

# The challenges of managing complex lymphoedema/chronic oedema in the UK and Canada

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## ABSTRACT

This article explores the professional challenges of treating patients with complex/severe forms of chronic oedema/lymphoedema with compression therapy. Four focus groups were held, two in the UK and two in Canada, to examine the challenges faced by practitioners in their everyday practice. A number of challenges were identified by participants in both countries and include the changing profile of lymphoedema/chronic oedema and how increasing complexity is outpacing the development of services and research-based guidelines. Focus groups also highlighted a lack of public awareness, poor professional knowledge, delayed diagnosis and inappropriate treatment as having a significant impact on practice. Other practice-related issues include a poor understanding of treatment options among practitioners, a lack of evidence-based practice as well as difficulties associated with managing psychosocial problems and of ensuring concordance with treatment. In Canada, services tend to be more rural and remote than in the UK, autonomous specialist practice is less developed and practitioners were generally less confident and felt more vulnerable than their UK colleagues. There is a need for integrated, multi-disciplinary services in both countries, with improved education and training, as well as the development of cost-effective compression bandaging systems that can make a major contribution to meeting the challenges of contemporary lymphoedema practice.

**Key words:** Challenges to practice • Complex lymphoedema/chronic oedema • Compression • Education and training • Lymphoedema services • Treatment decisions

## Key Points

- the complex nature of lymphoedema/chronic oedema includes a range of interlinked factors that can be described as physical, psychosocial and structural.
- the profile of lymphoedema is changing with increasing complexity outpacing the development of services, lengthening treatment times and putting pressure on resources and treatment guidelines.
- similarities between the UK and Canada include a lack of public awareness, poor professional knowledge, inadequate information, delayed diagnosis and inappropriate treatment, poor understanding of treatment options, a lack of evidence-based guidance and difficulties of ensuring concordance with treatment.

## INTRODUCTION

Lymphoedema is both common and complex (1). It is now known to be far more common in the UK than was believed to be

the case even until fairly recently (2). The complexity inherent in the management of lymphoedema is multifaceted and presents a range of challenges for health care professionals that have received little attention. Taking a holistic perspective, the complex nature of lymphoedema includes a range of interlinked factors that can be described as physical, psychosocial and structural. For the purposes of this article, the term physical complexity refers to the challenges involved in the clinical management of lymphoedema that has a level of severity of late stage 2 or stage 3 of the International Society of Lymphology (ISL) staging model (3). Such physical factors include caring for people with grossly swollen and heavy limbs, meeting the needs of the obese patient, managing lymphorrhoea, skin sequelae and

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the risk of cellulitis. Challenges also result from other physical problems associated with the condition such as pain, discomfort, reduced function and impaired mobility and difficulties with wearing clothing of choice and shoes that fit (4,5). Equally relevant are any continuing and residual effects of the original cause of secondary lymphoedema; for example the management of malignancies and severe trauma.

Psychosocial factors include fear, anxiety, distress, poor body image, depression, embarrassment, social isolation and employment difficulties, any of which can have a detrimental effect on the quality of life of the patient and their families or carers (5,6). Concordance with treatment is known to be extremely important if treatment is to be effective (7). The extent to which the patient is concordant with treatment might vary for many reasons but increased limb volume, a low satisfaction with treatment and poor understanding of their treatment regime have been shown to have a detrimental effect on concordance (8).

Structural factors are a reference to a raft of issues, other than physical and psychosocial, that can have an impact on lymphoedema and its management. These include the education of health care professionals regarding lymphoedema and their subsequent level of awareness and ability to recognise the condition. This is particularly important for nurses in the community (9) and also for General Practitioners (GP). Both have a key role in the early detection of the condition as well as on-going management in the community. It is known that delays in diagnosis and treatment can exacerbate the swelling, can lead to cellulitis, increase demands on time and resources and ultimately make management more problematic (10–13).

Structural factors also relate to the context of health care provision in which specialist practitioners work. This includes the shape of lymphoedema services and whether they are integrated with other services including community nursing arrangements (14). Geography is a key factor especially in more rural areas that require long distance travel by patients or practitioners (15). Access to prompt and appropriate treatment is vital no matter what the geography. The consequences of delayed referral in terms of increased severity and progression have been well documented (16) and include both functional and psychosocial

implications (17). A key component of access to treatment is reimbursement and in the UK expansion of the Drug Tariff has made progress towards improving the provision of some resources. The Canadian health care system is made up of a number of publically funded health insurance plans and there has been some frustration with the lack of funding for lymphoedema from both government and insurance companies (18).

Lymphoedema is a chronic condition that requires life-long treatment and the degree of complexity involved in its management can be considerable. The literature suggests a mix of challenges that can influence the management of lymphoedema and that can impact on the therapeutic relationship between patient and practitioner. It was the purpose of this study to explore how health care professionals manage the challenges that this complexity presents.

## MATERIALS AND METHODS

### Aim

The aim of the study was to explore the professional challenges of treating patients with complex/severe forms of chronic oedema/lymphoedema with compression therapy within two countries, the UK and Canada.

### Secondary aims

- To explore the professional challenges of controlling/treating the swelling associated with chronic oedema/lymphoedema.
- To explore how professionals seek to overcome these challenges.
- To explore the wider issues of managing patients with chronic oedema/lymphoedema within two different health care systems.
- To explore how professionals use and adapt different types of compression in treating patients within the context of care.
- To explore professional's views on how compression should be developed and adapted to meet the needs of this patient group.

### Design

This was a qualitative study using focus groups within two countries. Participants in Canada and the UK were invited to take part in two focus groups each. In Canada, lymphoedema

## Key Points

- specialist lymphoedema services are more developed in the UK although Canada has the disadvantage of remote rural communities and a context of care that is medically dominated and in which Canadian lymphoedema practitioners feel less confident and more vulnerable.
- there is a need for integrated, multi-disciplinary services in both countries, with improved education and training, to create a therapeutic environment in which specialist practitioners can confidently manage complex lymphoedema/chronic oedema including compression therapy in all its forms.
- there is a need for innovative approaches to the development of cost-effective compression bandaging systems that are light, flexible, can remain in situ for longer without slippage or loss of pressure and that can make a major contribution to meeting the challenges of contemporary lymphoedema practice.

patients are usually cared for by practitioners involved in wound management and leg ulceration rather than professionals trained specifically in lymphoedema care. As such wound management and leg ulcer specialists who were considered to be key opinion leaders in their field were invited to participate in the focus groups and were drawn from different specialities from both acute and community care. Participants attended one focus group each. Six attended the first focus group and seven attended the second. In the UK, therapy and nurse specialists were invited from dedicated lymphoedema services throughout the country. Six attended the first focus group and four the second. The same methodology and moderator were used for all focus groups. A second facilitator observed and recorded the group processes throughout each focus group.

### The focus groups

Focus groups have increased in popularity as a research method in the last two decades (19) and are increasingly used as a single research method as well as in studies which incorporate multiple methods (20). Focus groups provide an opportunity to gain information that would traditionally be sought through routes such as ethnography (21). The importance of focus groups is that the data they can generate extend far beyond a simple attempt to gain a collective view. An important aspect of this study was to try to understand how nurses and other practitioners involved in the care of patients with lymphoedema reach decisions concerning the complexities of managing lymphoedema/chronic oedema. Bloor *et al.* (22) argue that group or professional norms remain a major factor in determining behaviour, despite the increasing complexity and diversity of factors that may influence this process. It is in this context that an important aim of the focus groups was to allow the teasing out of previously taken for granted assumptions and to facilitate an exploration of difficult areas of professional practice that are often alluded to, but are rarely given opportunity for discussion, elaboration and challenge.

### Stage 1. Focussing and ranking of issues

A focussing exercise was undertaken at the beginning of each focus group. Focussing

exercises are intended to concentrate the group's attention on the research topic and seek to illuminate the assumptions that underpin individual and group beliefs on the topic area (23). A focussing question was posed: 'What are the challenges you face in managing patients with severe or complex lymphoedema/chronic oedema? (You may refer to an individual patient or to a number of patients)'. Each group was asked to brainstorm issues that arose when considering the question and responses were recorded by the second moderator on a flip chart. Each member of the group was then asked to choose five items from the identified list and rank them in order of importance (1 = most important to 5 = least important). This was performed on an individual basis to avoid the effects of group pressure on ranking.

### Stage 2. The discussion

The second stage sought to extend the discussion on the challenges of managing patients with complex lymphoedema/chronic oedema. This was achieved by returning to the issues raised during the focussing exercise. The principle aim was to illuminate attitudes, feelings and behaviour rather than specific events and therefore the discussion was focussed on professional approaches to challenging clinical situations thus seeking to extend and test the issues that had been identified in stage 1.

### Analysis

All interviews were tape recorded after having gained permission from the participants to do so. The process of data analysis used the 'Framework' method developed by the National Centre for Social Research (24). This is a matrix-based analytic method that facilitates rigorous and transparent data management so that all stages involved in the analysis can be systematically conducted. The framework classifies and organises data according to key themes, concepts and emergent categories. A thematic framework was constructed from the transcribed data comprising main themes and subdivided by a succession of related sub-topics. Once considered complete each main theme was entered into a thematic chart, with each case being given a column and each row denoting a sub-topic. Data were then synthesised within the thematic framework. The

themes and sub-topics were further refined, through familiarisation with the raw data and cross-sectional labelling, to construct five overarching categories and related themes. For additional rigour, the transcriptions were separately coded by two independent researchers and agreement sought on any disparity.

**Ethical considerations**

Ethical approval was applied for and granted by the relevant local ethics committees in accordance with the ethical guidelines of the 1975 Declaration of Helsinki. In addition, in the UK, in order to comply with National Health Service research governance guidance, research and development approval was obtained and permission was obtained from relevant NHS Trust managers. All participants gave written informed consent for the interviews and were assured that the information they provided would be treated confidentially, and would remain anonymous.

**RESULTS**

**The UK experience**

As outlined above, the first part of each focus group involved a focussing exercise in which the challenges faced when managing patients with severe or complex lymphoedema/chronic oedema were brainstormed and recorded on a flip chart. The priority issues raised by the two UK focus groups are presented in Table 1. The analysis of the overall focus group discussions identified four categories and their supporting themes. These are presented in Table 2.

**Table 1** Focus groups UK: issues identified and prioritised in response to the question ‘What are the challenges you face when managing patients with severe or complex chronic oedema?’

Focus group 1	Focus group 2
Ranked order of significance (1 most important to 5 least important)	Ranked order of significance (1 most important to 5 least important)
1. Compliance with treatment	1. Size of the patient
2. Weight	2. Compliance with treatment
3. Mobility restrictions	3. Cellulitis
4. Use of CDT and MLD	4. Problems of slippage with compression
5. Problems with compression bandages and hosiery	5. Rebound oedema

**Table 2** Categories and themes (UK)

Category	Themes
Category 1. A profile of complexity	Theme 1. The changing service profile Theme 2. The professional reality of increased complexity Theme 3. The bariatric patient as a complex case Theme 4. Cellulitis as a feature of complexity Theme 5. Psychological and social issues associated with complexity
Category 2. Professional challenges of managing complex patients	Theme 1. Joined up care Theme 2. Poor professional knowledge and skills Theme 3. Community nurses
Category 3. Using compression therapy by the specialist team	Theme 1. Problems with current methods of compression bandages Theme 2. Problems with current methods of compression hosiery
Category 4. Developing new compression methods for Lymphoedema	

**Category 1. A profile of complexity**

*The changing service profile*

There is a clear indication from the data that the patient profile within large lymphoedema services in the UK has changed in the last few years. The heightened awareness of the condition has led to an increase in patient referrals to all services. Although this has led to an expansion in the size and number of services, it has not kept pace with the increased complexity of the patient profile. Many patients present with co-morbidities and obesity that impact significantly on treatment. Treatment plans are increasingly complex and require much longer time periods to achieve results. Prolonged treatment adds to the pressure on clinical staff as well as concerns about the adequacy of funding.

There was evidence of a shift from treatment of cancer-related lymphoedema to the management of chronic oedema, causing one participant to consider renaming her service to a chronic oedema service rather than a lymphoedema service:



*...We are having a real shift from where we were when I started: 80% cancer, 20% non-cancer and now it is 50/50 and the non-cancer are taking over.*

Many of the services reported receiving referrals from outside of their geographical area that further stretched their resources. Many of these were complex patients who were referred very late and required prolonged periods of intensive treatment which was compounded by the difficulties of discharge back into the community. This was a major problem for all services except one which had an integrated service within their local community. The heightened profile of these lymphoedema services also led to greater expectations of what could be delivered without the necessary recognition and resource required to meet this change.

*...I get many more referrals than I used to and from further afield... it is becoming more and more difficult to see everyone referred to us and more difficult to discharge those we do see because there aren't the skills in the community to provide on-going care.*

#### *The professional reality of increased complexity*

There was recognition among the participants that the increasingly complex patients required a team with a remit that spanned both acute and community care. There was concern at the lack of access to other professionals who could provide advice and support. In addition, many participants understood that to effectively treat lymphoedema a holistic approach was required and there was considerable anxiety and frustration that this could not always be achieved. A number of participants stated that regional centres of excellence were required but all were concerned about the long-term support of patients once discharged and the problems of rapid rebound oedema. Participants identified that an important multi-disciplinary requirement included access to tissue viability nurses. Many of the lymphoedema therapist participants felt that they did not know how to treat complex wounds. For many participants, some of the greatest challenges were in increasing patient concordance with treatment and trying to cope with the realities of the many

psychosocial problems that impacted on their ability to provide effective care:

*...there are so many challenges in managing these patients. In addition to all the clinical problems there are all the issues of getting them to work with you on the treatment.*

An important issue that emerged was the lack of guidance or evidence to support management of complex patients. Traditional approaches to providing intensive treatment that had underpinned lymphoedema training simply did not fit with the reality of treating these patients, this led to enormous frustration.

*...We are all raised on the fact that you treat patients for a certain period of time but we are finding that this is not working for the complex patients. You need to keep them for longer. But that is a huge drain on your clinical resources; if you're doing them however many times a week, which is very, very difficult.*

Considerable discussion emerged about what was an effective outcome of treatment. Reliance on limb volume measurements was seen as the common method of evaluating the success of treatment. However, such measures were considered less useful in some cases where issues such as increased function, softening of tissues, reduced shaped distortion and reducing the likelihood of cellulitis were far more important. There was agreement that limb volume measurements were, in fact, highly varied and difficult to predict. It was also agreed that outcomes should vary according to what is important for the patient and that this should always be the governing factor. This was a challenge and a frustration when practitioners were required to show the success of treatment based on a set of criteria that did not necessarily fit with the realities of everyday practice.

*...I think one of the problems is that limb volume reduction doesn't correlate with quality of life. You can have somebody who feels a lot better and does not actually lose much fluid. But for others it's important.*

*...it could be shape distortion for someone who hasn't been able to get their shoe on, but then if you bandage and shape their foot then they can get some kind of footwear on and feel it is something that is acceptable to them. So, a lot of patients, the lymph volume has not gone down a lot but you have improved their shape distortion.*

What was perceived as a lack of professional interest in patients with lymphoedema was a major problem for the participants in this study. They felt that this contributed to the very late referral of many patients who, by the time they reached the service, were facing irreversible complications. Many reasons were thought to be contributing to this situation. Lack of professional knowledge was considered to be a problem that negatively influenced early detection and referral of patients. Many participants thought that professionals held negative views about whether treatment would improve the situation and tended to hold the belief that patients with lymphoedema were time consuming and therefore expensive to treat. Working towards a successful discharge and an effective plan of continuity of care was seen as a major hurdle by all participants.

#### *The bariatric patient as a complex case*

The proportion of morbidly obese patients was thought to be increasing dramatically in the participant's services with one therapist reporting that during a recent audit, 97% of patients in her clinic were classified as obese. Among the participants in this study, morbid obesity was always associated with a complex presentation of lymphoedema. The consequence of this was that treatment episodes were longer and the outcomes were often very poor or were not maintained. Participants agreed that guidance for this group of patients is particularly scant and that therapists often feel at a loss when providing treatment.

*...One patient is a real challenge ... she is 35 stone. She is a single mum with a child with learning difficulties ... She has severe shape distortion, lymphorrhoea and six admissions for cellulitis in the last year, She has wounds pouring fluid. Her housing is poor. It's this sort of massive challenge, where do you begin?*

A critical component considered to be essential in treatment was access to a bariatric service for advice on weight loss treatment programmes. In this study, good local support was not readily available. In addition, many patients were unable or unwilling to undergo treatment. The participants often undertook an advocacy role in trying to help patients to see how their obesity impacted on their condition and their long-term prognosis. Some participants recognised that for some patients their obesity defined them and consequently they were unwilling to change. There was also recognition that many patients became dependent on professional care for their lymphoedema and that this provided many different components. Improvement in their condition could lead to a reduction in the professional support that had become part of their social network. Attempts to use patient contracts to improve results had limited effect.

*...I could make this man better within 3 months if he would help me. The problem is the guy doesn't want to get better... I'm becoming a prop... he is not going to get better because he doesn't want to.*

Traditional approaches to intensive treatment require considerable adaption for bariatric patients. Fear of cardiac involvement led to extreme care in using compression that could shift large fluid volumes. Exercise regimens were reduced because patients were unable to undertake them and became exhausted. Staff found that these patients were physically challenging and arduous, often requiring two staff because of the weight of the limbs being treated. Patients required treatment on bariatric couches that were not available in all rooms of all services. Issues of patient hygiene and fungal infection in the groin area compounded the difficulties of treatment. It was also noted that it was difficult in the morbidly obese patients to determine the tissue changes that were occurring and the influence of manual lymphatic drainage (MLD). Limb circumference measurement and perometry measurements were also very difficult to undertake and possibly unreliable because of the procedural difficulties experienced.

A conflict for the participants in this study which generated considerable discussion was the ethical and professional issues of stopping

a treatment plan that was not working and was absorbing huge resource. This was compounded by the many psychosocial issues that obese patients experienced as well as the reality that the clinical situation would continue to spiral out of control if the level of intervention was reduced. This was clearly a highly emotive issue and one for which clinical guidance does not readily exist.

*... We are facing a stumbling block. She has been told she needs bariatric surgery but she is refusing and she will not diet... We have got rid of the cellulitis and lymphorrhoea but we know she will quickly break down again. We feel it is at crisis point... We did ask her to sign a contract and she did sign it... she did some of it but would not have the surgery.*

#### *Cellulitis as a feature of complexity*

Cellulitis was a defining feature of uncontrolled and complex chronic oedema. Participants reported that many patients have cyclical infections requiring hospitalisation and that there was a strong association with worsening lymphoedema after each episode of infection. Delayed referral for lymphoedema management was also associated with cellulitis as was the presence of lymphorrhoea.

Participants noted that there were considerable variations in the problems associated with the antibiotic policies for the treatment of cellulitis and long-term prophylaxis. In services where the therapists were able to prescribe antibiotics this was much less of an issue. A number of services had good multi-disciplinary teams who reviewed and endorsed the policies leading to greater uptake and compliance with GP prescribing of long-term antibiotics. However this was not the case in all areas. Some participants found GPs reluctant to prescribe antibiotics when recommended by a therapist even when an antibiotic policy was in place.

#### *Psychological and social issues associated with complexity*

Participants considered that the majority of patients described as having complex chronic oedema had social and psychological problems that contributed to the context of complexity, made treatment more difficult and influenced

outcomes. There is evidence from this study that the patient/professional relationship was negatively influenced in so far that a number of patients lacked the belief that the treatment they were undergoing would be effective. However, for many patients this belief must be seen against the reality of many months, or even years, of poor or inappropriate care that can erode the trust and belief that professionals could offer a realistic hope of an improved outcome. Many had been seen in many different parts of the health care system and offered different treatments with very varied effect. Most had been left to deteriorate and develop complications and were only sent to the lymphoedema services as a last attempt at treatment. The severity and complexity of the clinical problems many patients faced meant that undertaking an intensive treatment period was hugely costly in time and energy which for some patients was too great to consider. As a result, participants spoke of having to constantly alter or reduce the level of intervention so that patients could manage. This led to longer treatments and, in many cases, with less effect.

*... These are patients who don't easily comply with treatment; they can't... we have to amend treatment, because obviously ideally we do it daily, but they are exhausted and they can't manage to do it.*

Lack of patient knowledge about their condition and treatment was seen as a problem that affected concordance with treatment. A large part of the therapy role was in educating patients about their treatment and encouraging them to take ownership. Issues such as living alone were a major problem preventing the appropriate use of compression hosiery and skin hygiene. Poor housing and lack of help at home were associated with recurrent cellulitis, wounds and deterioration of the lymphoedema.

*... I think it is important for the patient to be in charge of the problem; and not the problem running the life of the patient. I think this will enable the patient to be one step ahead of his situation... Because the more in charge a patient becomes the more compliant the patient will be with treatment.*

Young patients with lymphoedema in particular faced issues of stigma and of people staring in public places. Compression garments were aesthetically unattractive to them and some sought to bandage at night rather than wearing hosiery during the day.

*...I have quite a lot of young 20 year olds that like to self bandage at night time, that is how they cope with it all.*

Traditional approaches to intensive treatment were not well accepted by young people and a number of reasons for this were identified by participants. For some, the treatment was too intrusive for their busy lives and the outcome was not considered sufficient to persuade them. The rigidity of booking systems was also a problem with some having to take annual leave to undergo treatment. For some, the slow rebound oedema that occurred after treatment caused them to consider that the effort of an intensive treatment was not worthwhile.

*...At the moment these young people are taking two weeks annual leave or they are taking sick leave to have this treatment, which is absolutely ridiculous. So you need something that ensures they are looking after themselves, living their lives, driving their cars, and then I think they are going to be more compliant.*

## **Category 2. Professional challenges of managing complex patients**

### *Joined up care*

A priority for improved lymphoedema care was the ability to provide continuity of care between services, particularly between specialist lymphoedema services and the community. There was a clear recognition of the need for multi-disciplinary complex case management and the extension of the current teams involved. Although participants valued their autonomous role as therapists, there were many times when they wanted access to support and advice.

Participants recognised that all complex patients should be treated by the specialist team but lack of resources and service configuration often prevented this. Services with link workers were able to achieve some success

in supporting care in the community. There were variations in admitting people for intensive treatment, and those participants without this facility recognised that it would be valuable to them. However inpatient services were costly and there was pressure to achieve rapid results when patients were admitted. Discharge programmes were varied. While one service might have a community element that allowed for community nurses to continue care at home with the support of the specialist nurse in a shared care model, other services could not offer this level of management.

Tissue viability specialists were frequently used for patients with chronic wounds and there was a growing recognition, by participants, of the duality of challenges faced by both lymphoedema and tissue viability specialists. All participants were aware of the need to provide evidence of outcomes of intervention and that resources will become ever scarcer in the NHS. Private providers of care were also facing the dilemma of reduced funding for patients while attempting to meet the increased expectation implicit in their packages of care. A central issue for all was the lack of a nationally agreed and applied tariff of charges that accurately reflected the work required to treat such complex patients.

### *Poor professional knowledge and skills*

There was an overall frustration among participants at the lack of professional knowledge and interest in lymphoedema. There was a consensus of views that such a lack of understanding and awareness leads not only to negative views about outcomes of treatment but also to inappropriate treatment choices such as diuretic therapy.

### *Community nurses*

Only one participant in this study was involved in a community-based service that had direct access to community nurses and was able to involve them in the treatment of patients. In this example, community nurses were trained in lymphoedema management and were able to undertake intensive and maintenance bandaging with the support of the specialist team. Training and updating were mandatory for community staff using a competency-based



framework. Participants agreed that services that were not based in a community setting had much greater difficulty in engaging community nurses for the purposes of long-term care. For many participants, local community nurses were either unwilling or were prevented from treating lymphoedema patients. Participants reported that community nurses were fearful of adapting the bandage techniques they were familiar with. Chronic oedema and lymphoedema management were not considered part of their role despite the reality that they had many patients with chronic oedema on their case loads who required daily dressings and bandaging for wet leaking legs that never improved.

Participants were generally agreed that a lack of education led to poor recognition of chronic oedema and methods of treatment. In this study, some of the major problems encountered by participants included; failure to bandage toes leading to toe and fore-foot swelling and lack of compression to the dorsum of the foot. Poor bandage technique was seen to be a major factor in increasing limb distortion. Community nurses were unfamiliar with full-length bandaging and very few were willing to undertake this.

*...Trying to get district nurses to take this on board is very difficult. They don't have the skills. Say toe bandaging to a district nurse and they run a mile. So we continue to get patients with great big dorsums, tiny little lower legs and swelling above the knee.*

There was general agreement that there was a lack of recognition that control of swelling was a major factor in reducing cyclical cellulitis which was a major challenge for many community nurses. Patients treated by community nurses were often frail with many co-morbidities and complex clinical and psychosocial problems. It was felt that these issues were compounded when patients who had undergone an intensive phase of treatment were unable to continue with bandaging in the community and as a consequence quickly deteriorated leading to negative attitudes towards lymphoedema treatment.

### Category 3. Using compression therapy by the specialist team

#### *Problems with current methods of compression bandages*

All participants recognised the central role that compression therapy played in treatment. However there was considerable debate about the contribution of MLD in different patient groups and recognition of the degree of creativity needed to solve some of the complex clinical problems.

*...for me there is a great issue about being unsure that MLD is particularly helpful. I'm not really convinced.*

General issues included the time spent on bandaging and the problems of bandage slippage that required frequent reapplication. All current bandages used by participants slipped following oedema reduction and cohesive bandages were used to extend the wear time. Participants described how they combined elastic and inelastic bandages and added hosiery to help prevent slippage.

*...No bandage would stay on because her shape distortion was just awful.....Our biggest problem was we needed to bandage to the thigh but the bandages slipped within one hour of putting them on. In the end we managed to bandage to her knee and then we got made to measure tights on top..... It wasn't the best.*

Bandage application techniques were modified for patients with limb distortion. Participants spent a great deal of time looking for and creating solutions with existing materials including cutting foam templates and chips to reduce fibrosis. All participants combined compression methods using bandages, hosiery, wraps and kinesio taping. Although there was a recognition that advanced materials were being produced for limb oedema, truncal oedema remained a major challenge with current compression bandages unable to adequately address this.

Bandaging skin folds caused particular concern because of the risks of pressure damage and the fungal infection if the areas of skin between the folds were not separated. Control of lymphorrhoea could be achieved

with compression although this could take a number of weeks in complex patients. Providing effective compression for bariatric patients and those with genital swelling was described as a great problem.

Participants faced a continual challenge in planning compression bandaging that patients were able to manage at home. Bilateral lower limb bandaging influenced the functional status of many patients and prevented patients driving their cars. Therapists recognised that many layers of traditional bandages were often required to achieve a good therapeutic effect.

*... my patients are wearing on one leg up to 20 bandages and they've got a shoe they can hardly walk in because its put together with Velcro ... you are limited.*

Bandaging of the arm was less frequently performed than lower limb compression in this study mainly because it was seen to be intrusive compared with wearing a sleeve. Common patient problems included the heaviness of the limb because of the number of bandages used and reduced flexibility and function. Intensive treatment of the arm, like that of the lower limb had unpredictable outcomes.

*...she lost very little the first time we bandaged. She has got about a 47% or 48% different arm. And she had recurrent cellulitis which made the arm bigger each time. So now we are trying to decide where to go from here.*

Providing patients with control over their compression was seen as a major goal and important in increasing concordance. Use of devices such as wraps were seen as a method of allowing self care and were particularly favoured if patients were unable to apply and remove hosiery. However, their appearance did not appeal to all.

#### *Problems with current methods of compression hosiery*

Participants recognised and appreciated access to the extended range of compression hosiery that was now available. Issues of measurement still proved difficult without access to perimeters and the correct choice of compression hosiery was not always quickly achieved.

Flat knit garments, because of their stiffness, were considered more effective at preventing rebound oedema but could be difficult to apply and remove. They were less aesthetically pleasing than 'lighter' circular knit garments. This was an issue for younger patients. Some of the newer flat knit garments were considered to have a better aesthetic appearance but were not so good at preventing rebound oedema.

Patients who had rapid rebound oedema were difficult to fit for hosiery. Limb size could change rapidly and custom-made garments did not always fit adequately when they were delivered. This was a significant budgetary issue for many participants. Correct fitting was considered to be of critical importance in improving concordance. The choice of garment was often influenced by the patient's ability to manage. Many patients were in a lower pressure garment than was ideal because of the difficulties they had in application and removal. This was a significant issue for bariatric patients many of whom did not fit into the standard range of garments despite the extension in sizes and styles that have been introduced. Many patients wearing hosiery required additional compression from bandaging or devices.

#### **Category 4. Developing new compression methods for lymphoedema**

The views of participants concerning what is needed in a new compression bandage system are aptly captured thus:

*... If I could put on a bandage that was going to stay in place, that was going to work, the patient was going to be able to carry on their normal life and hopefully I could bandage less frequently that would be very attractive to me and our service, and we could treat more patients.*

The views of participants regarding the required features of a new bandage system were that it must address a range of critically important patient-centred issues. In their view, new compression systems must have a greater flexibility to deal with the range of patients seen in clinical practice. The burden on specialist services is great and new compression systems must be simple and safe to use in both specialist and generalist settings as well as in self application by the patient or carer. Ease

of access and affordability are also key features. Current multi-layer systems are heavy and bulky and the potential to reduce this is imperative while retaining adequate pressure and stiffness. Slippage was seen as a common and frustrating problem for the patient and new materials must be constructed in a way that reduces this. In addition new bandage systems must be able to accommodate limb distortion without risk of skin trauma. Participants also felt strongly that problems with truncal oedema are not being effectively addressed through compression bandaging.

Participants stressed that the increased requirement for evidence to support practice was a very real pressure on procurement. They felt strongly that new bandage systems will require evidence of both clinical and cost effectiveness. This was felt to be particularly important in materials that are single use, bearing in mind that cotton inelastic bandages have historically been washed and reused despite the infection control and logistical issues of managing this in a hospital setting. It was agreed that a critical feature of new compression bandages will be whether they can help with the problem of rebound oedema and will have functionality that extends beyond discreet episodes of treatment to more prolonged treatment management.

**The Canadian experience**

*Ranking of issues of importance*

The priority issues raised during the focussing exercise in the focus groups are presented in Table 3. As with the UK, these issues were ranked in order of priority with 1 being the most important. The analysis of the combined data from both focus group discussions identified four categories and their supporting themes. These are presented in Table 4.

**Category 1. A profile of complexity**

*The challenge of unknown diagnosis*

Participants in the focus groups believed that chronic oedema and lymphoedema were an unknown problem to the general public in Canada. In addition, and more importantly, it was the consensus that the problem was not recognised by the medical and nursing professions. A basic differential diagnosis was often not performed and patients were frequently told their problem was due to obesity rather

**Table 3** Focus groups Canada: issues identified and prioritised in response to the question 'What are the challenges you face when managing patients with severe or complex chronic oedema?'

Focus group 1	Focus group 2
Ranked order of significance (1 most important to 5 least important)	Ranked order of significance (1 most important to 5 least important)
1. Not knowing how to treat chronic oedema with compression	1. Lack of specialist service
2. Lack of health coverage	2. Compression not used
3. Rural location difficult for accessing care	3. Complex patients with co-morbidities
4. Patient shame and social isolation	4. Patient beliefs about treatment
5. Poor professional knowledge	5. Lack of health insurance coverage

**Table 4** Categories and themes (Canada)

Category	Themes
Category 1. A profile of complexity	Theme 1. The challenge of the unknown diagnosis Theme 2. Clinical realities of complexity Theme 3. Psychosocial dilemmas of complexity
Category 2. Professional practice issues	Theme 1. Professional knowledge deficits Theme 2. Fear and frustration with treatment of lymphoedema
Category 3. Current treatment of chronic oedema	Theme 1. Strategies for managing wound exudate Theme 2. Current practice in the use of compression for chronic oedema
Category 4. Developing improved care for patients with lymphoedema	Theme 1. Improvements in health care delivery systems Theme 2. Improvements in compression therapy systems

than chronic oedema and that they should go away and lose weight:

*...I find that the condition itself is not taken seriously, and not so much by the patient ...I think by our health care system. ...I find the doctors say you've got this oedema, there's nothing we can do, lose weight.*

The lack of recognition was thought to be a major factor preventing adequate

reimbursement and access to treatment. Attitudes to oedema were also influenced by the speciality in which doctors worked. Lymphoedema did not register as an issue and there was a lack of recognition of lymphology as a medical speciality that required dedicated, specialised clinicians.

#### *Clinical realities of complexity*

Patients with chronic oedema had many different clinical problems contributing to their chronic oedema. Of particular importance were patients with long standing venous ulceration and diabetic foot ulceration. Many patients were described as having 'wet and leaking legs' although the true diagnosis was not defined. Multiple health and social problems, including poor concordance with therapy, further aggravated this profile.

*...He was in his late 50's and had lymphoedema, but he also had co-morbidities. He was an obese patient and he was diabetic as well. So he'd been treated over the years, on and off, for ulcers and different things. His adherence to the treatment plan was very poor. He was a real problem.*

#### *Psychosocial dilemmas of complexity*

Participants recognised the myriad of psychological and social issues that impacted on the patients' lives. Many lived in remote rural locations and were unable to access care, particularly during the winter. Health services were unable to provide home care and some patients received no compression during the winter months until they could attend clinics. This was of great concern to the participants who felt they were denying patients a basic standard of care.

Participants recounted how many patients felt shame and humiliation about their condition and were isolated and lonely in their communities. Patients were frequently unable to work leading to financial hardship and an inability to pay for treatment, a factor that further worsened their condition. Participants reported that patients felt helpless, hopeless and humiliated, feelings that a number of participants shared:

*There's hopelessness, and how could there not be, but I think it's on both parts. I think*

*it's on the part of the patient and the health professional as well. You feel hopeless as well because you are at a loss of how to treat such a massive limb with no resources.*

Patient beliefs about their condition and its treatment were a prominent part of the discussion. Lay beliefs were influenced by family and friends. Many believed that treatment would lead to amputation and death as this had been observed previously within communities. Some developed beliefs from inaccurate professional advice given to them by clinicians they trusted. Previously bad experiences with compression could have a significantly negative influence over their willingness to try new compression systems.

*If they've had a bad experience with compression in the past they can be really frightened about the visit. They are influenced by old wives tales passed down the years.*

Participants spoke of the difficulty of grasping the patient's view of their lymphoedema and told of treatment plans being prescribed that the patient was sometimes unable or unwilling to undertake. Participants frequently changed their plans or 'blended' treatment to meet their patient's needs. For young patients there were issues about undergoing treatment that was considered a problem of old age.

Issues of concordance were a prominent concern. Previous failed attempts at treatment were thought to be a major factor in determining whether or not patients would be concordant with treatment. Patients often tried to change their behaviour but tended to quickly revert which would lead to further deterioration.

*...I am not sure how deep the sense of hopelessness goes, if they have reached a point that they believe that there is no cure that nothing is going to help or work for them. It becomes difficult to motivate them.*

#### **Category 2. Professional practice issues** *Professional knowledge deficits*

Participants felt that a lack of recognition of lymphoedema as a medical problem was the



main reason why professional knowledge was poor. The participants reported that wound care and lymphoedema management were only taught in one medical curriculum in Canada, to their knowledge. However, it was felt that medical interest in the subject, particularly in younger doctors, was growing. Many more doctors recognised the knowledge and skills of therapists and turned to them for advice on management. However in Canada doctors remain the only group who can prescribe care. The participants had mixed views about changes to this status quo and some feared increased autonomy while others embraced it. All found themselves educating other professionals about the correct treatment for patients. For some, this extended to writing plans of care that the doctors simply signed. It was clear that the marginalisation of lymphoedema as a specialism affected participants greatly and led to a tangible lack of confidence within both focus groups. Participants were deeply concerned that their own knowledge base was insufficient to deal with the complex patients they treated.

#### *Fear and frustration with treatment of lymphoedema*

Fear and frustration were two dominating issues influencing professional practice. Lack of knowledge, coupled with the responsibility for making recommendations on treatment led the participants to feel vulnerable and exposed. The desire for multi-disciplinary services reflected these concerns. Many times there was reference to working at the edge of their competence. The health care system and reimbursement issues further aggravated this situation and much time and effort was taken up solving administrative problems. Participants recognised that in many situations they had to work outside of the system or use 'back-door' routes to access specialist care. They were aware that this was problematic and were anxious about talking about this in a public arena. The reimbursement system was a major frustration as many of the products they required were unavailable. Modification of products led to suboptimal treatment and poor outcomes exacerbating frustration for professionals and patients. Lack of treatment response led many patients to become upset and demanding, leading to feelings of professional failure and impotence:

*... We are the ones treating them every day facing all the issues and their frustration, every day we are on the frontline in this.*

### **Category 3. Current treatment of chronic oedema**

#### *Strategies for managing wound exudate and lymphorrhoea*

Central to the issue of managing chronic oedema for many participants was control of lymphorrhoea or 'wet legs' and wound exudate. The two subjects were often discussed synonymously despite the difference in cause and treatment. Therapists were concerned about the role of bacterial burden and when antibiotics should be used. Severe lymphorrhoea was tackled by using large absorbent dressings such as abdominal pads, when they could be supplied, and in some cases the use of diaper material that could be changed every few hours.

*... We have changed dressings on wet legs every three hours. Wash them, dry them off again. Hugely oedematous, but what do you do?*

*... I just get the super-duper abdominal patch, not the regular ones, I use a bandage that I can change regularly and put it on loosely.*

Participants reported that many patients required dressing changes every 8 hours. Issues of smell, hygiene and maceration were a major concern. Continuity and access to care were factors thought to influence whether control could be achieved and was often considered impossible for those in rural settings. Many patients had little option but to undertake self care placing a strain on families and those who did not have the necessary resource to take on this level of responsibility. Problematic patient groups included those with diabetic foot ulceration and obese, immobile patients. These patients were often unpopular because of the time and expense required to provide care.

#### *Current practice in the use of compression for chronic oedema*

Participants in this study felt that appropriate compression therapy was rarely used to

manage chronic oedema and lymphoedema in Canada.

*...I would say that the majority of patients who need compression, who could tolerate compression, are not getting it.*

In the collective view of the participants, this was due to a fundamental lack of awareness that compression should be the primary treatment. It was felt that this was symptomatic of the deficit in knowledge and skills.

*...Most patients don't get compression if they need it because people don't know how to apply it and because they won't do the right assessment, they just won't put it on. So it doesn't happen.*

Ineffective systems such as straight 'Tubigrip' were used cautiously and available multi-layer bandage systems were used although these were not being adapted for chronic oedema.

*...It's challenging getting enough compression going, and I tend to do a lot of 'Tubigrip' compression for that reason. Lower compression, so it takes longer, it will work eventually for most people, not all. Some people need higher levels of compression sooner than that.*

*...We had a lady the other week. Her legs were so wet. They had her on IV antibiotics for two weeks. The first thing I did was get some absorbent dressings and then I used a bit of 'Tubigrip' to get rid of the fluid. I find it's a good start.*

Common problems reported included increased swelling in the forefoot, toes and thigh of many patients. Thigh bandaging was viewed with anxiety and was not performed, nor was toe bandaging. There was a lack of awareness that compression could solve lymphorrhoea and reduce the burden of managing 'wet legs'. Dressings and antimicrobials were seen as the most important part of treating 'wet legs' with compression playing a very secondary role. Other practical strategies such as limb elevation and exercise used in chronic oedema management were not discussed. Access to, and reimbursement of, compression hosiery

was a major issue. Of particular concern was the small range of garments available and that did not meet the needs of patients.

#### **Category 4. Developing improved care for patients with lymphoedema**

##### *Improvements in health care delivery systems*

Participants felt that chronic oedema and lymphoedema care were in their infancy in Canada and in order for this to change many issues needed to be addressed. They expressed a real desire to work within multi-disciplinary teams for support and advice. For some, the solution was the development of a leg ulcer clinic. Others, who had already developed this type of service, expressed concerns that this had not solved the problems as the demand for treatment was so high and follow-up arrangements for patients were so poor. Community nursing services varied in their willingness to undertake compression although this was changing in some areas.

It was felt that fundamental to any change was increasing professional knowledge and skills. Participants felt that a campaign to increase awareness in Canada would help but recognised that the lack of services would be a problem if there was a sudden increase in demand. Education programmes needed to address all issues from diagnosis to treatment and conferences such as the Canadian Wound Care Association should be encouraged to include this within their programme.

##### *Improvements in compression therapy systems*

It was strongly felt that improvements in compression therapy were needed in Canada and must be accompanied by a comprehensive programme of education. Of particular concern was the ability to reduce the fear associated with compression therapy that pervades practice. The key opinion leaders in this study, who have the greatest experience of using compression within Canada, remained fearful of its use in many situations.

*...People are afraid to apply compression in the community because it's rural and they can't always get to a specialist and there's no consistency of application.*

Particular issues relate to the confidence of identifying peripheral arterial disease, which is

difficult when chronic oedema is present, and the ability to adapt compression to individual patient needs. Participants discussed the importance of having evidence for new compression systems. Of particular concern was the need to know the application pressures applied by a particular system. There is evidence from the discussion that this was an important reference point used to support the use of different compression systems. However, the concepts of elasticity and stiffness were not common vocabulary used to describe compression for these participants.

Some participants were using a new compression system (3M™ Coban™ 2 compression system) and experimenting with its use with very positive results. The geographical issues patients in Canada are considerable and many patients deliver their own care. Safe compression systems that can be used by patients at home are a key goal.

## DISCUSSION

The focus groups in this study clearly show the challenges faced by practitioners when managing the complex issues that are often inherent in patients with lymphoedema/chronic oedema. The challenges identified run the full gamut of professional experience and test the individual practitioner both in the UK and in Canada. Chief among these is the changing profile of lymphoedema, with increasing complexity outpacing the development of services, lengthening treatment times and putting pressure on resources as well as treatment guidelines particularly regarding the management of comorbidity including bariatric patients.

The data indicate a number of similarities between the UK and Canada. These include a lack of public awareness of lymphoedema/chronic oedema and poor professional knowledge leading to inadequate information, delayed diagnosis and inappropriate treatment. The issue of poor public and professional awareness and understanding forms a familiar context and is well documented in the literature (2,16,25–27). Poor understanding of treatment options, including compression, a lack of evidence and guidance to support practice, the difficulties of managing psychosocial problems and of ensuring patient concordance with treatment represent significant challenges for participants in both

countries, findings which, again, are supported by the literature (1,2,28,29).

There is clear evidence of differences that reflect the variations in service provision between the two countries. This study identified that specialist nurse/therapist led lymphoedema services are more developed in the UK although there are indications that it is far from adequate. In Canada, lymphoedema care is acknowledged to be in its infancy and because of a lack of dedicated lymphoedema services patients are seen in diverse settings with wound care and leg ulcer specialists often having to treat patients without appropriate skills and knowledge. Levels of autonomous practice differ between the two countries with practitioners in the UK leading services and prescribing and delivering care while in Canada service provision remains, for the most part, medically led. A significant finding of this study is that Canadian practitioners feel vulnerable and poorly supported and are mostly ambivalent regarding accepting greater responsibility within the context of care that currently exists in their country.

Very much linked to this is the expressed anxiety of Canadian participants about using compression bandaging compared with participants in the UK. An important finding of this study is that, in Canada, there is a lack of awareness of the central role of compression in the treatment of lymphoedema/chronic oedema and that appropriate compression is rarely used. This might reflect the structure of lymphoedema services and the very rural, geographically dispersed communities involved. The evidence from this study suggests that it might also point to less than adequate education and training of practitioners, the low level of autonomy and professional respect their role attracts and the poor access to support available to them.

A number of priorities of care and management are applicable to both Canada and the UK. There is a clear need, in both countries, for an integrated multi-disciplinary service approach that can link appropriate services, especially between primary and secondary provision thus ensuring effective discharge planning and continuity of care. Improving professional awareness and knowledge is recognised as being essential to timely diagnosis and appropriate treatment. This includes effective training and support in order to create a therapeutic

environment in which specialist practitioners can confidently manage patients with lymphoedema/chronic oedema including, and especially, compression therapy in its various forms. The economic situation being experienced around the world introduces added difficulties and challenges for patients, practitioners, health care providers as well as sources of funding and resources. There is now, more than ever, a need for innovative approaches to the development of cost effective, time efficient, compression bandaging systems that are light, flexible, can remain in situ for longer without slippage or loss of pressure and can make a major contribution to meeting the challenges of contemporary lymphoedema practice.

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