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The experience of patients with lymphoedema undergoing a period of compression bandaging in the UK and Canada using the 3M™ Coban™ 2 compression system

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ABSTRACT

This article reports on a qualitative study that explored the experience of patients who have undergone a period of complete decongestive therapy using the 3M™ Coban™ 2 compression system (Coban 2 system). Qualitative data were collected from 12 patients from the UK and 8 from Canada with a range of presentations of lymphoedema. Single semi-structured interviews were used and participants were asked questions relating to their experience of diagnosis, the impact of lymphoedema on their lives, previous treatment using multilayer lymphoedema bandaging and their experiences of the 3M™ Coban™ 2 system. Treatment with multilayer lymphoedema bandaging was seen as constraining in that it was tiring, time consuming, heavy, bulky and led to feelings of clumsiness and a restricted life. Treatment with the 3M™ Coban™ 2 system was reported as enabling in that it was quicker and easier to apply, increased mobility, enhanced patient confidence and provided a sense of control and well-being. The article also explores how aspects of the 3M™ Coban™ 2 system might be improved from the patient's point of view.

Key words: Complete decongestive therapy • Compression • Lymphoedema • Multilayer lymphoedema bandaging • Patient experience

Key Points

- the impact of lymphoedema on a person's life is influenced by two closely linked dimensions: the effects of the circumstances precipitating the onset of lymphoedema and the effects of the lymphoedema itself. These effects can be life altering and long lasting.

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INTRODUCTION

This article presents the findings of a qualitative study that explores the experiences of patients with lymphoedema undergoing a period of compression bandaging as part of complete decongestive therapy (CDT) using the 3M™ Coban™ 2 compression system (Coban 2 system). CDT has become widely accepted as the treatment of choice for lymphoedema of the upper and lower limbs (1) and comprises compression, manual lymphatic drainage (MLD), skin care and exercise with the single most important component being compression (2). Compression can be applied using bandages, hosiery or other means such as pumps. In the case of CDT, compression is traditionally achieved using inelastic, short-stretch bandages, which have the advantage of exerting high-pressure peaks while walking (massage effect) and low resting pressure (3).

There is a paucity of empirical studies to guide the practitioner regarding the use of compression. In response to this, international consensus has recommended the use of multilayer inelastic lymphoedema bandaging (MLLB) exerting a pressure greater than 45 mmHg undertaken daily by a trained specialist practitioner over a 2- to 4-week period as standard intensive therapy (4). Modifications to this standard, for patients with specific clinical needs, have been recommended (5). The long-term management of lymphoedema following a period of CDT is usually undertaken using compression hosiery, which helps to contain the swelling, reduces the likelihood of rebound oedema and also enhances self-care. The use of a combination of bandaging and hosiery has been shown to result in a greater initial and sustained volume reduction than hosiery alone (6). Given the chronicity of lymphoedema it is recognised that the success of any treatment regimen is critically dependent on the patient's concordance with therapy and involvement in the management of their own lymphoedema (7–9).

It is clear that any study of the patient's experience of compression bandaging should ideally be embedded in the patient's wider lived experience of lymphoedema. The impact of lymphoedema on a patient's life has generally been underestimated (10). There is, however, evidence from the literature to suggest that lymphoedema is increasingly recognised as a significant and complex problem that can represent a serious challenge to a person's quality of life (7,11). Quality of Life Studies have shown that patients with lymphoedema can have a wide range of psychological and physical difficulties including poor body image, anxiety, depression, embarrassment, impaired mobility and pain (12,13). The significance of quality of life studies is that they bring into focus not only the effects of lymphoedema but also how its treatment can have an impact on the lives of patients (14).

Lymphoedema of the arm following treatment for breast cancer-related lymphoedema (BCRL) presents particular psychosocial challenges including feelings of fear, anger and disappointment at the unexpected and rapid onset of the swelling (15). Many women express frustration at the limitations imposed by their swollen arm and can experience negative body image and reduced self-confidence (16). Studies in Canada show that the most difficult tasks for women with BCRL include activities often taken for granted as a part of every day life and can have a profound effect on women's work, leisure activities and relationships (17–20). Women have also spoken of the insensitivity and limited knowledge of health care professionals, the conflicting and limited information available and the lack of specialist treatment centres (21). Also highlighted are the time, financial costs and life-style disruption associated with lymphoedema treatment as well as concerns regarding its efficacy, which can, individually or collectively, act as barriers to concordance (21).

For many women with lower limb lymphoedema, following surgery for gynaecological cancer, lymphoedema has a negative impact on their self-image, finances, mobility and general well-being (22). Recent research shows that many of these women have a number of lymphoedema-specific unmet needs including the need for help with the physical burden of this condition (23). In a review that exclusively examines men with lymphoedema, those with lower limb swelling speak of the challenge of adjusting to wearing compression stockings, of having to slow down in daily life and of the impact on their social and leisure activities because of the heaviness of the affected limb. They also talk of the demands on their time and the need to adjust their daily routines to accommodate treatment regimes (24).

The 3M™ Coban™ 2 compression system

The 3M™ Coban 2 system was initially developed for the treatment of chronic venous leg ulcers. The system consists of a comfort layer comprising medical foam laminated to a cohesive bandage and compression layer. The reported advantages of this system are its comfort, low slippage potential, lightness, lack of bulk and the ability to remain in situ for longer, thus requiring less frequent applications. These features have the potential to increase mobility,

Key Points

- differences in health care systems notwithstanding, searching for a diagnosis and treatment was a challenge for participants in both the UK and Canada with many suffering the effects of their swelling and associated ill health, including cellulitis, for many years before being correctly diagnosed.
- traditional compression therapy using MLLB, although effective at reducing swelling, is viewed as tiring, time consuming, heavy, bulky and restricting by patients in Canada and the UK.
- while its integrated construction is a distinct strength, the 3M™ Coban™ 2 compression system did give rise to some issues, for example, feelings of confinement, increased pressure, tightness, excessive heat, itching, as well as issues relating to its disposal.
- the 3M™ Coban™ 2 compression system reduced swelling for the majority of patients. However, the dominant advantages of this system over others, in the extensive experience of the participants, are its ease of application, its lightness, neatness, flexibility and ability to facilitate mobility.

enhance quality of life and maximise treatment concordance, which collectively can have a beneficial effect on treatment outcomes. The Coban 2 system has been modified to meet the needs of patients with lymphoedema who have more extreme leg shapes and sizes than people with leg ulceration. The modifications include increasing the range of bandage widths and making adaptations to the application technique. The system has been designed to provide a high working pressure and low resting pressure, features considered important in a compression system and which have been confirmed by interface bandage pressure measurement.

MATERIALS AND METHODS

Aim

The aim of this study was to explore the experience of patients with lymphoedema who had undergone a period of compression bandaging using the Coban 2 system and to use the findings to make recommendations for management and care.

Secondary aims

- Describe and seek to understand the experience of patients with lymphoedema requiring treatment with compression bandaging.
- Explore the impact that living with compression bandaging has on day-to-day life.
- Explore the patient's understanding of compression bandaging and their expectations of treatment outcomes.
- Explore differences in the experience of patients from diverse backgrounds with a range of presentations of lymphoedema.

Design

This study involved the use of a descriptive qualitative methodology using semi-structured digitally recorded interviews to capture the experiences of participants undergoing compression therapy using the Coban 2 system. To explore the experiences of patients from different health care systems, participants were drawn from collaborating lymphoedema services within NHS Trusts in England and Wales (UK) and from clinician-led services in Canada. Participants were selected by practitioners and were eligible to take part in the study if they were over the age of 18, had a diagnosis of primary or secondary lymphoedema and showed a clinical need for CDT. An ability to give informed written consent and to speak and understand English for the interview were also required. There were no specific exclusion criteria. Compression was applied for a 19-day period according to clinical need and adaptations and modifications to the bandage system by specialist practitioners were permitted. Each patient was interviewed once at the conclusion of the treatment period.

Analysis

The process of data analysis used the 'Framework' method developed by the National Centre for Social Research (25). 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. In this study, a thematic framework was constructed from the transcribed data comprising main themes and subdivided by a succession of related subtopics. 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 was then synthesised within the thematic framework. The themes and subtopics were further refined, through familiarisation with the raw data and cross-sectional labelling, to construct five overarching categories and related themes.

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 sought from relevant NHS Trust managers. All participants gave written informed consent for the interviews and were assured that the information they provided about the care they were receiving would be treated confidentially and would remain anonymous.

RESULTS

Twenty patient participants were recruited to this study, 12 from the UK and 8 from Canada.

Table 1 sets out the key clinical and social characteristics of the participants from the UK and Table 2 of those from Canada.

Categories and themes

The results are presented within five overarching categories with their related themes (Table 3). The first category entitled *Living with lymphoedema* explores the participant's real life experiences of lymphoedema. The second category, *Treatment as constraint,* focuses on how the standard compression treatment, using MLLB, impacted on the everyday lives of the participants. The third category, *Treatment as enabler,* tells the story of how the use of the Coban 2 system influenced the participant's physical and psychological well-being. The fourth category, *The 3M™ Coban™ 2 compression system experience,* explores the participant's experience of using the Coban 2 system. Category 5, *Improving the 3M™ Coban™ 2 compression system,* sets out how the product might be improved based on the experiences of the patient.

Category 1: Living with lymphoedema

Searching for diagnosis and treatment. Finding a diagnosis and securing treatment was a challenge for many of the participants both in the UK and Canada. The data shows how many had suffered swelling and associated ill health for many years before being correctly diagnosed (mainly those with non BCRL). Their experiences are often characterised by frustration and anxiety. Examples include one participant who had polio as a child and first became aware of swelling in her leg 50 years ago:

> *... I first remember the swelling about 50 years ago, but it got worse after I had children. I just put up with it.... I was told it was lymphoedema about 4 years ago. I managed to get NHS funding for proper treatment 2 years ago after my local MP got involved (P1 UK).*

In Canada, following radiotherapy and chemotherapy for anal cancer one participant developed swelling in both legs but lymphoedema was not diagnosed until he was admitted to hospital with septicaemia:

> *... I was very seriously ill with multiple organ failure and was in hospital for eight months. Even then my wife had to fight with our doctor for treatment (for lymphoedema). I was given water tablets at one point ... they didn't work. We heard about compression stockings from a technician in the hospital but we had to fight for a referral to the lymphoedema people. We were told nothing about lymphoedema in oncology; I think if they work in oncology they should know about lymphoedema (P7 Canada).*

A participant with swelling of his right leg for 20 years tells of being diagnosed and treated for sarcoidosis. When eventually referred to a lymphoedema clinic in 2009 he was told that his lymphoedema had been treated inappropriately:

> *... I've had this for 20 years ... only found out what it was last year ... I'd never heard of lymphoedema. You trust professionals to do the best they can for you, but I think a lot of them are not up to speed on lymphoedema (P5 UK).*

The experience of participants with BCRL was similar in the UK and Canada. Generally, they were forewarned of the possibility of developing lymphoedema and in all cases except one it was noticed and diagnosed promptly. If anything, they received too much information (usually before breast surgery) when they were already apprehensive and one describes how she believed:

> *... Bogged down with it all and I didn't take much of it in (P6 UK).*

The one exception was a Canadian participant who was forewarned about lymphoedema and realised what might be happening when she first noticed the swelling soon after surgery. However:

> *... I wasn't told it was lymphoedema by any of the doctors who saw me at my six monthly reviews. I got no treatment. Then the swelling got a lot worse because I got cellulitis and had to be admitted for IV antibiotics. They referred me to a therapist then. (P4 Canada).*

An altered life. For all the participants, this theme has two significant dimensions. The first relates to the events precipitating the onset of lymphoedema, which in the case of this study

Table 1 Clinical and social characteristics of participants (P) from the UK

	P 1	P 2	P 3	P 4	P 5	P 6	P 7	P 8	P 9	P 10	P 11	P 12
Gender	F	F	F	M	M	F	F	F	F	M	M	F
Age (years)	71	61	52	46	58	64	58	67	61	79	54	68
Site of lymphoedema	Left whole leg	Both legs	Right whole leg	Both legs	Both lower legs	Right arm	Right arm	Right arm	Both legs up to trunk	Both legs	Right leg	Right arm
Cause of lymphoedema	Polio as a child	Radical hysterectomy in 1998	Primary: First appeared 30 years ago	Extensive burns trauma at age 28	Sarcoidosis primary: Has had untreated lymphoedema for 20 years	Right radical mastectomy 6 years ago	Lumpectomy, chemotherapy and radiotherapy 6 years ago	Lumpectomy 10 years ago	Primary	Stroke 3 years ago, worsening venous swelling	Primary	Radical mastectomy, chemotherapy and radiotherapy in 2006
ISL stage	ISL 3	ISL 2	ISL 3	ISL 2	ISL3	ISL 3	ISL 2	ISL 3	ISL 3	ISL 3	ISL 2	ISL 2
Family support	Lives alone. Widowed 21 years ago	Lives with husband	Lives with children. Daughter has Down's syndrome	Lives alone	Lives with wife	Lives with husband	Lives with husband	Widow, lives alone	Lives with husband	Lives with wife who is immobile following accident	Lives with wife	Lives with husband
Work status	Retired	Never worked	Full-time nurse	Unable to work		Retired	Part-time music teacher	Retired	Full-time teacher	Retired	Works full time	Retired

F, Female; M, male; ISL, International Society of Lymphology.

Table 2 Clinical and social characteristics of participants (P) from Canada

	P 1	P 2	P 3	P 4	P 5	P 6	P 7	P 8
Gender	F	F	F	F	F	M	M	M
Age (years)	70	67	77	66	57	33	45	77
Site of lymphoedema	Both legs	Both legs	Both legs	Right arm	Right arm	Left leg	Both legs	Both legs, with some swelling of both arms
Cause of lymphoedema	Primary: Always had big legs	Venous insufficiency. primary: First noticed swelling in her 20s.	Swelling first appeared 5 years ago. ? Cause	Mastectomy, chemotherapy and radiotherapy 1995	Right radical mastectomy 5 years ago followed by chemotherapy and radiotherapy	Primary: First appeared when 16 years old	Cancer of anal canal treated with chemotherapy and radiotherapy 5 years ago. Swelling appeared 3 years ago.	Does not know cause. Had groin surgery 5 years ago for extensive infection.
ISL stage	ISL 3	ISL 2	ISL 3	ISL 2	ISL 3	ISL 2	ISL 3	ISL 3
Family support	Lives with husband	Lives with husband	Lives alone (Widow)	Lives with her son temporarily before building her own house	Lives with husband and three sons	Lives with wife and 1-year-old son	Lives with wife	Lives alone
Work status	Retired	Retired	Retired	Retired	Retired	Works full time as a Public Health Inspector	Unable to work	Semi retired. Runs his own business

ISL, International Society of Lymphology.

Table 3 Categories and themes

Category	Themes
Living with lymphoedema	Searching for diagnosis and treatment An altered life Hiding it from others
Treatment as constraint	Tiring and time consuming Feeling heavy, bulky and clumsy A restricted life
Treatment as enabler	Quicker and easier Decreased swelling, increased mobility Increasing confidence, regaining control and well-being
The 3M-ORS experience	Understanding and expectations of 3M-ORS Experiencing 3M-ORS
Improving 3M-ORS	Recommendations for improvement

group range from the unknown, the traumatic, the terrifying, the unexpected and the distressing. Many participants are still coping with the long-lasting effects of these life-altering events. The second dimension relates to how their lives had been altered by lymphoedema itself. The effects of either one of these dimensions, or often a combination of both, ranged from psychosocial problems to a loss of mobility either in getting around (lymphoedema of the legs) or in managing tasks involving upper limb strength or dexterity (lymphoedema of the arm). It was clear from the data that such effects contributed to an impaired level of psychological or physical functioning that resulted, for some, in profound sadness, depression and an inability to do the things they wanted to do.

> *. . . I sit down to do most things . . . I find it difficult to manoeuvre because I'm always carrying this heavy weight about (P2 UK).*
>
> *. . . it makes me feel tired, cheesed off, sad and depressed. I think of myself as being young but my legs as old. I want to do things but I can't (P6 Canada).*

Loss of independence and a consequent dependence on others was clearly dispiriting to many participants and one describes how much he came to rely on his wife for almost everything:

> *. . . My wife had to help me clean myself up especially my legs because they would smell. She would help me to get my stockings and trousers on. You feel very dependent . . . . It does upset me . . . . I thought why am I bothering? I can't go on like this (P5 UK).*

For a number of others having to give up work was, understandably, a major upheaval in their lives. One participant who suffers the long-lasting effects of severe burns as well as gross swelling of his legs expresses his feelings:

> *. . . I was in the building trade, and had to give it all up. I feel very down some days. I'm just not happy with how I am. I feel it's destroyed my life. I always enjoyed working outside. I had a good set of mates, enjoyed what I did. I didn't have a trade but I was a general labourer. One day I had someone come here and lay a new path outside the house. As I was watching him I just started crying. I just wished it was me alongside him, working (P4 UK).*

A Canadian participant who had his own business in the building trade can no longer work and believes the loss of the breadwinner role greatly:

> *. . . I can't work; I can't support my own family. I feel bad about that, I just feel sad and anxious all of the time (P7 Canada).*

However, the dominant sense that comes through from these interviews is the stoicism and sometimes almost heroic determination not to let lymphoedema alter their lives more than is necessary, as this 66-year-old woman with BCRL explains:

> *. . .Even though there were times I had difficulties and got very frustrated I never let myself get depressed. I think you have to realise that you have a problem and you just have to deal with it (P4 Canada).*

Hiding it from others. The majority of participants were aware of the effect of their swollen limb on others and ultimately on themselves. The appearance of their affected limb(s) was clearly a factor that influenced their emotional and social interactions. Emotions ranged from embarrassment to irritation to self-imposed isolation. Almost all took steps to hide their swelling to some degree in the social situation, either physically or in how they explained lymphoedema to others.

> *. . . I feel embarrassed. I'm out with all these people and I've got this huge arm and in my sleeve it looks even more obvious. It does bother me (P4 Canada).*

> *. . . when people see me coming I always feel like they see my leg and not me, it's so huge. They are mesmerised by it . . . . I am a nurse practitioner and when I see a patient the first thing they say is 'what happened to your leg?' It totally throws the whole balance of the interaction . . . . It's not that I am embarrassed about it . . . . I just get sick and tired of explaining it . . . sometimes I really can't be bothered and I tell them I broke it or something . . . it's such a boring story (P3 UK).*

Category 2: Treatment as constraint

Tiring and time consuming. The participants in this study were all, except in one instance, experienced in undergoing CDT. Some had several courses over the years. The treatment experience varied but the majority described it as positive, mainly because of the MLD component and the success achieved in reducing the swelling albeit, for most, it was for a limited period. The general consensus, however, was that the standard compression therapy using MLLB was time consuming and tiring.

> *. . . it takes up a lot of the day . . . with the journey and everything it can take four hours or so . . . . I'm wiped out when I get back home (P2 UK).*

> *. . . I went back and forth for about five months. I was being treated for a foot ulcer and having wrapping at the same time. It was a lot of travelling and took a lot out of my day (P2 Canada).*

Feeling heavy, bulky and clumsy. The dominant feeling expressed by participants about the MLLB was that it was heavy, bulky and as a consequence left them feeling clumsy. It was often the appearance of bulk as well as the sensation of heaviness that many found off-putting as together they tended to emphasise their already swollen limb:

> *. . . when I first came here they had all this stuff on a table. I thought they were just showing me a range of different bandages . . . then they said it was all going on my leg. I couldn't believe it (P5 UK).*

> *. . . there were lots of layers which worked fine but it was very bulky. It was a nuisance because they wrapped my feet and I couldn't wear shoes and I couldn't walk anywhere (P3 Canada).*

> *. . . I found it quite clumsy when it was on, all the layers. It was difficult in bed and getting up and down stairs (P3 UK).*

A restricted life. The experiences of participants of the standard CDT using MLLB are varied and, as might be expected, very individual. Generally, participants found that the treatment was effective in reducing their swelling, but the size, weight and bulkiness of the bandaged limb was, for almost all participants, a major restriction on their lives.

> *. . . The bandaging was very restrictive, it was uncomfortable and hot. It did its job but it was very constricting (P6 UK).*

> *. . . It was very bulky with all the layers, very awkward. It made me feel handicapped, you know what I mean? But at least I was able to get up in the morning and walk (P1 Canada).*

> *. . . I had huge things, all the padding and I mean huge. I couldn't wear trousers and I wore size 14 slippers on my feet . . . mobility was very difficult because of the constriction that you had with bending the leg . . . my wife had to lift my legs into the car (P5 UK).*

> *. . . With the old wraps it was very difficult to do the things I wanted to do, like house cleaning. I just couldn't bring myself to do it; it was such an effort to be on my feet that long (P2 Canada).*

For some, the cumulative effect of a restricted life led to non concordance with treatment:

> *. . . I have to work. I am in a hot busy kitchen all day, this treatment is impossible for me. I had never completed a course of treatment; it wasn't possible (P11 UK).*

> *. . . things are difficult sometimes; I know I can do things differently and probably better, for me anyway. I have a nurse who helps me and we play around with the bandages to make it easier for me. It doesn't seem to make any difference to the swelling (P8 Canada).*

Category 3: Treatment as enabler

Quicker and easier. A dominant observation of the Coban 2 system was how much quicker and easier it was to have it applied compared with MLLB. For many participants this was an important improvement as it was less time consuming and less taxing physically and emotionally, both for themselves and the clinicians involved. Another observation made by a number of participants with arm lymphoedema relates to the neat appearance of the finished bandage. The untidiness of the standard bandage system, once it had been in situ for a few days, was a frequent observation and the Coban 2 system seemed to offer a welcome solution to this.

> *. . . it seemed easier to get on . . . it was less cumbersome and much neater (P1 UK).*

> *. . . they are so much easier for the therapist to put them on and honestly you don't know they are on when she has finished (P3 Canada).*

> *. . . it's much easier to get on. It is so flexible and manageable . . . the bandaging used to be difficult for me but it's so much better with the new bandage (P12 UK).*

> *. . . I remember the first time I had it put on, it was so quick and neat, I couldn't believe how quick it was (P5 Canada).*

Decreased swelling and increased mobility. Of all the differences between the Coban 2 system and MLLB reported by participants, the positive impact that the Coban 2 system had on their swelling and also on their mobility were the most significant in terms of enabling participants to regain aspects of their lives they had previously to forego. For many, it was the speed of improvement in their swelling, rather than the volume, that was most noticeable. In addition, the combination of a quicker reduction in swelling and the more compact integrated construction of the bandage brought to many a more speedy improvement in mobility.

> *. . . I was surprised at how quickly it worked . . . . I said look at that leg! It didn't look like my leg . . . . I can get my favourite trousers on now and I drove the car the other day . . . haven't been able to for a while (P3 UK).*

> *. . . It worked! My leg looked normal for the first time in a long time. Even my pain had gone. By the sixth day I was able to put my hand inside the wrap right down to my knee (P7 Canada)*

> *. . . it's made such a difference. The swelling and the leakage have really improved but best of all I can actually walk again by bending my knees. I can wear normal trousers and I got my shoes on (P5 UK).*

> *. . . It has really amazed me, when it came off the other day I said 'look I have knuckles on my hand!' I haven't seen them for 15 years (P5 Canada).*

Increased confidence, regaining control and well-being. It was clear from the data that the past experiences of participants had a cumulative negative impact on their self-esteem and self-confidence. The stories told of living with lymphoedema, including undergoing the necessary treatment, paint a picture of having to make compromises on almost every aspect of their lives including personal appearance, social life, working life and levels of activity. While there is evidence of a quiet determination to do the best they can under often difficult and challenging circumstances, the toll on levels of self-confidence and emotional well-being was clear.

The experience of the participants of the Coban 2 system is significant in that it shows a renewed sense of self that seems to be generated by regaining some control over their lymphoedema through the new bandaging system. The reduced swelling and the lighter, less obtrusive, more flexible bandage, which was less likely to slip, brought about an increased self-confidence and a more positive outlook.

> *... it always feels firmer, and stays up a lot better. I can drive again, I can do more around the house, and I do feel a lot better about things (P3 UK).*

> *... it stayed in place, it was more comfortable and I was able to wear my normal clothes and not the big sloppy pants I used to put on (P2 Canada).*

> *... I suppose this bandage wasn't any better than the other one in getting the swelling down. It's just the whole thing is lighter and it still gets the job done. I had a shower this morning. It just makes me feel good, happy about myself (P UK).*

> *... I can wear blouses and jackets I couldn't before, I can do my house cleaning and that means so much to me but best of all I can sleep for eight hours straight where I couldn't before. That is such a blessing (P3 Canada).*

> *... I have lost two litres of fluid, my leg is lighter to walk on, I'm wearing my own shoes, it's less noticeable, I'm wearing trousers again, psychologically I am boosted, it's not just physical (P11 UK).*

Category 4: The 3M™ Coban™ 2 compression system experience

Understanding and expectations of the 3m™ Coban™ 2 compression system. The treatment regime and how the Coban 2 system works were explained to all participants before the commencement of CDT. Patient's understanding and expectations were explored at the interview at the completion of the treatment. Most participants had a very basic understanding of compression:

> *... it squashes all the toxic fluid out (UK);*

> *... it keeps your legs slim (Canada);*

> *... it gets rid of the fluid out of your legs (UK);*

> *... it decreases the swelling but I'm not sure how it works (Canada);*

The expectations of treatment outcomes were almost exclusively talked of in terms of hopes and possibly reflect the often challenging experiences of previous lymphoedema treatment:

> *... I didn't really know what to expect but I hoped the swelling would be more easily controlled (P2 UK).*

> *... I hoped that, although I know my lymphoedema can't be cured, the new treatment would at least make it easier to manage (P3 Canada).*

> *... I remember hoping that the swelling would be reduced for longer and my quality of life made a little better (P4 UK).*

> *... I hoped it would help me to be more mobile and the swelling would come down more permanently (P6 Canada).*

Experiencing the 3M™ Coban™ 2 compression system. The experience of participants varied depending on the patient's clinical and personal situations, but was generally positive. Some issues were the result of the integrated structure of the bandage. For example, a number of participants felt, uncomfortable when their toes were 'encased' in the bandage that tended to cause irritation especially at night. Heat and smell similar to liniment were also a problem for some. Others experienced intense pressure around toes and ankle and some relieved this by cutting around the area with scissors because they could not remove the bandage as they previously would have done with the standard system. Intense itching was noted by a few patients, especially at night. Of the 20 participants in this study, just one (UK) found the itching so bad that it became painful:

> *... I found the feeling of tightness really bad I had to cut the wrist area to ease it. And the itching was really unpleasant and painful for at least eleven of the twenty days I had the treatment. To be honest I would prefer not to go through it again unless it was absolutely necessary (P7 UK).*

Although slippage was noted by a few participants, all those affected thought it was probably the result of the rapid reduction in swelling.

There was concern about bandages being discarded after use and many thought this was wasteful both financially and environmentally. Despite this, in general the experience of participants of the Coban 2 system was a positive one with the main distinction from MLLB being identified as its lightness, neatness and flexibility enabling mobility and improving quality of life:

> *. . . I just felt my leg was so light I didn't know the bandage was there. It was easier to do things. I would never want to go back to the old system (P7 Canada).*

Category 5: Improving the 3M™ Coban™ 2 compression system

Recommendations for improvement. Participants made a number of observations about their treatment with the Coban 2 system although the majority described their experience as positive and thought there was little needed to improve the bandage system. As mentioned previously, for some participants the heat generated by the bandage was uncomfortable and the itching many experienced was thought to be linked to this. Modifications that would reduce the heat and itching were thought to be an important priority.

A participant with lymphoedema of the arm and hand and another with swelling of the leg and foot felt that a glove would benefit those with swollen hands and a boot would help those with swollen feet. In addition, it was thought that the production of a range of bandage widths would enhance the bandaging process especially around joints and toes.

A number of Canadian participants thought the system would be improved if it was modified to enable patients to apply it themselves. Self-bandaging was a far more common experience for Canadian participants. There are a number of examples from the data where Canadian participants look for improvements in the system which would facilitate self-bandaging, whereas there are no examples of this from the UK data.

DISCUSSION

This study has examined the experience of two groups of participants, one group in the UK and one in Canada, undergoing CDT. It was considered important to ground these accounts within the context of each patient's own experience of living with lymphoedema. The impact of lymphoedema on a person's life is influenced by two closely linked dimensions; the effects of the circumstances precipitating the onset of lymphoedema and the effects of the lymphoedema itself. This study shows that these effects can be life altering and long lasting. The participant's stories of delayed diagnosis, struggles for treatment and the difficulties of day-to-day living with a grossly swollen limb support the findings of previous studies (26,27). Equally, the powerful presence of the cause of the lymphoedema and the impact this has on how an individual lives with the condition, including its treatment, mirror Carter's observation that separating out the cause of the lymphoedema from the lived experience of lymphoedema can be difficult (21).

Experience of MLLB was similar across all participants in the UK and Canada alike. Although it was effective at reducing swelling, it was tiring, time consuming, heavy and bulky. This resulted in a loss of independence and a restricted life and, in some cases, poor concordance with treatment. The restricting and costly nature of CDT using MLLB for the patient, both financially and in terms of time, is acknowledged in the quality of life literature (14,21). It has been reported that a comprehensive intervention consisting of skin care, MLD, MLLB and exercise can take approximately 4 hours/day to complete (28).

Problems of concordance were evident with a minority of participants when recounting their experiences of CDT using MLLB. Concordance is extremely important if treatment is to be effective (7,8) and studies have shown increased reductions in swelling with increased concordance with CDT (28). Perceived problems of discomfort and a restricted life with MLLB may have contributed to reduced concordance as low patient satisfaction with treatment has been shown to adversely affect concordance (29). Concordance has also been shown to be contingent on the patient understanding their treatment including likely outcomes and any anticipated problems (29). The understanding of compression showed by participants in this study was quite basic. However, this may not only reflect the complexity of lymphoedema and its treatment but also willingness on the part of the participants to defer to professionals for this aspect of their management.

Part of the answer might lie in the sometimes overwhelming burden, for patients and their carers, of the physical nature of coping with a grossly swollen limb, especially when applying compression. Assessment and advice is clearly needed in these circumstances and strategies to identify such lymphoedema-specific unmet needs (23) could be beneficial to patient, carer and professional. Equally, promoting an understanding of lymphoedema treatment in general and compression in particular, so that patients become knowledgeable contributors in their own care, as far as they are able, has been shown to be important in enhancing patient well-being and concordance with treatment (29,30).

The participants in this study received CDT using the Coban 2 system and while its integrated nature was seen as a distinct strength it did give rise to some issues, for example, feelings of confinement, increased pressure, tightness and excessive heat. However, the participant experience of the Coban 2 system was almost universally positive. At the heart of this is its ease of application, its lightness, neatness, flexibility and its ability to facilitate mobility in both lower and upper limb lymphoedema, all features that quality of life research report as being important (31). In addition, the subjective reporting of swelling reduction, in most cases, was that it was rapid and demonstrable. Although such a reduction is not necessarily responsible for an improvement in quality of life (12,32,33), it appeared to have a beneficial effect on morale, optimism and motivation which reflect findings elsewhere in which a reduction in limb volume brought about more positive patient perceptions of their lymphoedema (15).

This study highlights the patient experience of CDT using both MLLB and a new integrated system, the 3M™ Coban 2 system. The findings should be viewed with caution because of the relatively small participant group and it should be borne in mind that the participants were selected by their lymphoedema specialists/therapists. However, the study brings together a range of insights that enhance understanding of this central component of the treatment of lymphoedema and its effect on the patient as well as their swollen limb.

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