table 1). This was adapted during data collection to incorporate emergent themes from preliminary analysis.

### **Data analysis**

Data were analysed using a qualitative content approach guided by the research aim and questions (Coffey & Atkinson 1996). Interviews were transcribed into Word© documents and identifying features removed. To ensure their accuracy transcripts were read whilst simultaneously listening to corresponding recordings. Two researchers read transcripts repeatedly to ensure familiarity and deep understanding of the data and facilitate dependable analysis. Independently the researchers manually coded transcripts. Consensus regarding codes was achieved during joint discursive review. To visually identify data with shared codes, data segments with a common code were colour highlighted (Coffey *et al.* 1996). Codes were abstracted into sub-categories, categories and broad overarching themes, scrutinised for similarity and duplication, discussed, refined and reduced until mutual agreement between the researchers was reached (Table 2).

### **Rigour**

Rigour was enhanced by drawing on measures to achieve credibility, transferability, dependability and confirmability (Lincoln & Guba 1985). Collection of data from a heterogeneous group of participants in eight geographically and socio-economically diverse Welsh regions, meticulous transcription, checking of all interviews and rigorous data analysis by two researchers independently and collectively contributed to credibility. Detailed descriptions of experiences aided transferability whilst an audit trail of methodological decisions ensured dependability and confirmability.

### **FINDINGS**

Fifty-nine people, 49 women and 10 men aged between 22–86 years participated in eight focus groups. Average focus group size was 7, range 3-11 (Table 3).

**Please insert Table 3 here**

Twenty five participants (7 men, 18 women) reported cancer-related lymphoedema and 34 (3 men, 31 women) reported non-cancer related lymphoedema (Figure 1).

Data analysis identified three themes which captured participants' experiences, namely: living with lymphoedema; diagnostic delays and the positive impact of local lymphoedema clinics.

### ***'It is a battle': Living with lymphoedema***

In all focus groups there was consensus regarding the profound, unremitting and interlinked physical and psychosocial impact of lymphoedema on participants' lives. The magnitude of this is encapsulated in one participant's use of combat metaphor:

It is a battle: it has been a battle (...) [breast cancer] didn't change my life this [lymphoedema] did. (FGB)

Bulky, painful, heavy limbs, skin prone to uncontrollable weeping and enduring discomfort were articulated across all focus groups. Participants frequently drew attention to disrupted sleep and restricted physical functioning, particularly during warm weather. Several had experienced recurrent cellulitis precipitated by insect bites or minor trauma.

There was agreement across focus groups that these problems placed substantial limitations on living a normal life. This was because engaging in everyday living activities was difficult:

My legs just go double the size. You can just feel it and the tightness (...) I get pains then and cramp of the calves as well, so it is really hard work when you have a 6 year old. (FGH)

Many participants had continued working. However, this could be challenging as lymphoedema induced functional limitations impacted on work performance and enforced

sickness absence. Despite employers' support in terms of reasonable adjustments, some chose early retirement:

The senior nurse took me off the ward and I was office based (...) I decided then I had had enough and I just retired (...) I feel really grieved. (FGB)

The psychosocial effects of living with lymphoedema were considerable. Most participants had lived with lymphoedema for many years. Almost all spoke of adversely altered body-image, social isolation and emotional distress.

The shattering impact of lymphoedema on body-image was marked. Concerns about a discredited body in terms of appearance and attractiveness were persistently reported across focus groups. Several women felt unable to wear fashionable clothing and footwear. For some this was due to an inability to find clothes and shoes which fitted. Nevertheless, many participants articulated that enlarged limbs, poor skin condition, compression bandages and garments generated a sense of unattractiveness, shame and an internal perception of external criticism. Consequently many expressed a felt need to cover up:

People do look at your legs or arms and they might not be thinking 'ah look at her over there' but inside you think 'I have got to cover that up'. (FGF)

I would love to wear a short skirt. I do wear skirts but I do think I need to wear certain length skirts. (FGG)

Negative self-image, restricted mobility and uncertainty associated with an unpredictable, disobedient body engendered a degree of social isolation. One participant with primary lower leg lymphoedema explained that prior to referral she not had left home for fourteen years. Others, whilst not housebound, had become unable to fully partake in social events and leisure activities, notably overseas travel and sport.

I used to play golf a lot and it [lymphoedema] sort of got in the way. (FGB)

I used to go running 3 nights a week (...) I can't do that now. (FGE)

Some had sought to maintain social contact through leisure activity in local peer support groups. Nevertheless, accessibility and availability challenges meant this was not always sustained.

Emotional distress was prominent across all focus groups. Several participants articulated changes in emotional state:

The depression can set right in and you feel like you are on your own. I don't know if it is like it for you two?

**It was yes.** [together] (FGF)

We try not to be depressed but you can't help it especially when you don't really know what it is and no one is listening to you. (FGA)

In addition some voiced exasperation with the lack of recognition of the psychological impact of lymphoedema and were resolute that something had to be done:

There has got to be awareness of the psychological aspect of lymphoedema.

People don't realise how down and misunderstood you feel. (FGC)

***Nothing was done until about a year ago': Delays in correct diagnosis***

In participants' eyes, many health professionals had insufficient understanding of lymphoedema. There was consensus that this knowledge deficit had resulted in diagnostic delay and access to appropriate treatment and support.

Across focus groups diagnostic delay was the norm for participants with primary lymphoedema. Yet most participants treated for cancers reported diagnostic delays. Invariably delays were a consequence of insufficient awareness of lymphoedema and mistaken attribution.

The majority of participants lamented health professionals' limited awareness of lymphoedema:

There seems (.....) almost total lack of awareness of lymphoedema (....) health professionals are not looking beyond the obvious. (FGC)

Some participants with cancer related lymphoedema revealed they were unaware of its possibility as they had been inadequately informed:

I asked [dermatologist] about lymphoedema and she said by this time [1 year post diagnosis] if you were going to get it you would have it already. (FGB)

[I] was told if you went gardening wear gloves to save getting any prickles because you would get lymphoedema. Well I don't do gardening so I thought it won't happen to me and I had such a shock when my arm started swelling. (FGD)

A frequently reported view was that lymphoedema was not addressed in healthcare professionals' education. Some participants' believed health professionals' were simply disinterested. It was suggested that public awareness of lymphoedema was limited too:

You very rarely meet someone who knows what lymphoedema is, they automatically think cancer. (FGG)

Many participants with primary lymphoedema described how they had been treated, often over many years, for swollen legs, fluid retention, weight gain and leg ulcers:

I was treated at my surgery by the practice nurse who used to put dressings on and different bits and pieces but it got worse. (FGH)

I was told (...) ‘you are on your feet too much and here are some diuretics, take a couple of paracetamol and put your feet up’. (FGC)

A correct diagnosis and access to appropriate treatment was often serendipitous: the outcome of chance encounters with different nurses or physiotherapists who knew about lymphoedema and expedited referral to specialist lymphoedema services:

The district nurse I was going to for something else (...) saw my legs and she said, ‘My God we can do something about those, you have got lymphoedema’. (FGC)

[Physiotherapist] said ‘I think the best place for you is (...) lymphoedema clinic’ (...). ‘You have lymphoedema, so I will refer you’. (FGB)

Several participants revealed they learnt about lymphoedema through family, friends or their own research and requested specialist referral:

I diagnosed it myself from a medical article (...) I went to see my GP and said ‘I think this is what I have got’. (FGC)

However, before local clinics existed, accessing specialist services involved lengthy, costly journeys to specialist providers across the UK or Welsh hospices. While some were referred to regional Welsh cancer centres, access for individuals with primary lymphoedema was contingent on where they lived. One woman with primary lower limb lymphoedema explained:

(GP) referred me [to oncology centre]. He said ‘I don’t know if they will accept you because you are not in [names place].... we didn’t hear anything. (FGF)

Without specialist treatments individuals’ experienced substantial deterioration of their primary lymphoedema:

I was refused treatment in [names two oncology centres] (...) I have got it [lymphoedema] now in both arms and legs. (FGE)

***‘It has changed my life’: The impact of the local specialist led lymphoedema clinics.***

There was agreement that referral to local specialist lymphoedema clinics was positive. Needs based care delivered in close proximity to participants’ homes by named specialist practitioners and irrespective of lymphoedema aetiology was highly valued. People had the correct treatment by the most appropriate professional, mostly at right time. Clinics engendered local networks of support and were motivating forces for participants to positively engage in self-management. Ultimately participants’ felt their quality-of-life was vastly improved. Nonetheless, concerns about services’ long-term sustainability were voiced.

Even though initial appointments could take up to 26 weeks from referral local clinics were generally applauded across all focus groups. At one level the positive regard for clinics was related to geographical accessibility, enhanced in some areas through use of transportable healthcare units: local clinics were convenient, cost-effective, saved time and minimised interference with employment:

I find it very convenient, cost-effective as far as fuel is concerned. (FGH)

I haven't missed a day [off work] since coming here which is brilliant (...) I have no problem getting here, or getting to work from here (...) and it is so easy to park. (FGF)

Accessibility was important when daily compression bandaging over three consecutive weeks was required. Moreover, many participants articulated that once assessed practitioners offered telephone advice and created spaces in busy schedules to see them if required:

Last week both my legs were running with liquid into my shoes. I was in such a state I wanted to cut my legs off and I rang up at 9am on Friday morning and they said (...) there are only 2 of us on, come in and we will fit you in and they did. (FGD)

Participants valued this needs based individualised approach. Continuity was deeply appreciated and participants frequently described staff as 'fantastic' and 'wonderful'. Their specialist knowledge, expertise, flexibility, willingness to share information and attention to fine detail, a common example across focus groups being limb measurement, a new experience for many, was highly regarded. Applied expertise and continuity made significant positive differences in terms of participants' reported outcomes and quality-of-life. One person, a trained dancer with primary lymphoedema explained:

it [lymphoedema] nearly finished my career (...) the treatment has already made a difference to my life what they have done in the last few months here and I wish it had happened sooner (...) I have never seen my leg and ankle so small and I sometimes just stand and look at in the mirror because I can't believe it and it just gives me a bit of hope. (FGG)

Some participants in one focus group however were profoundly dissatisfied with their clinic. While the named practitioner was described as 'marvellous', some were discontented with the clinic's organisation:

The service is terrible. It could be a good service but it is just getting appointments. I have got so frustrated trying to get appointments (FGB)

For those in employment the prime concern was frequently cancelled appointments. Yet bureaucracy and a perceived disregard for individual's treatment preferences were also mentioned.

Many described how they were motivated to reciprocate by accommodating lymphoedema into their lives through engaging in self-management: meticulous hygiene, skin care, self-massage, protection from insect bites and trauma, wearing compression garments and taking regular exercise:

Coming here, it encourages you to do all the simple lymph drainage (...) the fact that someone has actually worked on you makes you feel I have got to give something back. (FGG)

Participants also spoke of seeking information and peer support through social media and the Lymphoedema Support Network:

I met with people from across the UK through the lymphoedema support network and I got involved in the young person's planning for lymphoedema (FGF)

The ultimate aim of self-management was to prevent and reduce the risk of adverse complications: cellulitis, hospitalisation, exacerbation of lymphoedema and associated effects and maximise quality-of-life. Yet not all participants could independently self-manage their

lymphoedema. Some described difficulties in putting on and removing compression garments unaided. Invariably this was due to arthritis and when people lived alone this was particularly problematic:

They did get me a pair of stockings which was brilliant because I have got arthritis and I couldn't open them to put them on so it was a complete and utter waste of time (...) there was no one to help me and I did try. (FGE)

Others required professional support, particularly with regard to infection prevention and prophylactic antibiotics. Nevertheless, several participants felt their concerns were not taken seriously and even trivialised by non-specialists:

I rang the nurse at the surgery and I said to her 'I've got these mosquito bites and I have got lymphoedema and I will need an antibiotic straight away.' 'What?' she said, 'for midge bites?' and I said 'No, because the midge bites could cause an infection' and she said 'I don't think you need antibiotics'. (FGD)

Participants were cognisant of increasing lymphoedema prevalence and potential associated future demands. Concern about long-term sustainability in a dynamic, fiscally bounded health care system was expressed as was unease about capacity to cope with demand:

I don't think it [the service] is adequate for all people who have got it [lymphoedema] (...) there is not enough staff. (FGE)

Moreover, many participants, particularly those in rural areas were worried about what would happen in the event of long-term sickness, practitioners moving on and funding changes:

You get somebody who knows what they are doing and then they move on and then there is a dip in the service (...) I don't want to see this service disintegrate.

(FGA)

## **DISCUSSION**

The All-Wales lymphoedema service is an exemplar which will be of interest to strategic managers and policy makers across the United Kingdom. This is because of the positive patient-reported outcomes illuminated in findings presented here. Furthermore subsequent analysis of the Service's economic impact, reported elsewhere, has indicated the potential for reductions in healthcare resource use (Humphreys & Fitzsimmons 2015).

In this unique study participants' voiced their experiences of living with lymphoedema and the influence of specialist local lymphoedema clinics on their lives. People's experiences of living with lymphoedema have been previously considered (Williams *et al.* 2004, Meiklejohn *et al.* 2013). However, the predominant focus has been women with breast cancer related arm lymphoedema (Johansson *et al.* 2003, Fu & Rosedale 2009). Service provision for this population may be better than for others living with lymphoedema. Indeed, Hodgson *et al.*'s (2011) Canadian study identified restricted access to treatment for many with non-cancer related lymphoedema.

For the first time our study reveals that access to specialist localised clinics made a meaningful difference to peoples' lymphoedema and thus their lives, engendered positive outcomes and improved adherence to lymphoedema self-management. The latter is a particularly important finding given international policies emphasising individuals' active engagement in managing chronic illness (Department of Health 2005, Welsh Assembly Government 2007, Health Council of Canada 2012). Yet, our data also revealed that some

participants did not have the physical capacity to self-manage their lymphoedema and had no access to alternate support.

The finding that lymphoedema related physical restraints and functional losses were considerable, generated immense challenges and at times placed overwhelming restrictions on participants' everyday activities reflects findings from earlier research (Lam *et al.* 2006, Bogan *et al.* 2007, Fu & Rosedale 2009, Vassard *et al.* 2010). What this study adds is a glimpse into the endless hard work of living with lymphoedema, an aspect articulated in focus groups through combat metaphor. Lakoff & Johnson (1980) contended that metaphor aids the definition and expression of subjective reality. In our study participants' use of metaphor illuminated the unremitting effort required to incorporate lymphoedema into their everyday lives, the resultant lifework challenges and disruptions they encountered and sought to overcome. It is of little surprise that inextricably entwined with physical and functional restraints and resultant demand was enduring psychosocial suffering.

Data revealed how lymphoedema adversely permeated social networks, activities and employment. This resonates with findings from previous studies (Bogan *et al.* 2007, Fu & Rosedale 2009, Ridner *et al.* 2012). However, the vocabulary of discredited, disobedient bodies, articulated embarrassment, shame and marginalisation conjoined with the propensity for bodily concealment and self-isolation indicated entrenched felt stigma, the internal perception of shame associated with having a visible, potentially discrediting condition and fear of others' reactions (Scambler & Hopkins 1986, Lebel *et al.* 2013). Few participants indicated that they had directly experienced lymphoedema related enacted stigma: prejudicial, distressing insults about their shape, size and skin condition. However, self-imposed avoidance and bodily concealment are protective coping strategies which may signal anticipated and feared enacted stigma. Ultimately the confluence of disrupted self-concept

and mediating strategies may contribute to the burden of lymphoedema by engendering deleterious psychosocial and behavioural outcomes.

The complex amalgamation and interplay of physical and functional restraints, disrupted lifestyles and psychosocial suffering signals the need for and importance of holistic supportive interventions. Regrettably our data revealed continued shortcomings in lymphoedema care and support in general hospital and community settings. In part, this seems to relate to healthcare professionals' insufficient lymphoedema knowledge and understanding and reflects findings from earlier studies (Williams *et al.* 2004, Lam *et al.* 2006, Bogan *et al.* 2007, Sneddon 2008, Vassard *et al.* 2010, Davies 2012, Barlow *et al.* 2014). However, the extent to which participants with cancer related lymphoedema struggled to access diagnosis and appropriate treatment was an unexpected finding. Lymphoedema prevalence is projected to increase. This will impact on demand for care. Accordingly investment in accessible lymphoedema education for non-specialist health professionals and updating for specialists is warranted to raise awareness, improve prevention, management and psychosocial support strategies, reduce diagnostic delay and ultimately enhance affected individuals' quality-of-life and sense of well-being. Yet there is also a pressing need to raise the profile of lymphoedema amongst policy makers.

The data showed that specialist lymphoedema clinics were highly regarded. In part this was because they were locally accessible. Innovative mobile clinics were valued for ease of access which generated less disruption to participants' lives. Wang *et al.* (2014) highlighted accessibility challenges experienced by rural Australians with lymphoedema and the impact of foregoing treatment and commuting long distances for treatment on quality-of-life. These sophisticated healthcare units are used internationally to reach out to under-served rural and urban populations in developed and developing worlds (Carmack 2010, Guruge *et al.* 2010).

Further empirical investigation of transportable healthcare units in terms of populations served, health outcomes and cost-effectiveness is required (Brooks *et al.* 2013, Browder *et al.* 2015). Nonetheless, their potential in lymphoedema service delivery, particularly in rural areas, should not be dismissed.

Specialist clinics were acceptable because participants experienced apposite, holistic patient-centred care which was not discontinuous. Essentially individuals felt both cared for and about. It is likely that this is because their needs were expertly met in a supportive relational space, an approach which connects with findings from early investigations into patients' perspectives of good care (Attree 2001). Importantly, our data revealed that the positive experience motivated participants toward sustained lymphoedema self-management and lifestyle changes. This finding contrasts with those from recent research indicating inadequate adherence to lymphoedema self-management, particularly wearing compression garments and self-massage amongst women with breast cancer related lymphoedema (Brown *et al.* 2014, Alcorso *et al.* 2016).

Lymphoedema self-management can be time-consuming and burdensome, particularly in the absence of additional support. Moreover, compression garments may generate discomfort and serve as visible reminders of the condition and, in cancer related lymphoedema, the disease and its treatment. It is entirely possible that these factors may influence decisions whether to wear garments or not. Nevertheless, enduring lymphoedema self-management is important to manage regional swelling, reduce the risk of complications and potential psychosocial ramifications and possibly healthcare use and thus costs.

The findings signal the need for further investigation of the barriers and facilitators of supported self-management in lymphoedema. They also have important implications for practitioners, strategic managers responsible for service development and policy makers

globally, not least because engagement in supported self-management may help temper escalating demands on scarce resources and thus save costs (Wanless 2004). However, this is by no means certain as influential commentators and researchers have observed (Greenhalgh 2009, Panagioti *et al.* 2014).

### **Limitations**

The study is not without limitations. Whilst the sample is small it is in accord with the study's aims and in terms of exploratory qualitative research adequate. Yet the findings reflect experiences of a heterogeneous sample of self-selecting participants in one region of the UK. It is probable individuals volunteered to participate because they wanted to share their stories about living with lymphoedema and how being able to access local clinics changed their lives. In terms of policy and practice important lessons can be learnt from the experiences of individuals living in Wales.

### **CONCLUSIONS**

Local specialist lymphoedema clinics can make a positive difference to the lives of people living with lymphoedema by improving accessibility, expert lymphoedema management and augmenting patient outcomes, for example, knowledge and adherence to lymphoedema self-management. It is plausible that these improvements may not only enhance individuals' quality of life and sense of wellbeing but also be cost-effective in the longer term by for example reducing healthcare costs due to complications such as cellulitis or deterioration in lymphoedema leading to adverse patient outcomes and socioeconomic costs. Nevertheless the magnitude of effect is uncertain and further empirical investigation, including economic evaluation of specialist clinics is required to capitalise on the findings reported here.

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