

Experiences of caregivers providing therapy to people with head and neck lymphoedema after head and neck cancer



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This study explores the experiences of caregivers who provide therapy to people with head and neck lymphoedema after head and neck cancer treatment. These experiences inform service provision at the author's institution, so that a model of lymphoedema therapy is created with information from and about the individual and their caregiver, ensuring they are central to the development of future interventions. **Methods:** Semi-structured, one-to-one Zoom interviews were undertaken with a caregiver and a researcher. The interviews were transcribed and analysed using interpretive phenomenology. Main themes, sub themes and categories were created to present the data. **Results:** The authors analysed nine interviews and defined two main themes, three subthemes and nine categories. Participants described their journeys as a marathon, hard and long with lymphoedema representing another hurdle from the point of their loved one's diagnosis of cancer. The authors identified the relational components of lymphoedema therapy that may concurrently challenge and support the partnership, the impact it has on the person providing care and important considerations for teams teaching individuals how to provide therapy. **Conclusion:** Lymphoedema therapy requires deliberate and careful teaching from the clinical team, to impart detail to the caregiver which includes both practical facets of massage and physical intervention; alongside acknowledgement and exploration of the impact and reliance on the pre-existing relationship of the caregiver and person with lymphoedema.

Head and neck cancer is the sixth most common cancer worldwide, with more than 800,000 global new diagnosis in 2018 (Alsahafi et al, 2019). Standard treatment for head and neck cancer involves surgery and/or radiotherapy and chemotherapy, all of which may result in myriad clinical symptoms, which require therapy and subsequent rehabilitation.

These clinical symptoms can include lymphoedema, a condition in which normal flow of lymphatic fluid is disrupted, leading to structural and functional changes in the affected region (Paskett et al, 2012). It is estimated

that more than 50% of people with head and neck cancer (HNC) experience lymphoedema due to changes in lymphatic flow caused by radiation, surgery or the impact of the tumour (Deng et al, 2012; Smith et al, 2014). Head and neck lymphoedema (HNL) is associated with discomfort, functional difficulties, and effects on mental wellbeing, social roles and self-image (Paskett et al, 2012).

The standard of care for HNL varies across the globe. In the UK, there is no standard HNL clinical pathway or referral process, and people tend to be referred only if their symptoms are

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severe and their clinical teams have access to this expertise (National Lymphoedema Partnership, 2019). Historically, US standard of care relied on self-reporting of symptoms by individuals prior to referral and initiation of lymphoedema treatment. Only recently has the standard of care begun to address early HNL prior to permanent changes in structure and physiology (National Lymphoedema Network, 2011).

Once initiated, lymphoedema care includes education regarding complete decongestive therapy (CDT; Deng and Murphy, 2016; Deng et al, 2018). Individuals and caregivers are trained in manual lymph drainage, the use of compressive dressings, exercise and skin care, and are scheduled for periodic follow-up sessions with a lymphoedema specialist to monitor progress and to adjust technique as necessary (Smith et al, 2014).

Studies have shown improved outcomes when CDT is effectively integrated into the home environment (Smith et al, 2014; Yao et al, 2020). Home caregiving of patients with HNC involves caregivers providing essential psychological and practical support, including tasks requiring complex technical skills, such as feeding tube and tracheostomy care (Aung et al, 2021; Wang et al, 2021). It is inherent upon the treatment team to consider the impact of the addition of CDT to other caregiving tasks. While caregivers have great potential to bridge gaps in healthcare provision from acute or community providers, they face personal and practical challenges, such as lack of time and work commitments (Wang et al, 2021).

The perspectives of caregivers should be a core consideration and reference point for clinicians and research teams as lymphoedema interventions are developed; however, this has not been explored or represented in available literature to date. Acknowledging this issue and disconnect, a study was conducted to understand the complexity of integrating lymphoedema care into the home environment, to explore the experiences of caregivers to consider what the intervention involved and how it impacted the caregiver and their loved one, as well as to inform future interventions to be personalised and holistic.

Methodology

Interpretive phenomenology was used to enable the authors to develop theory, while keeping the caregiver at the centre of research, attempting to capture the meaning and perceptions of their experience (Lopez and Willis, 2004;

Starks et al, 2007). The authors did not seek to bracket our experience as clinical academic speech-language pathologists (SLP), but rather recognise and use this knowledge to inform a reflexive interpretation of the data gathered. The authors' interpretation enabled us to couch the caregiver perspective within the context of our clinical experience and understanding of HNC treatment and its complex sequelae, creating concepts and developing findings to a broader audience, including social process and relational aspects of care.

Design

This study used a qualitative design. Participants were identified by review of a clinical database of people treated for HNL at a single institution which provides teaching for carers on how to provide lymphoedema therapy. A purposive sampling method was utilised. A non-clinical member of the research team reached out to potential participants by telephone to describe the study and to invite interested parties to participate. If an individual indicated interest, a Zoom conference was scheduled for the participant and the researcher.

All interviews were completed via Zoom platform as this study was performed during the COVID pandemic, so it was not possible to have face-to-face, in-person interviews. The researcher then explained the study in detail and answered questions. The researchers provided the participant with the option of declining to participate, to consider participation and follow-up at a later time point, or to proceed with the interview. Inclusion criteria included age >18 years, spouse or caregiver of a person with HNL, >2 months following completion of clinical HNL treatment, English-speaking and able to provide informed consent.

The interview

The study used in-depth, semi-structured, 1:1 interviews with individuals who provided home-based HNL therapy. Interviews were performed via Zoom and were audio recorded for transcription. Duration of the interviews ranged from 35 minutes to 1 hour.

The interviewer was an SLP at the study site and provided lymphoedema care to a number, but not all of the participants. This potential bias was identified as a practical issue from the outset, as the treatment centre is one of only a handful in the US or UK that provides this treatment intervention, thus other patient cohorts who had not received training from the SLP researcher could not be accessed or

Table 1: interview guide questions and expansions.

Primary question	Expansions
What are your greatest concerns about your loved one's lymphoedema?	What bothers you about the lymphoedema? What concerns do you have about lymphoedema in the future?
How did you initially feel about being asked to be an active participant in lymphoedema treatment?	Did you feel you had a choice? How did your feelings about participating in the treatment change over time?
Can you tell me about the support you have received from the clinical team?	What training did you receive? What type of support did you have outside the clinical setting? How well did you feel prepared to provide care?
What were some of the challenges you encountered in providing lymphoedema care?	What physical challenges did you experience? How difficult did you perceive the treatment to be? What sorts of logistical challenges did you encounter?
How did providing lymphoedema care impact your relationship with your loved one?	Were there any stressors that arose due to this new relationship? Did you feel appreciated for the care you were providing?
Tell me about what you think burden is.	What aspects of treatment have felt most burdensome to you? Do you feel like burden impacts your function and quality of life?
To what degree did you feel that providing lymphoedema care at home was a burden?	Are there particular parts of care that were more burdensome? Was the degree of burden manageable? How would you compare this level of burden to what you have experienced in other areas of caregiving?
What helped you to manage lymphoedema care at home?	What have you learned that you think may be helpful to other caregivers? Why did those strategies work? Did they work all of the time?
What do you think would make lymphoedema care less of a burden?	What could the clinical team have done differently to reduce burden? Is there a schedule of treatment that you think would be less of a burden?

interviewed. To reduce this potential bias, the interviews were conducted after active intervention concluded and participants were reassured of the study aims and the importance of their views being captured.

Outside of the COVID pandemic, themes would have been checked by participants; however, due to funding, time and personnel issues related to the pandemic, this element of the study was not carried out. Semi-structured interviews included interview guide questions with expansions based on participant responses [Table 1].

Verbal consent was obtained from the participants before inclusion in the study. Full ethical approval was granted from the Stanford University Institutional Review Board. All personal identifiable data was anonymised. The relative rarity of HNL coupled with identification

of the researcher and study centre meant that specific information about participants needed to be omitted from the analysis for participant confidentiality.

Sample

Sample size guidance for phenomenological research ranges from 1 to 25 (Creswell, 1998; Starks et al, 2007). It was anticipated that 8–20 people would participate in the research in accordance with the numbers of people who had been trained to carry out lymphoedema therapy and the limitations of availability for interviews during the COVID-19 pandemic. Alongside these practical issues, the research team decided that recruitment would stop when new patterns ceased to be identified in the transcripts as they undertook reflexive analysis during the data collection (Parahoo, 2014). The data were transcribed and analysed as collected, so the point of saturation was identified in a timely manner and agreed upon by the research team.

Analysis

Each audio file was transcribed verbatim. For quality assurance, review of two transcripts was completed by a member of the research team who was not involved with either conduction of the interviews nor the initial transcription. Three reviewers independently analysed each transcript using inductive thematic analysis, parsing sentences, phrases and words into meaningful units. An iterative approach to coding took place, where the senior author collected the codes and created broad themes, sub themes and categories. This was a reflexive process involving changes and challenges to the categorisation and definition of the themes. The titles of the themes are all direct quotes from the data. Discrepancies between the raters' perceptions were highlighted, discussed and reconciled through written and verbal communication.

Results

A total of 18 potential participants were contacted. Nine individuals either did not return calls or indicated they were not interested in participating. Nine caregivers of people with HNL were interviewed. Due to the small number of participants and potential for identification of subjects, only composite information regarding demographics is presented here. All participants were women and Caucasian with an age range of 42–80 years, with the majority of participants in their 60s.

Table 2. Identified themes, subthemes and categories.

Main theme	Subthemes	Categories
It's a marathon	Once I got comfortable, I was fine	Fear of touch
		Uncertainty
		Improved confidence with time
	I think that was my job	Slogging through
		Feeling empowered
		Logistics
Another hurdle	My heart was in my hand	Fear of the unknown
		Tug of war
		Being with us

There were two main themes identified during analysis: "it's a marathon" and "another hurdle" [Table 2]. The concept of HNC treatment as a marathon and the lymphoedema treatment as one component of that marathon was echoed by multiple participants.

"It's a marathon"

"I think the lymphoedema part was a little easier but it's more of an, it's still a marathon, you know, the radiation's a marathon and then lymphoedema is just kind of another thing" (Kate).

"It's a marathon" was mentioned 20 times by participants. Within this theme, two subthemes were identified: "once I got comfortable, I was fine" (mentioned nine times) and "I think it was my job" (11 times).

In regard to getting "comfortable" with the treatment, different themes around discomfort manipulating the area of treatment and worrying about hurting the loved one were identified. The head and neck itself seemed particularly concerning for participants, as the location of the radiotherapy was also the location of the original cancer.

Sally and Kate explained their concerns and challenges regarding the location of the treatment and anxieties around causing discomfort or harm: "I mean if it was a knee, if it was an arm, if it was something like that, I think I'd be more comfortable. But when you're dealing with the neck and the throat and, you know, with him having the surgery and the treatment he had and the rawness of his neck. It's a real personal thing because it's, it's touch on your face" (Kate).

"Being nervous touching him ... and fear that I may hurt him, and I mean I was constantly saying: 'Am I hurting you? Am I hurting you?' He says: 'No, you're not'" (Sally).

Additionally, participants reported some

uncertainty about whether they were doing the treatment correctly initially, with reports of increased confidence over time, these issues formed the categories "fear of touch" (mentioned 13 times), "uncertainty" (15 times) and "improved confidence with time" (12 times).

Emma described feeling disconcerted about the effect of the treatment she was providing: "Even though we could see results, it was just ... is the pressure right? ... Am I moving in the right direction?" (Emma).

"I think that was my job"

"I think that was my job" was mentioned 11 times. Within this subtheme, many of the caregivers expressed a sense of obligation, believing it was their job to undertake the therapy and to participate in care. In some cases, that sense of obligation was akin to "slogging through it" (mentioned 13 times), which formed one of the categories, while in others, participants felt empowered by having something that would help their loved one. Two caregivers also mentioned their own physical discomfort providing the treatment as part of the "slogging through it" category.

The positive facets of the "empowered" category (mentioned 12 times) were described by Kate as she explained how with experience and expertise, initial burden became more manageable and positive.

"So, it was a burden at first, but it's like anything you know, you have something that you need to do, and you, uh, figure out how to do it systematically and ... then it doesn't become a burden" (Kate).

"Feels like a lot on your plate between you need to be doing this, this, this and this" (Anna).

"I would relieve him and then I would put him to sleep, and he'd just go to bed and sleep, and I would be the one hurting" (Pam).

"In a way that I'm now helping him where in the other treatments I felt useless. That I couldn't really do anything ... Except give him his meds to make him feel better. But I didn't feel involved" (Sally).

For many, identifying strategies to optimise the practicalities of treatment was paramount to "getting the job done".

Emma detailed her experience of embracing and engaging with the experience, while Pam described how she embedded the process into her daily routine. This formed the category "logistics" (mentioned 15 times).

"I embraced it ... I was happy to be [x's] primary caregiver because I knew he would get the best quality of caregiving care ... I've

always taken that role in our relationship, so it was absolutely not an issue" (Emma). "I had everything very scheduled. So, I just scheduled it. It has to be scheduled" (Sally).

"I give him his breakfast, you know, then it's the exercise, the massage. So, it's just kind of folded itself into the family routine" (Pam).

"Another hurdle"

"Another hurdle" was the second primary theme and was mentioned 12 times. Many participants shared their feelings about having a new issue to address after already participating in a lengthy and complex cancer treatment, and recognised lymphoedema therapy as an addition and separate to the primary treatment.

"We were just getting over the radiation treatment part of it and, and then that happened afterwards" (Kate).

"It came at a point when we thought everything was over... And then this showed up... in that perspective, the timing sucked" (Emma).

Several participants indicated that the emergence of another cancer-related issue left them with a sense of "my heart was in my hand" (mentioned nine times). For several, this was reflected as fear of the unknown and/or fear of recurrence. Participants worried that the lymphoedema represented something new and unknown. In other cases, a sense of loss within the relationship was expressed when the management of the lymphoedema was discussed.

"There was a concern as to whether this indicated that there was a more serious problem, um, post-treatment, if it was any indication of, of return of the cancer or you know, just some kind of a, a bad signal" (Emma).

"If it doesn't resolve. Could it, could it escalate, could it go to something bigger?" (Pam).

Through the analysis, the authors also identified the impact HNL treatment had on the pre-existing relationship, at times creating challenges between the individuals, this information formed the basis of the category "tug of war" (discussed 15 times). It seemed that the caregivers had absorbed the responsibility of CDT into their day-to-day routine, but for some, this came with a cost to their relationship.

Pam provided insight to the loss she felt, associated in part with the changes caused by the HNC treatment and lymphoedema. Kate described an acceptance of the intertwined role of the relationship and the lymphoedema treatment consigned within it.

"I feel that everything is now fallen on me. The

husband that did more than half of his share is not. And sometimes I do tell, whisper in his ear when he's sleeping. I miss you" (Pam).

"It's just gonna be part of [x]. So it's just part of our, our relationship now" (Kate).

Finally, participants expressed gratitude to the treatment team for being there to hold their hand as they helped their loved one recover. This sense of the clinician "being with us" (described 10 times) was integral to the caregivers feeling comfortable and adequate to provide the home care and formed the final category.

"From the beginning all the way through. You know, what's happening, what's gonna happen, what to expect. Everything was really clear. So that made him feel comfortable. And as long as he felt comfortable and was able to tell me what was going on if I wasn't there, um, made things much more easy. And um, I don't think we ever felt like we were unaware of what was gonna be happening" (Lucy).

"Without that support, um, I don't even know. I, I just don't know. I just don't know what I would have done" (Sally).

This theme was important as it provided insight into the importance of meaningful and supportive relationships created between the clinical team and the individual. These relationships moved beyond the transfer of clinical information, they encompassed a sense of support and comfort.

Discussion

This research uncovered novel and important facets of the experiences of caregivers who provided lymphoedema therapy. Following analysis, the data raised important questions about the impact of the caring role, the intimacy and dynamics entwined in these relationships, and the value of the clinical team to recognise, acknowledge and facilitate discussion around these issues. The results suggest HNL care requires a specific transaction of a skilled therapy in the context of a pre-existing relationship along with a targeted and unique support system and training from the clinical team, which has not yet been explored in detail in research literature.

The results uncovered positive and negative aspects of providing HNL therapy. Many participants expressed a sense of empowerment and appreciation of their ability to actually "do something" to help their loved one. This was positive and seemed to be an important achievement and output of what was difficult and initially complex therapeutic intervention. Our small sample size limited the authors' ability

to explore whether this positive outcome would have been identified had the carers not believed they achieved improved function for their loved one. While most participants struggled initially, all indicated they felt comfortable providing care at home over time as learning and adaptation took place.

In contrast to prior literature suggesting that increased physical care requirements correlated with increased caregiver burden, most of the caregivers interviewed indicated they felt CDT was associated with very little burden (Chen et al, 2009; Patterson et al, 2013). It is possible that the timing of lymphoedema therapy after the majority of cancer treatment has concluded provides a different point of reference in regard to perceived burden. This is consistent with research suggesting that burden decreases after completion of acute treatment (Balfe et al, 2016). This is an important consideration for clinical teams, who have limited data on the perception of burden, capacity and demands for caregivers, and has the potential to help navigate discussion around what type, frequency and intensity of lymphoedema therapy the carer may be able to provide.

To the authors' knowledge, there is little information for clinicians around how best to explore the engagement or buy-in from carers specifically related to lymphoedema therapy, and there are no standardised questionnaires, information leaflets or online resources to help inform carers of what may be expected. The data have the potential to inform and create resources for both carers and clinicians.

This study helped the authors understand the role of training and support from the clinical team, and the importance of being alongside the caregivers as they developed and perfected their lymphoedema skill, rather than simply imparting information and expecting the individual to know what to do. Effortful learning was obvious in the data, and this learning seemed to rely on the relationship and communication with the clinician.

In the authors' dataset, caregiver training typically included demonstration by the clinician followed by return demonstration by the caregiver. Feedback was provided in real time by the clinician, as well as the patient, and caregivers were provided with recommendations regarding body mechanics and setting up the optimal environment for home treatment. Written instructions, pictorial examples, and/or video instructions were provided. Patients and caregivers were encouraged to provide each other with feedback

about the process to help both parties feel more comfortable. One successful treatment dyad reported, "He would say, you know, 'Press a little softer' or 'That's too hard,' so you know it was easy to adjust."

Caregivers were encouraged to contact the clinicians with any questions or concerns they may have, which likely helped create a sense of support as the caregiver learned to provide CDT. Further, they were invited to participate in subsequent visits for review of technique. This was time intensive, but seemed to manage and support the iterative learning participants described. While this collaborative care was the treatment model, some caregivers still expressed some trepidation with the initiation of therapy due to the fear of the unknown, as well as concern that they may do something to hurt their loved one.

One participant stated: "The tutorial was wonderful. In the beginning it was shaky. I mean, with anything learning something new, and especially with someone's health. It's scary."

This finding reinforces the need for continued support by the clinical team, even when patients are delegated to a home-based intervention. Literature around learning and needs of caregivers is limited in HNC (Wang et al, 2021); however, within broader topic areas there is clear reference to the importance of ongoing support about illness and treatment information as this is frequently reported as an unmet need.

Caregivers made observations regarding challenges that they faced in providing lymphoedema care which are important considerations for clinicians working with HNL. The physical burden on caregivers was a common theme when pre-existing caregiver injuries were not initially disclosed. Over time, some caregivers noted increased pain due to their participation in treatment, particularly if they had underlying conditions, such as rheumatoid arthritis or carpal tunnel syndrome. The importance of a frank and candid conversation between the clinician and the caregiver to explore these issues seems fundamental, but is possible to overlook within the pressures of busy clinics and without standardised models of service provision. Both physical and emotional challenges should be addressed in an open and supportive manner to ensure carers receive holistic and personalised support.

Lymphoedema care teams may consider completion of caregiver needs surveys, such as the Cancer Caregiver Information Needs Checklist and the Partners and Caregivers

Supportive Needs Survey (Girgis et al, 2011; Longacre et al, 2015).

Another hurdle for many was finding time to integrate treatment into the daily routine. Motivational interviewing and discussing the family routine are both strategies the clinician could employ proactively to identify and work through barriers before they become problematic (Pollak et al, 2015).

While most caregivers expressed appreciation for being able to help their loved one, many also expressed fear, both of recurrence, as well as the unknown, as described by Hodges and Humphris (2009), who explained that caregivers often have high levels of fear and anxiety around the potential for recurrence. This theme was clear in the interviews; most caregivers were concerned that HNL may have represented recurrence, and the focus of a manual therapy in the region of the cancer kept that concern front and centre.

The lymphoedema treatment was couched closely in the experience and diagnosis of cancer. The intimacy of touch to the head, face and neck was also raised in the context of fear. Individuals explained the anxiety of touching the location of the cancer. There was also a sense of responsibility in being able to identify the difference between swelling and new cancer and making sure they got this right.

These physical and emotional tolls need to be carefully considered when engaging caregivers as part of the treatment team. The authors' data suggest that caregivers may be grieving for altered relationships, while vigilantly monitoring for disease and trying to avoid harming their loved one. With this in mind, it is pertinent to consider how lymphoedema therapy may also impact sexual relationships. The intimacy involved with touching the neck and face, making sure you "get it right" is likely to exist among other elements of physical and sexual relationships. It is possible lymphoedema therapy could provide an appropriate opportunity for discussion of intimacy and sexuality (Carter et al, 2018), and the authors' hope to develop this concept in future studies.

The data suggested that the caring required for home CDT relies in part on an intact caregiver-patient dyad. It seemed that the caregiver needed to be engaged in the recovery of their loved one, which relied on effective communication between both parties. Unfortunately for many, when HNL arises after treatment, the patient and their caregiver have already endured months of challenging treatment and subsequent impact on their

relationship. Adding in a new treatment task was described as placing the caregiver into the role of "taskmaster." However, when these partners worked together to make this a priority, a symbiotic relationship developed.

One participant stated: "I guess it's a positive thing ... it's our little interlude." Many caregivers expressed that they enjoyed the time together, focused on one another.

A key limitation to this study is that only female caregivers were interviewed. While we were able to represent a wide range of caregivers' ages (40s-80s), despite our attempts through purposive sampling to identify male and culturally and ethnically diverse caregivers, none agreed to participate. Thus, the points of view presented exclusively represent the experience of female caregivers. Future research would benefit from a richer representation of individuals and experiences.

This finding raises an important issue about diversity within research, and the importance of developing innovative ways to engage groups of people who may be less likely to take part in clinical studies. Ngozi et al (2011) suggest considering individual, community, researcher and scientific barriers to provide solutions to issues in recruiting and retaining people of diverse backgrounds in research, there are plans to utilise these concepts in future studies to ensure robust representation (Ejiogu et al, 2011).

Another potential limitation is that many of the caregivers had worked directly with the interviewer in learning to care for their loved one's HNL. This prior relationship may have influenced responses; however, owing to the novel nature of the intervention and the practical implications of the emerging COVID-19 pandemic, the authors needed to make pragmatic adaptations. While these limitations are acknowledged, this work provides an important look into the experience of caregivers providing care for loved ones with HNL, and forms the basis for future work, which will deliberately mitigate the practical challenges the authors faced.

Recommendations for clinical teams

- Caregivers require clarity, an iterative and staged approach to learning how to perform CDT.
- Caregivers benefit from ongoing relationships with clinicians who recognise the realities and multiple spheres that their physical and emotional experiences exist within when they are providing CDT.
- There is an opportunity to explore intimacy

in line with CDT, which may otherwise be overlooked.

- Caregivers experience a range of emotions, tensions and expectations which arise from themselves, their loved ones and/or their relationships. These require space for discussion and acknowledgement from the clinical team.

Conclusion

Lymphoedema therapy has the potential to have a significant and positive impact on individuals following HNC treatment. When this intervention is provided by a caregiver, it brings inherent challenges and experiences warranting acknowledgement and support from the clinical team. The intervention seems to be learned in an iterative way, slowly building the caregiver's confidence. The emotional impact on the caregiver is complex with some positive and negative repercussions. In recognising these subtle and wide-ranging issues, the clinical team has an opportunity to optimise this important and unique therapeutic intervention. **WINT**

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