Using telehealth to support self-management of lymphoedema: clinicians' and patients' perspectives

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Key words

Lymphoedema, Telehealth, Self-management, Qualitative

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Abstract

Background: People with lymphoedema are commonly required to self-manage their condition. Telehealth may offer a way for clinicians to support self-management. **Aim:** To explore clinicians' and patients' perspectives relating to telehealth for lymphoedema management. **Methods:** Semi-structured interviews were conducted with 21 clinicians and 19 people with lymphoedema, in Australia. Data were coded independently by three coders, then grouped into themes. Data were analysed using an interpretative phenomenological analysis approach. **Results:** There were notable differences in the provision of lymphoedema care through the public and private health systems, as well as between different disciplines. Potential benefits of telehealth included providing education, improving access to specialised lymphoedema care, and remote monitoring. Limitations of telehealth were identified, including the difficulty of assessing lymphoedema remotely, challenges with technology and the security of sensitive information. **Conclusions:** Telehealth would be best used to deliver education to patients, provide supervisory support to non-specialist clinicians and to monitor patients' self-management. Concerns about security of sensitive images and access to the appropriate technology would need to be addressed prior to implementation.

Lymphoedema is characterised by the accumulation of protein-rich lymphatic fluid in the interstitial tissue of the affected region. People with lymphoedema can experience significant swelling and reduced function when limbs are affected, and are at increased risk of skin infections. Cancer treatment is the most common cause of secondary lymphoedema in Australia, with an estimated 10–20% of people treated for breast, gynaecological, genito-urinary, head and neck cancers, sarcoma and melanoma, likely to develop the condition within 2 years of their cancer diagnosis (Cormier et al, 2010; DiSipio et al, 2013; Beesley et al, 2015). Primary lymphoedema is less common, but is an inherited condition and often affects multiple regions in the body (Medical Service Advisory Committee, 2006).

Without treatment, lymphoedema can progress, leading to significant increases in limb size and/or swelling of the genital area, trunk, head and neck, and worsening physical symptoms. Current recommended treatment is complex and expensive, involving combinations of compression therapy and manual lymphatic drainage. These treatments are commonly prescribed as an intensive treatment programme for 2–4 weeks, after which patients are advised to self-manage the condition to maintain any improvements. The treatments are inaccessible to many people, particularly those living in rural and remote areas, with limited mobility and/or low income (Sierla et al, 2013; Wang et al, 2014; Finnane et al, 2015). The cost of lymphoedema treatment is recognised as a significant burden in Australia, with out-of-pocket costs increasing with the severity of the condition (Boyages et al, 2017).

Despite the ageing population and increasing numbers of people with chronic conditions in Australia, the current health care system is far better equipped to respond to acute conditions (Faett et al, 2012). Redesign of existing systems and consideration of alternate models of health care are greatly needed. Telehealth services have been developed as alternate models of care for a number of chronic conditions in recent years, including diabetes, heart disease and musculoskeletal conditions (Cottrell et al, 2017; Hwang et al, 2017; Bohingamu Mudiyanselage et al, 2018). These models recognise that the role of clinicians in chronic disease management is often to support patients to largely self-manage their condition (Hanlon et al, 2017).

The purpose and components of telehealth interventions vary, but can include education, monitoring of physiological markers, remote assessment and guided treatment. The reported efficacy of telehealth for improving chronic conditions differs, but notably these interventions have not been reported to lead to negative outcomes (Hanlon et al, 2017). Studies of telehealth systems developed specifically for people with lymphoedema suggest this model can be used to support the remote assessment of lymphoedema, as well as provide education to support self-management (Faett et al, 2012; Galiano-Castillo et al, 2014).

The authors proposed that the development of a multidisciplinary telehealth service could support people with lymphoedema to be more actively involved in their care, enable clinicians to increase their scope of practice and limit the burden on the Australian healthcare system. Existing services combining store-and-forward and video technology (Biscak et al, 2013; Galiano-Castillo et al, 2014; Finnane et al, 2016; Richardson et al, 2017), could be adapted to enable assessment of swelling, range of motion and skin changes, and could be used to teach techniques for simple lymphatic drainage and limb exercises. While previous research has shown this is possible in research settings, little is known about patients' and clinicians' views about integrating telehealth into current models for lymphoedema care.

The aim of this qualitative study was to explore the feasibility and acceptability of a proposed telehealth intervention for lymphoedema, from the perspective of both patients and clinicians currently receiving or providing lymphoedema treatment.

In 2020, the emergence of the SARS-CoV-2 (COVID-19) pandemic has seen the sudden and urgent need for healthcare professionals to provide services to patients remotely, including for people with lymphoedema. While the current situation varies markedly across the world and remains uncertain, there is increased interest in models of remote healthcare delivery, and the need to adopt telehealth options that address the needs of both clinicians and patients. While this study was conducted prior to the COVID-19 pandemic, the findings are of the utmost relevance during this time.

Methods

Sample

Adults who had received a clinical diagnosis of lymphoedema were invited for interviews through patient support organisations in Queensland, Victoria and South Australia. Purposive sampling was used to ensure representation of people living in multiple states in Australia, including men and women, with primary and secondary lymphoedema, to provide information-rich qualitative data relevant to the research question.

Clinicians who are involved in lymphoedema management were also recruited, to ensure both perspectives were included, and to enable data triangulation. Clinicians were invited via the Australasian Lymphology Association's National Lymphoedema Practitioners Register (NLPR), as well as the Australian Physiotherapy Association's Cancer, Lymphoedema and Palliative Care Network. Clinicians from any discipline were included, as long as they had treated at least 10 lymphoedema patients in their role. This study was approved by The University of Queensland Human Research Ethics Committee (no. 2015000819).

Data collection

Telephone interviews were conducted by two interviewers; one expert interviewer (with a background in lymphoedema research), and one nurse interviewer. A semi-structured interview guide was used to invite participants to reflect on their experiences of managing their lymphoedema (in the case of people with lymphoedema) or assisting people to manage their lymphoedema (in the case of clinicians), as well as their perspectives related to telehealth. Interviewers maintained a flexible and informal style, to enable deeper exploration of topics that arose. All interviews were audio-recorded following verbal consent from all participants. Initial notes and codes were written by the primary investigator (AF) following interviews to identify the point when data saturation was reached. This occurred after 21 interviews with clinicians, and 19 people with lymphoedema.

Data analysis

The interviews with both clinicians and patients were transcribed verbatim, de-identified and checked for accuracy by AF. Each transcript was read and coded independently by AF and a second coder, who both had prior knowledge in the area of lymphoedema. Major themes were identified through an iterative process, and examples were documented. Both coders met to discuss the developing themes, then came to a consensus on the final themes that related to the research aims. At this stage, a third data coder (AG) was introduced who was blinded to the original coding and thematic analysis, and who had no prior knowledge of lymphoedema or through an iterative process, identified themes, to reduce the risk of expert bias. AG and AF independently made quote selections, then met to discuss the developing themes and quote selections to ascertain if there was congruence with the original themes identified. The interview content in each of these themes was analysed using an interpretive phenomenological analysis approach (Smith et al, 2009). This method offers insights into the "lived experiences" of participants, which was appropriate given the study aims. Indicative quotes are referred to according to their

Table 1. Participant characteristics.

Clinicians' Occupation	**n**
Physiotherapist	13
Nurse	3
Massage therapist	3
Occupational therapist	2
Years in Practice	
0–5 years	5
6–10 years	5
11–15 years	5
16–20+ years	6
Clinicians by State	
Queensland	10
Northern Territory	3
South Australia	2
Victoria	2
New South Wales	2
Western Australia	1
Unknown	1
Health Sector	
Public	11
Private	6
Public & Private	3
Not for profit	1
Patients by State	
Queensland	11
South Australia	4
Victoria	2
New South Wales	1
Unknown	1
Lymphoedema type	
Secondary	16
Primary	3

Table 2. Experiences with managing lymphoedema in Australia.

Theme	Indicative quotations
Lymphoedema under recognised in Australia	2.1 "It doesn't have this term 'chronic' in front of it that gives people the ability to have a certain level of recognition for the way it affects their lifestyle and their quality of life, this is particularly what our debate is about, is do we need to on some level actually change the terminology to change the mindset about how we deal with lymphoedema." NA p.20 2.2 "Oh, there's a barrier right at the start with the GPs not understanding about lymphoedema in the first place and waiting until someone gets really bad before they even bother to find anything for anyone… I have seen a few times… where if it could have got on earlier… it would have been a whole lot more pleasant for the patient." HH p.11 2.3 "… (Lymphoedema) falls between the cracks…" MB p.20 2.4 "… Don't think there's enough recognition of the lymphoedema and not enough knowledge of it." LB p.7 2.5 "Educating the GP to understand [lymphoedema] therefore being able to respond to it more appropriately is really important." GS p.20
Differences between professions	2.6 "I have noticed a difference between say physiotherapists and occupational therapists. Occupational therapists tend to bandage more and we tend to do the drainage more. I've noticed just a basic sort of thing. So we actually work quite well together." DE p.12 2.7 "…We give them the exercise… and diet together and wear your garment. If we just do any of those individually, without the three, it just doesn't work. So if you can get a dietician involved, it just really – it puts the icing on the cake or it actually enhances the whole thing…" DE pp.12-13 2.8 "If you can get a discipline who will own [lymphoedema], I think that would make a lot of difference." KS p.22
Public vs Private	2.9 "… in public health our initial consultations are half an hour… the initial consultation in private practice is a bit different, because it's generally an hour." RH p.15 2.10 "… the most difficult thing with… treating lymphoedema in Australia is the cost to the patient." RH p.12 2.11 "… because we are funded, it's like $10 a visit – we're often seeing those people who are very needy in the community. So when you're asking to see them multiple times and there's a cost associated with that then that can be difficult for them as well." KB p.10 2.12 "… I've been fortunate to be able to fund my own courses… because I felt that that was absolutely critical to being able to treat patients properly if you get that sort of education." MM p.9 2.13 "… I have been very lucky because I'm in a small community to have been sponsored to go to… the ALA [Australasian Lymphology Association] conference in Freemantle. A few things have happened where the community has sponsored me to do stuff. Because I'm committed to the town..." FG p.12 2.14 "so there are barriers in access to continuing education in a way but there are also barriers in terms of people in public and private care being able to access a day off work for study leave, or the money to be able to attend various conferences interstate or courses." TL p.7
Access to services	2.15 "… there are services that are restricted to breast cancer patients, there are services that are restricted to where you live. So if you don't live within the catchment area of the hospital then you can't access that particular service. If it's not cancer related lymphoedema then you can't access the cancer related lymphoedema service." TL p.9 2.16 "you know you sit there and… you hear a conversation and then you hear how far people are travelling for treatment… I literally walk out of there going oh my God, I'm so grateful that I have all of this available in Brisbane." VV p.14 2.17 "I live in the country so we're four and a half hours from Adelaide. That is a big disadvantage when it comes to your health." HC p.2 2.18 "… I think that's a bit of the issue. There are supposedly physios out there that say they do lymphoedema treating, but not necessarily have they been trained specifically in that area..." DW p.11 2.19 "They said they're fully booked" AS p.6 2.20 "… We've got a very generous garment scheme up here [in the Northern Territory]. The government, the Health Department, provides four sets of garments free [per year] and a set is, say, if you need a sleeve and a glove, that's one set." SP p.7 2.21 "The cost of garments is a big issue… most of the time I have worn off-the-shelf garments, which, stockings cost me about $100 a pair. The custom made garments cost $730 a pair. So that is a huge difference…" LB p.17

table and quote number (i.e., Table#. Quote#), throughout the results section below.

Results

Twenty-one clinicians and 20 lymphoedema patients were interviewed, however, one patient was excluded as they had lipoedema, not lymphoedema. Participant characteristics are detailed in *Table 1*.

Health system context

In order to understand the perspectives of both the clinicians and the patients interviewed in this study, it is important to understand the health system context in which their perspectives have been formed. There are three models of healthcare systems in the world; the market model, the welfare model and the hybrid model (Dixit and Sambasivan, 2018). The welfare model is fully funded by tax funds and the government of that country takes full responsibility of all healthcare services, whereas with the market model the onus is on the individual to pay for the health services they seek. Australia employs the hybrid model, meaning healthcare is partly funded by government taxes (referred to as the public health system), but Australians also have the freedom to choose private services, which attract additional costs (Dixit and Sambasivan, 2018). Some individuals pay for private health insurance, which reimburses some healthcare costs, but there is usually a 'gap' payment that the individual must pay.

Lymphoedema under recognised in Australia

While there has been growing recognition of lymphoedema as a chronic condition in recent years in Australia, with governments now providing financial support in some states, progress has been slow, and this is particularly the case for primary lymphoedema. The under recognition continues to be felt by patients and clinicians (*Table 2: 2.1*). It was evident that the clinicians interviewed in this study had extensive knowledge of not only lymphoedema but also their patients' needs. However, they reported that this was not the case within the broader health sector.

Clinicians and patients spoke extensively of the lack of knowledge about lymphoedema within general practice settings. As general practitioners (GP) are often the first clinician a patient will see with their concerns, the GPs lack of understanding can result in delays in diagnosis, which the clinicians explained often makes treatment harder and more complex (*Table 2: 2.2*). The patients elaborated on this further (*Table 2: 2.3–2.4*), expressing the need for clinicians, especially GPs, to be educated about lymphoedema (*Table 2: 2.5*), with one patient saying they were "lucky" to be diagnosed.

Table 3. Benefits of telehealth.

3.1 "I'm sure everyone is resistant to change, doing things a bit differently initially, but I think this is definitely the way we have to go with healthcare. New innovation and using technology, I'm all for it." RT p.22

3.2 "Yeah, I definitely think so because a large part of it is a lot of education and advice. That would be quite easy to provide over [telehealth]." AMC p.8

3.3 "Knowledge is certainly something that I feel empowers you" HC p. 13

3.4 "…It's also good if you've got someone more experienced around you clinically, that you can talk to because not everyone's straightforward in their management as the textbook cases. So just to have someone more experienced clinically around you to ask questions, sort of mentor you a bit as well." LMC p.5

3.5 "…If you work through a local physio [using telehealth] and say, can you look at this or what does that show you… The physio can phone me and say, this is what I'm seeing or this is what I'm doing and I'd say, okay well measure here and measure there and let me know and then I can guide you." MG p.11

3.6 "…I think it's a great idea, especially for people in remote areas that can't get to anywhere…" DL p.12

3.7 "…there's a big fear factor that goes with lymphoedema or the possibility of lymphoedema… a lot of people come to me and they're absolutely terrified…" MG pp. 9

3.8 "I think the knowledge that there is support there and that they have access to lymphoedema management… more specialised people at their fingertips… more confidence in how to manage themselves." MC p.13

3.9 "…to reinforce it again and yeah, that could all be done over telehealth. You would just get them to show you what they're doing and correct it if it's not right…" RT p.18

3.10 "…peace of mind…" MC p.25

3.11 "well if you've got any doubts if you can talk to somebody straight up and you're worried about something they can alleviate it." SG p.11

Differences between professions

Clinicians from different disciplines described some differences in their treatment approaches. An example of this, noted by both patients and clinicians, was the focus on lymphatic drainage amongst physiotherapists, compared with occupational therapists, who were more focused on compression (*Table 2: 2.6*). The treatment plans and initial assessment appointments with professionals from these disciplines were otherwise quite similar. While some clinicians worked alone in private practice, and some patients had one dedicated lymphoedema therapist, others worked in multidisciplinary teams.

The common consensus across the interviews was that a multidisciplinary approach is best in the current health system in Australia, as professionals from these different disciplines complement each other and perform different and necessary functions. One clinician who works in a multidisciplinary team explained the importance of bringing a dietician into the treatment plan (*Table 2: 2.7*), which is uncommon in practice. Some patients spoke of how there was not consistency in their care, and they felt that if one discipline would take ownership of managing lymphoedema in Australia, this might make a difference to their care (*Table 2: 2.8*).

Public vs Private

Lymphoedema services are delivered through the public and private health sectors in Australia. There appears to be a difference in the length of initial consultations, with private consultations generally lasting longer than public (*Table 2: 2.9*). Unlike public initial consultations, private consultations also included treatment in addition to an initial assessment, as private clinicians felt the need to provide value for money, given the high cost to patients. The financial burden of lymphoedema management was mentioned by all clinicians, regardless of whether they worked in the public or private systems, and was said to make treatment inaccessible for patients on low incomes (*Table 2: 2.10–2.11*).

Access to ongoing professional development (PD) differed for clinicians working in the different sectors, with public sector clinicians mostly having access to PD funds, and private sector clinicians having to cover their own costs (*Table 2: 2.12*). In one case, a private sector clinician was supported by her community to attend extra training, however, this was not the norm (*Table 2: 2.13*). An additional barrier to accessing PD is the requirement for private practice clinicians to take time off work (losing potential income), whereas public sector clinicians mostly had PD days built into their pay structures (*Table 2: 2.14*).

Access to Services

Difficulty accessing lymphoedema services was a significant issue noted by both clinicians and patients. The main issues related to eligibility for services, catchment areas associated with public sector services, the travel distance and time for some patients and, lastly, the lack of adequately trained clinicians specialising in lymphoedema management (*Table 2: 2.15–2.18*). In some cases, eligibility for treatment is dependent on the type of lymphoedema a patient has, as well as where they live. One patient spoke about how her local clinic was not able to accommodate her, and she had to travel from Townsville to Brisbane (1,300 kilometres away) to receive the treatment she needed (*Table 2: 2.19*).

Compression garments were considered an important part of lymphoedema treatment plans, but clinicians reported vast differences in what was available to patients living in different states. The Northern Territory was reported to have the most supportive garment rebate scheme, providing up to four sets of garments per year (*Table 2: 2.20*), while in other states only two sets could be claimed. Garments add significantly to the cost of treatment, particularly those custom made to fit (*Table 2: 2.21*).

Table 4. Limitations of telehealth.

4.1 “Yes and not provide something that actually diminishes what should be provided because somebody says this is a good cost-effective way of providing it when in fact it doesn’t provide the quality of service.” RB p.20.

4.2 “If they were more chronic [stage lymphoedema, telehealth] would be fine. If they are in acute stage, I’d really want to be seeing them face-to-face at some point…” LMC p.15.

4.3 “…one of the issues is garment fitting is always tricky. I guess you always would need to see a patient for garment measurement. I think that’s pretty important.” MM p.16.

4.4 “Limitations [of Telehealth] would be that the personal aspect is, depending on, I know how I might use it but I guess with any form of technology that some [HPs] may see this as a really good money making opportunity and just to sit at their desk and not to actually be proactive and manage things.” JH p.25.

4.5 “We’ve got quite an aged population in this area. So a lot of my patients are over the age of 70 and aren’t very technology savvy. They might balk at the idea...” RT p.18.

4.6 “…there are people, older people, not so much young ones, who don't have access to computers and that sort of thing.” HR p.19.

4.7 “I guess too from my point of view, being an employee, I don’t have the capacity to implement those changes…” MM p.21.

4.8 “…I do so many privacy things these days and everything like that that you'd hope that their companies would protect your information…. . I would certainly think twice about sending photos of my breast area purely because of, yeah, the sensitive nature and stuff.” JM p.17.

4.9 “…how do you control that or how do you make sure that that is controlled and that your information you’re storing is not accessible to other third parties…” MM p.20.

4.10 “I wouldn’t have any concerns with having a Telehealth system and connecting to my computer, I would really look forward to having that in my case.” GS p.22.

4.11 “…I’m being looked after and what [Telehealth] would have to offer me would not add to what I’m currently getting, then it would be a waste of resources for me to be accessing that too.” LC p.18-19.

4.12 “Well, it’s better than nothing. That was the option you were faced with, nothing.” AS p.18.

Benefits of telehealth

There was an overwhelming positive response to telehealth as a possible adjunct to current lymphoedema management strategies. Participants spoke of it being the way of the future (*Table 3: 3.1*).

Telehealth was often identified as having a role in education. Clinicians could see it as a useful tool for educating patients about lymphoedema and self-management (*Table 3: 3.2*), and patients agreed this access to more information about their condition could be empowering (*Table 3: 3.3*). Clinicians also saw telehealth as a great opportunity to connect with their peers and receive education themselves (*Table 3: 3.4*). Some of the more experienced clinicians expressed enthusiasm that a telehealth platform could be used to help educate less-experienced clinicians and improve the level of lymphoedema knowledge in healthcare settings.

Clinicians could see a role for telehealth in improving access to specialised lymphoedema care for people living in rural areas. For example, clinicians with limited experience in lymphoedema care could be directed by a trained lymphoedema therapist via telehealth to assess the patient and potentially provide treatment as well (*Table 3: 3.5*). This was seen as valuable by the patients also (*Table 3: 3.6*).

Clinicians and patients could also see benefit in using telehealth to provide/receive reassurance between appointments. A few clinicians spoke of the fears patients have around lymphoedema (*Table 3: 3.7*), and explained how a telehealth service could help build patients' confidence in their self-management (*Table 3: 3.8–3.9*). The patients agreed with this idea saying it could alleviate worry, and bring "peace of mind" (*Table 3: 3.10–3.11*).

Limitations of telehealth

Clinicians expressed concerns about Telehealth being used to replace face-to-face consultations, to save costs (*Table 4: 4.1*). Many expressed either explicitly, or inherently, that initially patients needed to be seen in-person, due to the role of touch in assessing oedema and skin changes. Some felt an intensive period of face-to-face treatment was needed to get swelling under control, at least in acute presentations (*Table 4: 4.2*). Another issue raised by the clinicians was that of garment fitting, which they felt should be done in person (*Table 4: 4.3*). Some clinicians suggested that telehealth could be seen as an easy way to make money, and could compromise the quality of lymphoedema care (*Table 4: 4.4*).

Concerns about computer literacy and computer access for older patients were raised by clinicians and patients themselves (*Table 4: 4.5–4.6*). Clinicians also spoke of not always having access to reliable internet connections or computers in their workplaces; this was particularly evidenced in the interviews with private sector clinicians. One clinician explained that all her patient records are paper-based and given she has no access to a computer or internet at work, could not implement telehealth services easily (*Table 4: 4.7*).

Another area of concern that both the clinicians and the patients raised was around security of information. Both groups expressed concerns about sending sensitive pictures or video across the internet (*Table 4: 4.8*), and questions were raised about access to and ownership of patient data (*Table 4: 4.9*). However, this was contrasted by views of some participants who voiced no concerns about this (*Table 4: 4.10*).

Lastly, a minority of patients said they wouldn't use telehealth for various reasons: they prefer hands-on service, they have issues with their internet dropping out and dislike technology, and they were happy with their current treatments (*Table 4: 4.11*). Interestingly, however, these patients could all see the usefulness of telehealth for other patients and were still positive about its potential future implementation as an adjunct to current lymphoedema management, particularly for those with limited healthcare access (*Table 4: 4.12*).

Discussion

This study examined patients' and clinicians' experiences of lymphoedema treatment, and explored their views towards using a telehealth service to support lymphoedema management. This was the first qualitative study to explore the use of telehealth for lymphoedema, allowing exploration of issues specific to managing this condition. Findings from this study suggest both groups perceive telehealth as a mostly positive adjunct to currently available healthcare models, but identified important aspects of lymphoedema assessment and treatment that should not be overlooked.

Participants identified a number of barriers to providing or receiving appropriate lymphoedema care in the current health system, including a lack of recognition of lymphoedema, difficulties accessing services, and variation in service provision between disciplines and the public/private sectors. The under-recognition of lymphoedema by governments and the broader medical workforce has been noted previously, (Meiklejohn et al, 2013; Sierla et al, 2013; Lymphoedema Action Alliance, 2017) and was highlighted again by this study.

Current advocacy efforts are focused on building the workforce and making lymphoedema treatment more accessible, irrespective of lymphoedema type, and geographic location. Recent changes to compression garment schemes to make these more accessible and affordable for patients are promising, but inequities in access to compression and other forms of treatment still exist (Lymphoedema Action Alliance, 2017).

While early surveillance of patients at high risk of developing lymphoedema has been reported to lower the incidence and reduce the severity of lymphoedema (Koelmeyer et al, 2019), and subsequently, the associated costs (Stout et al, 2012) the mechanisms for achieving this in an already strained healthcare system are unclear. Authors of a recent study comparing an early surveillance model with the traditional referral model reported the benefits of identifying lymphoedema early, and proposed home monitoring using bioimpedence spectroscopy as a way of monitoring people at high risk for lymphoedema to identify sub-clinical lymphoedema and enable early intervention (Koelmeyer et al, 2019).

A major benefit of incorporating telehealth into lymphoedema management protocols would be the provision of specialist lymphoedema care to people who otherwise would not be able to access treatment. In this study, the use of telehealth was seen favourably as it meant patients would not have to travel to reach appointments, and clinicians could effectively see more patients in a given time-slot due to the lesser appointment time. Patients liked the idea of being able to contact a lymphoedema expert more readily when they were concerned about changes to their condition, or to seek reassurance that they were performing self-management strategies correctly. Participants could see the benefits to people living far distances from health services as well, as this could prevent unnecessary appointments when a person's lymphoedema was stable.

However, both the patients and the clinicians cautioned that telehealth should not be used as a substitute for all appointments. The importance of touch in skin assessment, as well as the accurate measurement for compression garments, were raised as common components of lymphoedema assessments, which could not be performed using telehealth. However, Galiano-Castillo and colleagues (2014) found caregivers were able to assist people with lymphoedema with an assessment using telehealth and results were highly concordant with face to face assessments performed by an experienced physician. While it is common that proposed changes to clinical practice can raise concerns and be met with resistance, if these changes could improve patient outcomes it is important to consider these options.

While lymphoedema treatment varies depending on severity of the condition and peoples' access to health services, self-management strategies are widely prescribed to manage the condition in the long term. Basic self-care can reduce the frequency and severity of infection, and while there is less evidence for limb volume reductions following self-care, greater benefits are reported for those with earlier stage lymphoedema (Douglass et al, 2016).

Effective self-care requires people with lymphoedema to be educated appropriately, and instruction and demonstration by an experienced clinicians is necessary (Douglass et al, 2016), but this could be an ideal use of telehealth to reduce the travel, financial burden and excess time involved in face to face appointments.

Clinicians interviewed for this study appeared to have a very good understanding of their patients' needs, which differs from an earlier study that reported differences in the perceived treatment barriers between patients and healthcare providers. It is possible the clinicians who participated in this study did so because they are particularly dedicated to their work and invested in the health outcomes of their patients, and are motivated by the potential for research to contribute to change in policy and practice. This could mean the views represented here are not reflective of the views of the wider network of lymphoedema therapists.

However, in the larger quantitative study reporting differences in patients' (n=162) and health professionals' (n=98) perceptions of treatment barriers, clinicians consistently reported that the proposed barriers to self-management were greater (more significant) than the patients themselves. The authors concluded that the clinicians did not have a good understanding of the barriers facing their patients, however, this could also indicate an empathic view among clinicians, who were more likely to acknowledge the difficulty of adhering to a long-term self-management programme. This latter perspective would be consistent with the authors' findings, but would need further exploration.

Conclusion

Treatment experiences for people with lymphoedema vary markedly across Australia. While there is a dedicated workforce of lymphoedema therapists who appear to have a good understanding of their patients' needs, the condition remains under recognised, leading to vastly different experiences depending on where patients live, and who they see. People with lymphoedema, and clinicians involved in treating lymphoedema, expressed positive views towards using telehealth for lymphoedema management. In this context, telehealth would be best used to deliver education to patients, provide supervisory support to non-specialist clinicians, and to monitor patients' self-management. This could save unnecessary patient travel, and free up clinicians to provide in-person appointments to those who require hands-on assessment or treatment. Concerns about security of sensitive images and access to the appropriate technology will need to be addressed prior to implementation.

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