Climate and Climatic Variations’ Impact on Lymphoedema: Patient Perspective

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Abstract: Lymphoedema is a chronic and dynamic condition that requires the investment of time and resources to appropriately manage. It fluctuates in response to illness, activity, and age, as well as in response to environmental conditions. This qualitative study explored the impact of the climate and climatic variations on lymphoedema. Focus groups were completed with patients (n = 12) and therapists (n = 7) to explore, in depth, their experiences of managing lymphoedema throughout the year. The results suggested that heat and humidity definitely alter the severity of lymphoedema, and a range of individual strategies are required in order to control symptoms. Central to effectively managing lymphoedema is the notion that every body is different and every lymphoedema is different, and therefore understanding one’s own body, what it needs, and what resources are available is essential in maintaining lymphoedema in the face of climate change.

Keywords: climate; climate change; lymphoedema; seasonal variation; symptoms

1. Introduction

Lymphoedema is a significant problem worldwide and results in a substantial burden on both the affected individual and national and international health services [1]. Lymphoedema results from a failure of the lymphatic system to cope with the load of extracellular fluid [2,3]. Lymphoedema is a lifelong condition that requires ongoing management to prevent disease progression. There are no curative treatments, therefore, conservative management is applied, including compression garments, bandaging, manual lymphatic drainage, laser therapy, skin care, and exercise [4]. Stasis of the lymph fluid increases the risk of infections and, as such, cellulitis is a common complication of lymphoedema.

Climate change is said to be the largest threat to health in this century [5–7]. Impacts are predicted to indirectly impact health systems, cause increased adverse weather events, and contribute to direct health impacts, including an increased core temperature, endocrine dysfunction, and dehydration [8–10]. Despite this knowledge, gaps remain in understanding the epidemiology and physiological response to heat, humidity, and other extreme weather events, especially among vulnerable groups. There also remain gaps in the knowledge of which interventions can protect people against heat and extreme weather conditions.

When the temperature increases, vasodilation occurs to increase blood flow from the core to the skin, resulting in heat dissipation to maintain a normal body temperature. This increase in blood flow may present difficulties for those with impaired lymphatic drainage, causing further oedema. Indeed, this has been reported anecdotally from patients who indicated that increased heat and humidity exacerbated their symptoms of
lymphoedema [11,12]. It has also been noted qualitatively that patients report difficulty in wearing compression garments due to discomfort from increased warmth [13,14] and difficulty in donning garments over sweaty, damp skin. With climate change predicted to raise average temperatures across the globe by 2–5 degrees Celsius [15], these difficulties will continue to be exacerbated. The limited research addressing quantitative measures in relation to seasonal climatic variation has produced mixed results [16]. One study found no correlation between heat and limb volume or extracellular fluid [12], whilst another reported a low correlation with heat and limb size [11].

The purpose of this study was to determine how people with lymphoedema experience symptoms in response to variations in climatic conditions, and a further aim was to understand how climate and climatic variations impact the management of lymphoedema from the patient perspective.

2. Results

A total of six focus groups were conducted. Three focus groups were with patients (n = 12) and three focus groups were conducted with lymphoedema therapists (n = 7).

2.1. Patient Participant Characteristics

Although the intention was to only interview people from Australia, and all recruitment materials were only sent through Australian networks, there were some responses from people in other countries who saw the recruitment flyer online. Therefore, there were two patient participants (PPs) from outside Australia: one from the Netherlands and one from Italy. All participants were female. Table 1 summarises the key characteristics of the PP.

Table 1. Participant characteristics—patients.

<table>
<thead>
<tr>
<th>No.</th>
<th>Age ¹</th>
<th>Yr. Dx ²</th>
<th>Age Dx ³</th>
<th>Type ⁴</th>
<th>Location of Lymphoedema ⁵</th>
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<td>Darwin</td>
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¹ Current age, ² number of years since they were diagnosed with lymphoedema, ³ age at diagnosis, ⁴ classification of lymphoedema (P = primary lymphoedema, S = secondary lymphoedema), ⁵ where their lymphoedema is located (LL = lower limb, UL = upper limb, and CBT = chest, breast and/or trunk).

There was a fairly even representation of the various forms of lymphoedema, with five PPs diagnosed with primary lymphoedema and seven PPs diagnosed with secondary lymphoedema. Similarly, five PPs had lower-limb lymphoedema, six PPs had upper-limb lymphoedema, and one PP was affected by both upper-limb and lower-limb lymphoedema. In total, 83% of the PPs (n = 10) had been living with lymphoedema for over 5 years. The PPs were aged between 27 and 76 years of age.

2.2. Therapist Participant Characteristics

A total of seven therapists (TP) participated in the focus groups (Table 2). All were experienced lymphoedema therapists and represented a cross-section of both private and public settings, as well as tropical (Darwin) and temperate (Alice Springs/Adelaide) climates.
Table 2. Participant characteristics—lymphoedema therapists.

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Profession</th>
<th>Years as Lymph Therapist</th>
<th>Location</th>
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<td>1</td>
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<td>3</td>
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<td>Darwin</td>
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<td>MT</td>
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<tr>
<td>7</td>
<td>PT</td>
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<td>Adelaide</td>
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</table>

1 OT = occupational therapist, RN = registered nurse, MT = massage therapist, and PT = physiotherapist.

2.3. Themes—Patients

The patients participated in one of three focus groups. Relaxed, open conversation generated a large range of ideas and topics that were coded and then thematically analysed. Three major themes emerged from the patient focus groups. These were weather, self management, and compression garments, each with distinct sub-themes, as indicated in Table 3.

Table 3. Key themes—patients.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-Themes</th>
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<tbody>
<tr>
<td>Weather</td>
<td>Heat, Humidity</td>
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<td></td>
<td>Cooling, Compression, Treatment options, Sport/Movement, Skin care</td>
</tr>
<tr>
<td>Self Management</td>
<td>Heat/Humidity, Self Management, Challenges, Social acceptability/patient attitude</td>
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<tr>
<td>Compression</td>
<td>Heat/Humidity, Social acceptability/patient attitude</td>
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</table>

2.3.1. Weather

Heat

There was a very clear consensus across all focus groups that heat and humidity have a direct impact on lymphoedema. The PPs described their limbs as feeling more swollen in warmer temperatures. One PP stated that she noticed that her watch no longer fit, or the compression garment felt tighter than usual. They also described feeling tiredness, heaviness, and/or tightness in the limb. This was connected with a general fatigue. As one PP stated:

I feel (the tiredness) as well in my limb and it’s a sort of unusual kind of fatigue rather than general tiredness if you can put it like that. My limb feels fatigued, it’s like I can feel that the lymphatic system is saying I’m working so hard, I’m just exhausted . . . it just feels worn out. (PP3)

There was also some discussion around behaviour changes as a direct result of the climatic conditions. Some PPs reported engaging in less exercise or avoiding certain activities if it was a hot day:

. . . I’m worse when it’s humid but with anything over 30 degrees, basically I try to avoid going out because I can really tell it affects my lymphoedema . . . (PP8)

Interestingly, changes appeared to have a stronger influence on symptoms. For PPs living in tropical climates, they reported noticing their lymphoedema more during the build-up (this is common term used for the shoulder season between the wet and dry
seasons when the humidity levels are changing) as opposed to the middle of the wet season. Likewise, when there was a daily change, or when they moved between climatic zones, the symptoms were more apparent:

... for me, the trigger to wear a garment is that it’s going to be over 25 degrees Celsius or five degrees warmer than what it was yesterday. So in spring and autumn where the temperatures yo-yo, I may not wear the garment on the cooler days, but I will always make certain I wear it on a warmer day. Because I know my system. I’m more prone to swelling and my system needs the help that the garment gives me. (PP5)

Humidity

Humidity appeared to be an additional factor impacting lymphoedema symptoms for people who were not exposed to it on an ongoing basis.

I spent five days in Darwin... and my leg just went out of all proportion! The humidity was very high and it just expanded. I was trying to do a lot of walking in the morning, but by the afternoon I couldn’t walk at all ‘cause my feet were hurting too much. And it was a real shock. I was only there for about six or seven days and then came back to Melbourne and then things settled down pretty quickly. So it’s yeah, it was just an impact of changing from one to another. (PP4)

This raises the question of acclimatization and indicates that the body may adjust to conditions and remain stable. For PPs exposed to tropical conditions, they did not indicate humidity as a particular issue in relation to the stability of their lymphoedema.

2.3.2. Self Management

A wide variety of techniques were implemented across all groups in order to maintain their lymphoedema during seasonal changes. These have been broadly categorised into techniques to cool the body down, compression, accessing a variety of treatment options, completing sport/movement, and attention to skin care.

Cooling

Five PPs stated they felt a need to cool their body down to maintain control of their lymphoedema. This ranged from staying inside in air-conditioned comfort to implementing strategies to cool the limb such as spraying water on the legs, having a cold shower, putting their garments in the freezer prior to donning, or immersing the body in water.

... when I’m feeling that in the heat then I know that my lymphatics are really under stress and I just it’s not even just about cooling down, I need to be immersed in water so that that compression from the actual water can just totally help my body cooldown and just have that extra compression all through. (PP3)

Accessing water and swimming as an alternative to compression garments was a common theme. Using the water to both cool the body down and provide additional compression was deemed important. One PP indicated that she needs to remain for a minimum of 45 min to an hour in water in order to benefit from the compression. The benefits of water were not only for cooling the body and providing compression. It seemed to also have an impact on general well-being:

... swimming anyway, just generally is very good and makes me feel so much better in the heat. (PP3)

Dressing for the warmer climate was also noted. This involved wearing looser, flowy clothing that promoted good air flow around the body, as well as being conscious of fabrics, such as wearing linen, which is known to be comfortable in hot weather.

Compression

Many PPs agreed that maintaining compression was essential, particularly in the warmer summer months. Several PPs stated that they felt as though their body was craving
compression, and they would often add extra compression if the swelling increased. One PP stated:

*I was taught that when it’s hot, and when it starts to hurt it actually means you need to put on additional pressure because it’s getting too stretched out .... obviously that’s the last thing you want to do when it’s already hurting and it’s really hot, but that’s what I do. And it really helps.* (PP9)

The notion of performing what was necessary to manage their symptoms was echoed by several PPs, indicating that short-term discomfort was preferable to any potential long-term negative changes to their lymphoedema.

*Obviously if you’re wearing a stocking everyday it’s warmer than not wearing anything, but the fact is it’s achy and painful if the swelling builds up and sits there. So my leg is a whole lot more comfortable if I’ve got the stocking on, so I’ve not allowed it to bother me. The wearing of compression garments brings so much more benefit than the frustration of wearing the garment that might add a bit of extra warmth.* (PP10)

Compression was applied in multiple forms. Several PPs reported using bandaging, either over their garment or as an alternative to their garment. Some PPs wore multiple layers of compression garments, and a few PPs included night time compression to their treatment regimen.

**Treatment Options**

All PPs reported implementing a variety of additional treatment options in response to changes in their lymphoedema. These included:

- Taping
- Laser therapy
- Increasing use of their pneumatic pump
- Adding overnight compression
- Dry body brushing
- Having increased MLD sessions with their therapist

Challenges in accessing appropriate services were raised with the variations in public vs. private options, the access to appropriately qualified therapists, and the capacity to obtain appointments when required, with all being mentioned as barriers to managing lymphoedema.

*I bandage every night and when it’s hot ... I put on additional compression and I get the (muscle) pump going. It’s really annoying because it’s hot and you already know you have a big challenge coming up for the day. But every morning I stand up and I walk for at least 5–6 kilometres to get my muscle pump going. And the rest of the day when it’s a really hot day or something I tend to spend in the shade or I keep on walking for at least three four times a day. I have a dog so just keep the compression on and keep going. But 24/7 compression actually. Always.* (PP9)

**Sport/Movement**

There was a general consensus amongst the PPs that sport and maintaining movement was an essential component to managing their lymphoedema, but the preferred activities varied greatly among the participants. Many people mentioned water-based activities as a high priority in summer, however, others indicated that they either could not tolerate time out of compression garments or the general stress with wearing garments and managing damp skin made swimming too inconvenient.

*I have a small spa pool and in the build-up for example, I would definitely be in that every day and doing particular leg exercises. That helps. So the flow, kicking in the water does seem to help ... the pressure of the water having an impact on reducing the swelling. But that definitely helps in that build up.* (PP10)
The importance of finding the right fit for each individual was nicely stated by this participant, who said:

...every patient is different. Every lymphoedema is different. So I think what is the most important is that everybody finds what works for them. And perhaps they push themselves sometimes a little bit to see where they can go, but then they have to know the techniques on how to manage the lymphoedema afterwards you know. So I think this is so important that you learn your own body and you learn and you do what you like, because you have to love also to do the exercise, not just for exercising sake. (PP6)

Several PPs mentioned increasing indoor options such as yoga, tai chi, Pilates, cross trainers, or exercise bikes, or simply performing specific exercises to target their area of difficulty, such as leg pumps or completing the Encore breast cancer program. The time for sport was also dictated by the weather, with several PPs indicating they needed to complete any sport early in the morning before the temperature increased.

I've got an exercise bike in here and if it's hot outside and running is not an option or I can't go in the cool of the morning, then I'll actually exercise in here with the air conditioning on and the fan going. And I find that sort of thing really helps my drainage. (PP8)

Skin Care

Being vigilant with skin care was recognised as essential, particularly in warmer or more humid weather conditions. One patient reported having cellulitis soon after moving to Darwin when she went camping and received multiple mosquito bites. This was echoed by another PP, who reported being extra cautious with her skin whilst in a tropical climate to maintain good skin integrity and prevent any potential infections.

I was wanting to shower more and make sure I was aware of the condition of my skin ... I just know that I was being much more vigilant. It might just be because it felt different. Everything felt a little bit different, but I would be concerned about maybe getting some sort of topical fungal infections or things like that you know, in the more humid weather and you know possible bites that could possibly lead to Cellulitis and other infections. So I was being very, I was very careful. I was much more careful, yeah. (PP3)

The importance of moisturising more in summer was raised, with several reporting that they used the process of applying moisturiser as a self-massage technique.

2.3.3. Compression

Heat/Humidity

Direct links between compression garments and climatic conditions were strong across all focus groups. For some PPs, they indicated that they wore additional compression in the heat, whereas for others, they reported challenges maintaining compression for the whole day, as the temperatures made it too uncomfortable. Humid temperatures caused additional difficulties when donning garments due to the dampness of the skin. Several PPs also mentioned that silicon bands caused a rash when living in humid environments.

Flat knit garments were often mentioned as having a cooling effect on the skin due to the weave of the fabric. One PP reported that the limb wearing the compression garment often felt cooler than limbs without the compression garment.

Many PPs reported wearing compression overnight when it was warm. Sometimes, this was in combination with other techniques to cool the body, such as sleeping with the air conditioner on.

...I go and I get my garden hose. So before I bandage for the night I hose down the leg, really cold. I do that, or if I can get in in any place where there is like super cold water...

(PP6)
Self Management

Several PP's discussed altering their compression in response to climatic conditions. This could involve adding nighttime compression, using bandaging rather than a compression garment, adding a second compression garment over their existing garment to provide additional pressure, wearing a lower-grade compression garment overnight, or applying taping as an alternative to compression.

So usually the heat doesn’t stop me. In fact, it’s the opposite. The heat wants me to keep the compression garments on. Like my body wants it, needs that compression. But of course, sometimes you just need a break from it. (PP3)

Challenges

Some of the challenges of wearing compression garments have already been mentioned, such as difficulties in donning garments in humid conditions and an increased occurrence of skin irritation under the silicon band. The cost of garments was also raised. Having the right compression garment makes a big difference to the ability to manage lymphoedema, and, therefore, not being able to afford to replace garments every 6 months directly impacts the capacity to manage symptoms. It was noted that compression garments do not last as long in tropical environments.

The other thing with stockings that I’ve noticed (since moving to Darwin) is that they haven’t lasted as long, like I’ve recently had to change mine over. It was a good month or two before I would ordinarily need to, just because it wasn’t really like containing my swelling. (PP11)

The importance of understanding one’s own body was again emphasized. Finding the balance between the right amount of compression to counteract the impact of the climate, without exacerbating symptoms, was significant:

I wear a class 4 stocking on my left leg with a class 3 toe cap. I have a Class 3 from my ankle up to my knee and when it’s really hot I put that on so I have a class four and a Class 3. But then obviously I need to really, really move because otherwise my knee will blow up. Literally! So it’s a very thin line in the balance. At night I will put more bandaging on my knee, so you know it’s always like making a puzzle with all your compression garments and bandage sets. (PP9)

Social Acceptability/Patient Attitude

There were very mixed views in terms of the social impact of wearing compression garments. One patient reported avoiding skirts or shorter clothes, as she wanted her compression garment to remain hidden:

My solution is that that I don’t ever wear skirts. I don’t like the look of wearing a garment all the time, so I wear slacks all the time. If I’m going somewhere, you know that I consider my presentation is important I’ll wear boots so they can’t even see my foot. So yeah, I disguise if I’m if I’m wanting to impact on my presentation. (PP10)

This was in direct contrast to another patient, who stated:

... I discovered Lympha Divas in America. Now that’s off the shelf ... but it’s pretty so I could wear things that matched. I still in summer will often wear my pink bling with the cancer thing if I’m going to a breast cancer event. I figure I may as well make a fashion statement out of the fact that I’ve gotta wear this bloody thing and I need to wear it more when it’s summer. (PP5)

Some PP’s were happy to attract additional attention from the exposed sleeve in summer, whereas others reported that, at times, they lacked the energy to respond to questions and explain to others what they were wearing or why. On these occasions, they would avoid the social stigma and either cover it up or choose not to wear any compression garment for the duration of the event.
2.4. Key Themes—Therapists

Being conscious that people who respond to a call for research participation tend to be those who are well tuned in to their own bodies or have a vested interest in the topic, it was deemed essential to also speak with therapists to see if their experience matched that of the focus group participants. Three focus groups were conducted with therapists (TP) who were based in either Adelaide, Alice Springs, or Darwin. Key themes from the therapists related to weather, behaviour changes, compression garments, and education.

2.4.1. Weather

All TPs agreed that their patients reported an increase in symptoms during hotter and more humid conditions. Although one TP stated that, for some of her patients, she felt that the tissue quality was better in cooler, winter months, none of the other therapists were consciously aware of any measurable limb differences throughout the year. The importance of listening to patients was highlighted:

"I listen to my clients and what they say about the feel all the time. Because I know that it doesn’t always show up in any other way it’s just it feels heavy or it feels sore . . . so I do tend to go on feel quite a lot and go “Oh, if it’s not feeling right, then we need to do something”. (TP2)

Most stated that patients appeared to have more difficulty in humid weather and that some were sensitive to other environmental changes such as the full moon or an increase in atmospheric pressure.

"I have a couple of people who very much respond to changes in air pressure. So not so much the humidity, but the, you know, if there’s like a thunderstorm coming, I’ve got some people it swells up hugely with, and can actually predict a thunderstorm by their swelling. (TP5)

Changes in climatic conditions appeared to be when symptoms were most strongly detected. This was reported particularly during a seasonal change, such as the build-up or a sudden dramatic geographical change, such as going on holiday.

"I definitely hear that from my patients. Typically in the build-up. I’ve had people that say, “oh, I don’t need to wear my garment in the dry season, and then as soon as build-up hits, I need to be back in my garment again”. (TP1)

And then you know patients when they go down South and they come back and they’ll say “I didn’t have to wear my garments as often”, “My swelling was so good with the cooler weather down South”, or you know “I went to someone’s wedding and I managed without my garments”. So, you know, you get that feedback as well. How they love being in cooler weather and how it just, you know, their swelling was . . . better. (TP4)

Another factor related to weather was an increased risk of infection. Patients are encouraged to be extra vigilant with their skin care and consider the risks of sunburn and insect bites. If garments are removed, then it is recommended that they wear long sleeved clothing to avoid direct sun exposure. One TP noted that there are often travellers to Darwin who require attention because of flare ups with their lymphoedema, thought to be partly due to long periods sitting in the car, which they do not normally do, as well as challenges wearing their compression, or not wearing it at all, and the exposure to multiple vectors that cause skin irritation, itchiness, or infection.

2.4.2. Behaviour Change

So, whilst there was a general consensus that patients reported more problems with their lymphoedema in hot weather, it was suggested that perhaps it is not just climatic changes that are the problem, but rather a range of behavioural changes that occur.

"I would say the majority of people would suggest that they have seasonal change in their oedema . . . I think it depends a lot on other factors other than just climate. I don’t think
we can blame climate. I think, weight, exercise, diet, I think all those things have an influence. (TP6)

There was a suggestion that, when it is hot, people generally move less. They may not be wearing compression as much, they are engaging in less exercise, there is a factor of stress related to heat, and perhaps, in general, they do not take as good care of themselves and their lymphoedema. This is perhaps reflective of the variety of patients seen by the lymphoedema therapists, with varying levels of self-motivation and connection with their bodies. It could also reflect the individual nature of managing lymphoedema, in that what works for one patient may not work for the next patient. Several TPs indicated that their patients just refused to wear compression garments when it was hot, or appeared to use the heat as an excuse.

It's almost a hall pass, isn't it? An excuse to take your garment off. Oh, look its summer and we can't possibly cope. So we won't. (TP6)

2.4.3. Compression Garments

The use of compression garments was also a significant theme across all focus groups. Closely related to both climatic conditions and behaviour changes, it was noted that, in increased humidity, people have difficulty wearing their compression garments.

So... at the moment we’re going through the build-up, so it’s definitely been mentioned to me in clinic how it’s harder to get garments on in the morning unless the air con is on. And if they don’t get it on in the morning, then it’s just harder to get them on during the day, ’cause you’re already sweaty and sticky. But that is a catch 22—too hot to wear them some days, but also more swelling because it’s so hot, so you need to wear them. Is the swelling getting worse because they’re not wearing it as often? Or is it getting worse because it’s hotter? ... I think it’s both. I think they both have the factor that potentially not wearing garments as much, so the compression isn’t as effective and the heat itself causes more swelling. (TP4)

The additional challenge of donning garments in humid weather was a common theme, primarily due to the increased moisture on the skin. However, it was also noted that patients needed to have the mindset that the ongoing use of compression is the key to managing their lymphoedema. Once they have accepted this, then the additional warmth does not seem to be as much of a factor for them.

Usually the people that are complaining about getting them on and off are the people that don’t like wearing them regardless, you know? They just say, “I don’t like this. I don’t want to wear them”. (TP2)

Closely related to this theme was the importance of finding the right garment. For some, wearing overnight compression was sufficient and avoided the need for daytime compression. For some, flat knit appeared to give their patients the most relief, whilst for others, a circular knit with a high cotton component was more suited. Taking the time to explore the patient’s needs, educate about the various compression materials, and find a wearing regime that best suited their needs was highlighted as an essential step.

Patients have their preferences. No matter what... choosing the garment and fabric that will best suit that patient’s needs. And the right strength to hold the compression. That’s almost more important than the temperature. (TP4)

I often recommend for the legs the Sigvaris with cotton, because I think people seem to like the idea that it’s got more cotton in it than some other sort of nylony thing and that it will be cooler. One of my patients preferred the flat knit... which looks thicker and you would think would be more hot but actually she, preferred it. (TP3)

In addition to the comfort in wearing compression, the ability to get it on and off was also a factor.
I do tend to find that people think the Comfiwave is going to be hot. And actually that’s probably one of the cooler ones to wear . . . the knit is more of an open weave, it’s more comfortable, and the other option is that it’s easy to take on and off. I say, look, if it gets too much with it, you can just whip it off. And it actually is, they’re more likely to wear it because they can take it on and off much more easily. (TP3)

The TP based in Darwin also noted that compression garments do not last as long in tropical conditions and definitely require replacement after 6 months when they are worn regularly.

2.4.4. Education/Self Management

Central to all discussions was the notion that every individual is different, every lymphoedema is different, and that patients really need to discover for themselves what their body needs. Advice across all groups suggested that patients should expect fluctuations with their lymphoedema, particularly in relation to temperature changes. The range of recommendations included:

- If you have trouble wearing your garment for the whole day when it is hot, then put it on in the morning and wear it as long as possible
- Swimming provides additional compression, as well as cools the body
- Movement is essential—both in water and on land
- Patients with upper-limb lymphoedema may need to wear their garment in the water
- Taping can be an alternative to wearing garments
- A compression pump can provide additional treatment, but is not a replacement for compression garments
- Self-MLD is important
- Expect fluctuations
- When gardening or camping, wear an old garment. It protects the skin, provides sun protection, and provides compression. Better to have an old one on than nothing at all
- Place garments in the fridge or freezer so they are cool when putting them on
- Cool the body down—a spray bottle of water, cool gel bandages wrapped on the limbs, cool showers, or permission to use air conditioning
- Skin care, including considering sun exposure and the associated risks
- Elevate your limbs
- Maintain a healthy weight
- Compression, compression, compression

It was emphasised that advice and recommendations tend to be a balance between education and reassurance. It can be a lot for patients to absorb and it is important that they take time to understand their body. Additional stress can exacerbate symptoms and, therefore, any risks need to be phrased carefully.

You don’t want people to become so fearful. That would be my approach . . . just provide advice rather than a firm guideline. (TP4)

I had a patient that cancelled a trip to Bali because she didn’t want to get sunburnt. And I was like . . . well you live in Darwin!! What’s the difference? But she’d read that somewhere and you know didn’t want to risk it. So you know, don’t stop living. Just be mindful. (TP4)

It was noted that, particularly for public clinics, patients who are self-motivated will change their treatment, seek additional MLD sessions, perform more exercise, or alter their approach on their own, and will not necessarily discuss this with their therapist. So, the therapist becomes one of the many tools in their tool box of strategies, which they can call on when they need support. But the therapist is not the central component and is not necessarily aware of everything that is occurring in order to continue to manage lymphoedema.
3. Discussion

Although there were several key themes that were drawn from the discussions, they do not exist in isolation. There is an intricate interplay between all themes. For example, when it is hot, the limb with lymphoedema feels more tired and swollen, exercise becomes more of a challenge, and patients need to find ways to cool the body down.

Focus groups are an effective method of qualitative research whereby the researcher gains an “insider perspective” from the participants [17,18]. The data are collected through group discussions, with key insights arising during the interactions among the participants [19]. As they share their experiences, the participants are interested in how their perspectives are similar or different from each other, and the richness of the conversation enables researchers to clarify not just what the participants think, but why they think the way they do [19]. The conversation is fluid and the topics are built and shaped by the participants and the issues raised by them.

Whilst recruitment occurred only through Australian networks, the information was posted online and resulted in several participants from other countries and from across Australia. This highlighted some differences in how the approach to managing lymphoedema varies. The European participants appeared to be much more familiar with bandaging as a regular compression option, whereas it is rarely used in Australia. Australians also discussed a variety of alternatives, such as low-level light laser therapy, which is not found as commonly overseas.

Additionally, various garment support schemes appeared to be a significant factor in how affordable compression garments are and how often they can be replaced. It was noted several times that when the funding scheme changed and patients were able to access new garments every 6 months, they saw very favourable changes in the overall management of their lymphoedema.

Central to all discussions, for both patients and therapists, was the perception of increased difficulty in hot and humid conditions. This was described by the patients as a feeling of fatigue in the limb or a feeling of heaviness. From a therapist perspective, there were no objective measures to support this perception. Some had completed bioimpedance measures or circumferential measures, but there did not appear to be a notable difference. This suggests that either patients feel a change and immediately alter their approach in order to manage their lymphoedema, or there is no increase in the size of the limb. So, perhaps they perform more exercise, cool their body down, wear additional compression, or remain inside in the cool to avoid the main heat of the day and do not allow their lymphoedema to increase.

Patients are at the centre of their own health. Therapists are just one tool in the box in terms of the treatment and ongoing management of symptoms, and it is important for patients to understand their own body, test their limits, and find their own way forward.

Strengths and Limitations

The recruitment of participants occurred via the purposeful sampling of people who had lymphoedema [20,21]. This approach meant that people who had a vested interest in the topic were the ones most likely to respond to a generic recruitment flyer for research. Whilst this enables fabulous rich discussions and the open sharing of experiences and ideas, it can provide a bias of results. This potential bias was balanced by discussions with the therapists, who had a large range of patients and could reflect on those who were self-motivated and those who required a large amount of support and guidance.

Whilst gender was not an inclusion criterion, all participants were female. This may have had an influence on the results. It would be interesting to explore this theme with men to understand their own body, test their limits, and find their own way forward.
The small number of participants in the focus groups generated higher levels of engagement, as each person had more room to talk and the participants quickly got to know each other [19]. This gave the interviewer the opportunity to make sure that each person was given a chance to respond to every point raised, and, therefore, ensure an equal representation of the views of the whole group, not just a few. The limitation, however, is that the end result becomes the views of a few, rather than a representation of the general population.

4. Materials and Methods

Following ethical approval from the Flinders University Human Research Ethics Committee (HREC), participant recruitment via purpose sampling methods occurred. This involved the circulation of a recruitment flyer via the Flinders University website, through the South Australian Lymphoedema Support Association, and through the Northern Territory Lymphoedema Special Interest Group. People who were interested in being involved in this study were asked to contact the author via email.

The qualitative approach was framed by using a phenomenological approach, defining the focus group outline and structure, including initial prompting questions proposed to the participants [22,23]. This was deemed to be the most appropriate framework for exploring the lived experience of climatic influences for people who had lymphoedema. A total of six focus groups of two to five participants were conducted. The inclusion criteria for the patient participants was that they had a diagnosis of lymphoedema and had been diagnosed for 1 year or longer. This was to ensure that they were able to comment on the changes throughout the year reflecting seasonal climatic changes. The interviews were all conducted via Microsoft Teams online and were video recorded to enable accuracy with transcription. Due to the online format, there were some minor technological issues, such as poor sound connections and the occasional interrupted internet connection. This did not, however, significantly interrupt the flow of conversation. The interviews followed a semi-structured format, which means that initial prompting questions were posed to the group to generate discussion, and based on the conversations that ensued, further probing or clarifying questions were asked. This created a rich array of information unique to each focus group and is reflected in the heterogenous experiences of patients vs. therapists. To ensure consistency, the same interviewer conducted all focus groups. The consolidated criteria for reporting qualitative research (COREQ) was used as a guide in the development, preparation, and analysis of the focus groups [24].

The interviews were initially transcribed using the automated Microsoft Teams to Word feature. They were then reviewed by the interviewer and edited for accuracy to ensure verbatim transcription. A thematic analysis then occurred to identify, analyse, and document patterns (themes) within the data [25]. Guided by the recommendations from Braun and Clarke [25], initial codes were identified using Microsoft Word (version 2405) and then collated into potential themes using Microsoft Excel (version 2405). To ensure consistency, quality, and transparency, the intercoder reliability (ICR) methodology was implemented [26]. A portion of the transcripts was separately coded by two other supervisors and then correlated with the primary author to ensure consistency and reliability across all codes. Similarities and differences were sought both within the transcripts and between them, which further developed the thematic categories. The themes were broken into sub-themes and reviewed by all authors. Further refinement occurred before the final themes were agreed and illustrated by quotes.

5. Conclusions

Heat and humidity appear to alter the severity of lymphoedema, with participants indicating increased swelling, lethargy, and heaviness. Different people respond to this change with individual strategies based on their own needs and their understanding of their condition. Lymphoedema is a chronic, dynamic condition that requires a lot of time and personal cost in order to maintain. Every body is different and every lymphoedema is
different, and, therefore, individuals need to test and understand their own bodies, finding the strategies that help them to maintain their condition.

The sharing of ideas is essential in understanding how the environment influences lymphoedema, as well as the strategies that can be undertaken to counteract any negative impact. Additionally, the ideas generated may contribute to the production of new materials or new strategies that can prepare us for the future.

The key themes from these focus groups have been developed into a questionnaire that is currently being translated and circulated around the world. It is hoped that a large number of respondents will complete the questionnaire to create both a greater comparison between climatic zones and geographical locations, as well as to give a greater weighting to the results of these focus groups and allow for generalisations across the lymphoedema population. The results from the questionnaire will be published in a subsequent article.

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