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ORIGINAL ARTICLE

Patient experience of head and neck lymphedema therapy: a qualitative study

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Abstract

Purpose Lymphedema is a common late effect from head and neck cancer and/or its treatment. Guidelines recommend that patients with lymphedema should be referred for therapy in a timely manner to maximize control of lymphedema-related symptoms. However, there is paucity of information regarding treatment outcomes in the head and neck cancer population. To address this gap, we conducted a qualitative study to gain understanding of head and neck cancer patients' experience pertaining to lymphedema therapy, barriers to treatment, perceptions concerning physical and psychological benefits, opinions about therapists, and suggestions to enhance outcomes.

Methods Twenty head and neck cancer patients who underwent lymphedema therapy completed semi-structured face-to-face interviews. Interviews were audio-recorded, and verbatim transcriptions were completed. Thematic analysis was employed to analyze the interview data.

Results A majority of the participants ($n = 15$, 75%) completed a full course of lymphedema treatment. Most participants expressed physical ($n = 18$, 90%) and psychological ($n = 14$, 70%) benefits about the lymphedema therapy, e.g., decreased swelling, increased swallowing function, and multi-faceted healing. More than one third of the participants described barriers hampering their lymphedema therapy, e.g., insurance coverage, return to work, and availability of lymphedema therapy. Many participants proposed suggestions for improvement of lymphedema therapy, e.g., personalized education, longer treatment time, and caregiver education.

Conclusions The study has underscored the potential benefit of lymphedema therapy in the head and neck cancer population. Substantial barriers to therapy were reported and need to be addressed. Opportunities to improve lymphedema therapy outcomes were suggested. Personalized strategies should be considered for ensuring optimal patient outcomes.

Keywords Head and neck cancer · Lymphedema · Lymphedema therapy · Experience · Qualitative

Introduction

Therapy for locally advanced head and neck cancer is associated with significant late toxicities [1]. Among the late effects, soft tissue toxicity as manifested by lymphedema and fibrosis are common and impactful late effects [2–4]; however, until recently, soft tissue toxicities have been under-recognized and under-treated. Recent data have focused attention on this critical late effect. It is now evident that head and neck cancer survivors treated with combined modality therapy are at high risk for developing lymphedema (defined as swelling due to lymph fluid accumulation within interstitial spaces) and lymphedema is associated with increased symptom burden, functional impairments, and poorer quality of life [3–7].

Currently, lymphedema is an incurable but chronic, manageable condition. The optimal strategies for managing head and neck cancer treatment-related soft tissue toxicities have yet to be clearly established as level I evidence to support interventions is lacking. Available evidence and clinical experience suggests that early identification of lymphedema

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followed by timely therapy may result in regression of swelling and prevention of chronic fibrofatty changes. Thus, current usual care (standard of care) for treatment of lymphedema regardless of site is *complete decongestive therapy* (CDT) that includes manual lymph drainage, compression techniques (garments and bandages), remedial exercise, skin-care, and self-care training [8, 9]. The Oncology Nursing Society's Putting Evidence into Practice protocol has rated CDT as "Recommended for Practice" (highest level evidence) [10]. However, this recommendation is based upon a scientific literature review of the data from studies conducted primarily in individuals with extremity lymphedema.

A recent retrospective chart review explored the impact of CDT on head and neck lymphedema [11]. The authors reported that approximately two thirds of participants had clinically significant responses to therapy [11]. This study supports current practice patterns; however, prospective longitudinal studies are needed to provide level I evidence to confirm the effectiveness of CDT in the head and neck cancer population. In order to inform clinical trial design and help determine appropriate study outcomes and metrics, we need to have a better understanding of the patient's experience surrounding CDT. In addition, a conceptual framework that reflects the critical aspects of lymphedema therapy as perceived by the patient needs to be developed. To fill these gaps, we undertook a qualitative study to explore important components of the treatment experience, barriers to treatment, perceptions concerning physical and psychological benefits, role of the lymphedema therapists, and suggestions to enhance outcomes.

Materials and methods

Study participants

A qualitative, descriptive study design was used. To obtain detailed and rich data, a purposive sampling method was used to recruit the study participants. The following procedures were employed to recruit potential participants from the VICC Head and Neck Cancer Clinics. First, potential participants were informed by their oncologists about the opportunity to participate in the study. To avoid perceived coercion, the oncologists did not discuss the study in detail or obtained informed consent. Second, the trained research staff approached potential participants who expressed interest in the study. Potential study participants were provided one copy of the informed consent to read and review. They were given ample time and opportunity to ask questions, and all questions were answered by research staff. For those who were willing to participate in the study, they were asked to sign a written informed consent document as the research staff witnesses.

Written informed consent forms were obtained from all participants prior to initiating any study-related research activities. Eligibility criteria for participation were > 21 years of age; > 3 months after head and neck cancer treatment; currently free of evidence of cancer; a history of lymphedema therapy; and able to provide informed consent. During the study recruitment period (July 1, 2014–February 5, 2015), the trained research staff members approached 38 potentially eligible participants and enrolled 22 of them. Patients who declined participation cited the following reasons: time constraints ($n = 9$); lack of interest ($n = 4$); and travel limitations ($n = 3$). Two participants were withdrawn by the Principal Investigator (first author) due to lack of compliance with study activities. Thus, we reported data from a cohort of 20 participants who completed study measures.

Study procedure

After signing the consent form, each participant completed a demographic questionnaire. Then, the research staff conducted a physical examination to determine soft tissue status in the head and neck region. Next, the research staff conducted one-on-one, face-to-face, semi-structured interviews with each participant by using a standardized script. The interviewers were two registered nurses and trained by the Principal Investigator (first author) to ensure consistency and fidelity of interview process, probing questions, and questioning style. Interviews were audio-recorded and then transcribed verbatim. A research staff member who was not involved in either interviewing participants or transcribing checked accuracy of all transcriptions through listening to each interview recording. Recruitment and enrollment of new participants ended when data saturation was achieved.

Study measures

Demographic questionnaire

The form was used to collect the following demographic characteristics from participants: age, gender, educational level, marital status, and employment status.

Head and neck cancer disease and treatment form

The research staff used the form to obtain participants' head and neck cancer disease and treatment data through chart reviews, including primary tumor site, tumor stage, and cancer treatment received.

Interview script

In the parent study, a standardized script with 21 open-ended semi-structural questions was used to elicit participants' symptoms, lymphedema therapy experience, and status of lymphedema self-care. For the purpose of this article, we focused on reporting the responses to six questions that were related to participants' experience about lymphedema therapy (see Appendix 1). The participants were also asked to respond to additional probe questions to ensure that the interviewer understood and captured their responses on the interview questions in a clear and accurate fashion.

Data analysis

Conventional content analysis was employed to analyze the transcriptions from the interviews [12]. The analyst triangulation method of using different individuals in analysis of data was utilized as a strategy to establish credibility [13]. In other words, three trained coders were involved in the qualitative data analysis, including the first author, one registered nurse with a bachelor's degree, and one research analyst with a bachelor's degree. The coders analyzed all transcriptions and identified emerging codes through the standard procedures of the qualitative content analysis. Discrepancies in coding among the coders were reviewed, discussed, and reconciled during regular team meetings. Emerging codes were presented, reviewed, and discussed in these team meetings to ensure clarity and consensus of all the codes. The constant comparison method was utilized throughout the data analysis to identify similarities and differences between the codes. Qualitative analysis was ended when no additional codes emerged from the data. In addition, descriptive statistics were used to describe participants' demographic, disease, and treatment characteristics.

Results

Sample characteristics

Participants' characteristics are summarized in Table 1. The participants were White, median age was 58.7 years old, 65% were male, and 55% were employed. They all received multimodality treatment (Table 1). All participants completed a face-to-face audio-recorded interview. The median duration of interviews was 23 min. Family members/caregivers were present among 20% of the interviews.

Table 1 Demographic and clinical characteristics

Characteristics	Frequency (%) (*N* = 20)
Sex	
Male	13 (65.0)
Female	7 (35.0)
Marital status	
Married/living with a partner	17 (85.0)
Single/windowed/other	3 (15.0)
Smoking history	
Prior/current smokers	11 (55.0)
Never smokers	9 (45.0)
Drinking alcohol history	
Prior/current	15 (75.0)
Never	5 (25.0)
Primary tumor site	
Oral cavity	6 (30.0)
Nasopharynx	1 (5.0)
Oropharynx	10 (50.0)
Larynx	1 (5.0)
Salivary gland and other	2 (10.0)
Tumor stage (TNM) at diagnosis	
Stage I	2 (10.0)
Stage II	4 (20.0)
Stage III	2 (10.0)
Stage IV	11 (55.0)
Could not be staged	1 (5.0)
Complete cancer treatment received	
CCR only	3 (15.0)
Chemo-induction and CCR	8 (40.0)
Surgery and CCR	4 (20.0)
Surgery and radiation	2 (10.0)
Surgery, chemo-induction, and CCR	3 (15.0)
Characteristic	Median (min, max)
Age (years)	58.7 (42, 75)

CCR concurrent chemoradiation

Deciding factors for initiation of lymphedema therapy

Most participants (*n* = 18, 90%) delineated several factors that influenced them to make the decision to initiate lymphedema therapy. The themes identified included the following: compliance with doctor recommendation/suggestions, success with cancer treatment brought trust in aftercare process, open and willing to follow suggestions that may improve the condition, fear with living with lymphedema permanently, concerns with cosmetic appearance, insurance coverage helped with decision, and assumed treatment would resolve issue. The exemplar quotations are presented in Table 2.

Self-reported experience of lymphedema therapy

Completion status of lymphedema therapy and perceptions of barriers

A majority of the participants (*n* = 15, 75%) reported that they completed a full course of lymphedema treatment, although

Table 2 Deciding factors for lymphedema therapy

Themes	Exemplar quotes from participants
Compliance with doctor recommendation/suggestions	"Well I was just doing what the doctor said to do." (ID1015) "Again, I was just up for whatever they (patient's doctors) suggested." (ID1022) "She (patient's doctor) thought that would be a good idea. Uh so I said yeah. I did not see any down side to it (lymphedema therapy), I did not see any risks to it." (ID1006)
Success with cancer treatment brought trust in aftercare process	"Well I mean everything that, that they have been having me do was. Everything worked, you know. They were treating me and getting me through this whole deal. So wasn't no need not to believe them and push on." (ID1017)
Open and willing to follow suggestions that may improve condition	"I would do anything they (patient's doctor) told me to do to get rid of the discomfort." (ID1010) "Uh I, I mean I was I was open and willing to you know to you know to do the therapy and to uh you know. Anything to help out." (ID1011) "I was. I have done everything I have been told to do…If they told me to stand on one leg and jump like a. Jump, I would have done it. You know I want to live." (ID1021)
Fear with living with lymphedema permanently	"Yeah I was afraid, because I kept asking everybody 'am I going to have to live with this the rest of my life?'. Because for a while it bugged me a little bit, but then it just gradually and gradually got better." (ID1021)
Concerns with cosmetic appearance	"Well I did not like the way it looked, mainly. It did not hurt but it just it, I did not like the way it looked." (ID1008) "Well I, I did not want my face to be lopsided like that. So I figured whatever I could do to manage that." (ID1018)
Insurance coverage helped with decision	"Insurance covered it, doctor said do it, and I was willing to do everything." (ID1015) "…um it was recommended to me and I was told that it would help. And um I guess my insurance covering it helped." (ID1001)
Assumed treatment would resolve issue	"Uh, I do not recall my initial thoughts. I do remember being uh, mistakenly impressed that, well okay this is something that I am going to go through a little bit then it is going to be finished and then I will be cured and then we'll will live happily ever after. But that of course did not happen, has not happened, and is not going to happen." (ID1018)

25% of the participants ($n = 5$) specified that they completed a partial course of treatment. More than one third of the participants ($n = 7$, 35%) described barriers hampering their lymphedema therapy. The themes identified included family problems, financial restrains/insurance coverage, driving concerns/transportation issues, return to work, time constraints, physical limitations (e.g., feeling ill), availability of lymphedema therapy locally, and switching lymphedema therapist/location (see Table 3 for exemplar quotes from participants).

Perceptions concerning lymphedema therapy

Themes: Positive experiences of lymphedema therapy—physical and psychological benefits Most participants ($n = 18$, 90%) expressed physical benefits about the lymphedema therapy provided by their lymphedema therapists. The themes included marked improvement, quick results, decreased swelling, increased range of motion, pain relief, improvement in appearance, improvement of symptoms, increased swallowing function, increased lung function, and fluid movement (see Table 4 for exemplar quotes from participants). A majority of the participants ($n = 14$, 70%) also reported psychological benefits from lymphedema therapy. The themes identified included multi-faceted healing, appreciation of attention, pleasurable experience, relaxing, calming, importance of motivation, and establishing a routine (see Table 4 for exemplar quotes from participants).

Themes: Positive experiences of lymphedema therapy—role of the lymphedema therapists Many participants ($n = 13$, 65%) described that they had a pleasant experience with lymphedema treatment, owing to the role of the lymphedema therapists. The themes related to the role of the lymphedema therapists included knowledgeable,

Table 3 Perceived barriers to lymphedema therapy

Themes	Exemplar quotes from participants
Family problems	"Yeah um for a few weeks (lymphedema therapy). Yeah and then things got difficult so I quite going…Um with my family, Medical, My mom. After I had problems then my mom started having problems, so…So I uh decided it would be better for, easier, if I did not have to do them (lymphedema therapy)." (ID 1003)
Financial restraints/insurance coverage	"No, he (patient's lymphedema therapist) recommended that but they (compression device) are quite expensive and I did I was not in pain so I did not consider…I do not think (compression device covered by insurance), I do not know. I do not. I think it was at the time my insurance was up. Um but I just did not feel that I needed it so I did not pursue that." (ID 1001)
	"I do not know how many (therapy sessions) were recommended. I went to all of em that they recommended until my insurance ran out and it did not run out until like in December. So I only had to miss a couple of weeks..." (ID 1004)
Driving concerns/transportation issues	"Then they sent me to another place at xxx that was closer to where I lived because by then driving was becoming an issue and I could not drive well enough to get myself to and from xxx and I did not have anybody to take me." (ID 1004)
Return to work	"No I did not (finish all of the recommended treatments), because something was going on. I had to go back to xxx (patient's working place)...Mm hmm. Because of my job, I had to go to another state. Mm hmm. Yeah so, while I was recovering at home, in xxx (home state), I went to these this going to this therapy. But once I went back to xxx (patient's working place) that was impossible, because it's 7 h to the house." (ID 1012)
Time constraints	I am not sure why I quite going out there um. Oh I know, we decided that I was going to go to the hyperbaric chamber over at xxx hospital and I could not do everything. I could not go to the lymphedema clinic and the hyperbaric treatment and come out here once a week or once every other week. There just wasn't enough days in the week to do everything that they wanted me to do um." (ID 1004)
Physical limitations (e.g., feeling ill)	"I think what would happen was they would schedule me so far out each time that I was there. They would give me certain appointments and stuff and a lot of them got canceled because like I would have real thick mucus and stuff and just literally I'd be sick. It made me sick, you know the mucus did and some of them got canceled you know and then once treatment was over I think I might have went some more…I cannot remember. I think I went a little bit after treatment was over and then I just I stopped going." (ID 1013)
	"Um, my first round of lymphedema therapy here was prematurely stopped because I wasn't physically able to go. I have no idea." (ID 1020)
Availability of lymphedema therapy locally	"…this side of my face would get real tight, but I was going to different therapists. I went to so many different people that worked on this um and there's not that many people in xxx (patient's home city) that work with lymphedema. You know." (ID 1004)
Switching lymphedema therapist/location	"Uh, Dr. xxx (patient's oncologist) wanted the lymphedema (therapy) to continue, the lymphedema therapy to continue. Uh, even though I wasn't getting the results that I get down here. Um, when they submitted, because she wanted me to have um posture therapy too and they submitted orders and they did not submit orders to her for the lymphedema therapy too so the lymphedema therapy was dropped and it should not have been. And when she tried to resubmit for the lymphedema therapy Dr. xxx (patient's oncologist) had already felt like it would be beneficial for me to attend here. So that's when I restarted down here…So it was going to be ongoing…But it fell through the cracks." (ID 1020)

supportive, thorough explanation, demonstration, informative, realistic, talented, competent, personable, caring, and encouraging (see Table 5 for exemplar quotes from participants).

Themes: Negative experiences of lymphedema therapy Some participants ($n = 4$, 20%) described issues related to lymphedema therapy. The themes identified included slow progress, less experienced therapist, therapist

Table 4 Positive experiences of lymphedema therapy—physical and psychological benefits

Themes	Exemplar quotes from participants
Marked improvement	"I mean, it was just amazing that it really, how I would feel after they would do it. I mean I would walk out of there feeling like a 100 times better than when I went in." (ID 1013: marked improvement) "I believe everything, it (lymphedema therapy) worked out well. So knowing what I know now versus what I would do again I would probably do the same thing all over again. I believe it helped me you know back to mighty close to normal again." (ID 1014: improvement) "Positive (lymphedema treatment experience), um I could tell the difference, there was a numerical difference and I could I could tell the difference. Um and that's why I wanted to go back when the insurance would pay for it again or when, you know, kick in with the insurance. My insurance renews in August and I went back in August because it was getting a little bit stiff around here and she did some work on that again. Now it's a lot a lot better um and she gave me all the exercises to do at home." (ID 1015: improvement) "And we did not realize the full extent of it and why it needed to be done until he, the first time he went and she was doing so much. He could feel it, he could tell the difference then. So then he kind of got on board with it." (ID 1012: improvement) "Yeah, um use it do it. There's all kind of, 99% of therapies out there, to me, is just a bunch of you know…But, um Lymphedema therapy, if you have head and neck carcinoma um that is legitimate therapy. It's important therapy, if you do not do anything else do that. That's the final word I got to say on that one." (ID 1012: believe that lymphedema therapy is preeminent)
Quick results	"No I think, I would not change anything (about lymphedema therapy). Um (pause) no I think the, you know, the massages he (patient's lymphedema therapist) went through really benefitted me. And I did them for a period of time thereafter, but I noticed some pretty quick results." (ID 1006: quick results) "Now I mean, when she (patient's lymphedema therapist) would start the massages and I could immediately feel the difference, you know what I mean." (ID1018: immediate difference) "…it (lymphedema therapy) was positive. It was one of the few times I have actually gone in and got treatment and actually walked away feeling, you know, some sort of relief instantly, from that very first session." (ID 1019: instant relief)
Decreased swelling	"I mean they (the patient's lymphedema therapists) were really really good at what they do and they could get it to go down, I would go in out there just almost in tears because it was so swollen and they could get it…It (lymphedema treatment experience) was very positive, very positive…" (ID 1004: decreased swelling) "…Certainly it (lymphedema therapy) helped with the swelling um but it also helped educate me about what was going on." (ID: 1001: decreased swelling) "…I would say that it helps me manage it (swelling). You know, I have not noticed any. Well Dr. xxx here, my radiation oncologist, has been working with me on that. He, he's my third party examiner, you know, and he will say 'it's looking great, it's really not bad at all'. I have had a number of people tell me that whatever I am doing is working because if they do not really look for it they do not see it, you know, and that's truly the same for me." (ID 1018: decreased swelling) "Uh, it (lymphedema therapy) was great. I looked forward to the therapy. And I mean, you know, it really helped. I could see results for that. …something…and you know it did not really help me and um. But this (lymphedema therapy), I could tell results. I could see that it was, I could feel things happening, fluid moving, so. It was good." (ID 1012: facilitating fluid movement)
Increased range of motion	"Yes, yeah it I do not know it just it (lymphedema therapy) did something for me because I mean I had limited in my jaw anyway and it (lymphedema therapy-massage) helped take some of that pressure you know off of it." (ID 1013: increased jaw range of motion) "I would go in you know and, because I had a lot of problems, I would feel better when I left. You know and it was very helpful to me because, you know, when this is swollen it's a different feeling. Especially when your jaw will not open. You are like I cannot even open it to get the cheeseburger in. It was all together so it might have been more intense for me, you know, than someone who could move their jaw because the pain was all sort of just all in there together. Yeah I think, but I mean they were great. Very helpful." (ID 1013: increased jaw range of motion) "Well, giving me stretching exercises, routines um. Then he would massage it and rub and see where it was tight. He basically would spend about an hour with me every visit and it was a lot of getting my range of motion, just pushing me back until he I would say that's, you are going passed more than the tight range now. You know right to the point where something might pop, you know a ligament or something or a muscle might tear or strain. He would bring me, I'd let him know when I got right to that edge and then he'd back off and then, but he would remember where that was and he'd remember right where that was and he would come back the next time I came back and he would say I want you to move this farther than where you were last week. That was the basic procedure for the whole thing, but he gave me back a huge percentage of my range of motion." (ID 1009: increased range of motion) "…she (lymphedema therapist) did measurements and range of motion measurements and so you could look at the numbers and see there was an improvement and plus I could tell there was an improvement.' (ID 1015: improvement in range of motion)
Pain relief	"Um one thing that helped me a lot with the lymphedema therapy. I was having an earache due to swelling in my tubes. And the um xxx, who was a lymphedema massage therapist, knew how to relieve the earache by pressing a certain point in my inner mouth and outside and she cleared up in about five minutes. Did not take much to get attention and help for that, so I was very pleased with that result." "mm hmm. She put a glove on and she felt back there and pressed a certain place and pressed it on this side. And it just It drained it, it opened right up and it did not hurt anymore…it was immediate relief." (ID 1001: earache relief)

Table 4 (continued)

Themes	Exemplar quotes from participants
Improvement in appearance	"Oh a big big change. I mean this right here was just." "She did not even look like herself." (from patient's friend) (ID 1008: improvement in appearance) "I mean, at the time well I just. Just to improve uh you know, just to improve my uh my good looks (laughs). But uh, you know just the outward appearance..." (ID 1011: improvement in appearance) "But I mean, you could tell that, I mean you know my puffiness and everything went down. So the uh massage therapist stuff worked." (ID 1017: improvement in appearance)
Improvement of symptoms	"I feel like everything uh went well. The, well one thing I noticed was the improvement that I had from the initial session I noticed that a few months later it was like I needed like a more because some of the symptoms returned. Um and that is why I did go back, eventually, for another round in August because there was some stiffness and some swelling and what I was doing wasn't really adequate. So it was like that, going back that second time was, I do not know if it was better or if I was just paying more attention. Um but it's." (ID 1015: improvement in symptoms)
Increased swallowing function	"It's uh oh yeah. It's not perfect but it (swallowing function) it's a heck of a lot better than it was. There's still um, if I eat too or if I put too much food in my mouth at one time, yeah that's not good. It will hang up in my throat or if I. If dry food really, small dry foods will um make me choke so I have to flush it down with water or whatever…" (ID1011: increased swallowing function)
Increased lung function	"…she (lymphedema therapist) gave me whistles…I remember that because they were fun." "He (the patient) got to play with the little bubble blowing stuff (from patient's wife)". "It's excellent (for my lung function)… I am barrel chested, I got lungs the size…"(ID 1012: increased lung function)
Fluid movement	"There were places where that it was, you could feel the fluid going down, you know, and some kind of like some firmer spots, you know." (ID 1012: fluid movement)
Multi-faceted healing	"It (lymphedema therapy experience) was very positive overall and it was very healing for me in a lot of ways…it also helped educate me about what was going on…it was psychologically good for me. It was good for me to have someone touch my neck, believe it or not. …But um, that part of my face I had not really learned to accept yet so to have someone else touch it and be okay touching it because I could not touch it myself (after cancer treatment). Was very healing for me." (ID 1001: multi-faceted healing: educational, psychological, and facilitating acceptance of changes)
Appreciation of attention	"Yeah Dr. xxx (patient's physician) ordered it and set it up. I thought it was worth trying if it helped me heal better. Also I will say I liked the attention at the time. (laugh)" (ID: 1001: appreciation of attention)
Pleasurable experience	"I kind of looked at going to see xxx (patient's lymphedema therapist) and having the massage was pleasurable. Then what I did at home was more therapy (laughs)." (ID 1002: pleasurable) "Yes it (lymphedema therapy) was (good experience). Yeah it was because the people that was uh, while I was doing it, the people helping me was easy to get along with and it was it was, I guess maybe I would have to say it was a little bit fun if anything, you know." (ID 1014: fun/pleasurable)
Relaxing	"Oh it was wonderful. It felt great. I loved the massage. Of course they were very sweet, so, very pleasant. I started out going every week and then we got down to every two weeks then every three weeks and then once a month. And the last time I went she released me but said I could come back if I felt like I needed to…A very good experience. If she (patient's lymphedema therapist) had not talked so much I would have gone to sleep because it was so relaxing." (ID 1008: relaxing)
Calming	"…she (patient's lymphedema therapist) had some very uh calming uh gestures and her voice would take on a different. She was, it was very calming situation." (ID 1018: calming)
Importance of motivation	"I think she (lymphedema therapist) kind of like gave us hope that it would get better. Like you know, you can learn paths to drain and you know. She kind of motivated us to really try it." (ID 1021: Motivation)
Establishing a routine	"…Massaging or whatever, I mean it felt uh you know. Then he (lymphedema therapist) gave me exercises I was supposed to do in between you know various therapy sessions. And um, that plus my swallowing exercises I had quite a routine of what I had to uh what I had to uh to do. Um, yeah I mean I was uh. It was a good experience." (ID 1011: Establishing routine)

demanding, and symptoms not improved (see Table 6 for exemplar quotes from participants).

Suggestions for future improvement of lymphedema therapy

More than half of the participants (*n* = 11, 55%) proposed some suggestions and additional needs in the improvement of lymphedema therapy. The themes included need for lymphedema information prior to cancer therapy, need for personalized education (e.g., show anatomy picture, assist in explaining of surgery with effects), preventative activities/exercises, beginning lymphedema therapy sooner, more discipline for exercise by patient's self, push patient more, longer treatment time (e.g., need to go for more treatment sessions), group support/treatment, caregiver education, alternative therapy should be considered (if conventional therapy does not work), altering therapy when continued improvement stalled, and a warmer room (see Table 7 for exemplar quotes from participants).

Table 5 Positive experiences of lymphedema therapy—therapist attributes

Themes	Exemplar quotes from participants
Knowledgeable	"Well actually they (lymphedema therapists) they are very knowledgeable there and I mean it was a great experience." (ID 1013: knowledgeable)
	"Very good, yeah I love them (lymphedema therapists) over there. Very knowledgeable, very good at what they do." (ID 1020: knowledgeable)
	"Yeah, she (lymphedema therapist) was very knowledgeable, informative, and uh nice." (ID 1021: knowledgeable, informative)
Supportive	"It (lymphedema treatment experience) was really good. Yeah I liked…I thought he (lymphedema therapist) was really good. He knew what he was doing and he was very supportive." (ID 1006: supportive)
Thorough explanation	"He (lymphedema therapist) is just very thorough and you are going to do it xxx's way or you are not going to do it. He was very, this is how we are going to do it. He just had it down pat, what he thought you ought to do and he was very thorough in telling you what to do and, you know, showing you." (ID 1004: thorough explanation)
	"…yeah he was very helpful in explaining" (ID 1011: thorough explanation)
	"I mean the therapist I had he explain what he was doing, why he was doing you know certain things and he would uh. Different days, different treatment days he would perhaps adjust and focus on another aspect or whatever. Another um, he he'd have the same basic routine but then again he might focus on one area or one massage whatever more than others as we went through the various treatments. But yeah he was very helpful in explaining." (ID 1011: thorough explanation)
Demonstration	"She (lymphedema therapist) would do the manual stuff first and then the stretching exercises and then eventually it morphed into, she would show me how to do the manual stuff and correct me if I wasn't doing the massages correctly or I had, I wasn't channeling the fluid in the right path that she wanted to follow." (ID 1018: demonstration)
Informative	"Yeah, xxx (lymphedema therapist) was pretty informative um. He was very explanatory of everything that was going to, what we were going to do and how we were going to do it and how we were going to get there to do it." (ID 1009: informative)
	I would think that they would need to go see someone like xxx (lymphedema therapist) and then develop what they are gonna do at home away from there. But I also think that, you know, that that that patient is gonna need to come back from time to time so that the clinician can check their home progress to see how they're doing there and then either give encouragement or further instruction or whatever. If they are not getting the results, you know, at home um. (ID 1002: instructive)
Realistic	"I felt that they (lymphedema therapists) were (clears throat) giving me information, uh they were being very positive but at the same time being very realistic." (ID 1002: realistic)
Talented	"She was an excellent therapist. Now I mean, when she would start the massages and I could immediately feel the difference, you know what I mean. She was very talented." (ID 1018: talented)
Competent	"Excellent. Um the lymphedema massage therapist, if that's her right title, sure seemed like she knew what she was doing and then the fellow that lead me through just regular arm and back, neck exercise. Strengthening back muscles and so forth um. They seemed well versed in what they knew what to do or what had me do." (ID 1017: versed)
Personable	"…again especially like xxx (lymphedema therapist), as knowledgeable as he is um and as personable as he is um." (ID 1002: personable)
	"Yes. You know, xxx (lymphedema therapist), great I mean she was very personable, professional. You know, she knew what she was doing." (ID 1012: personable, professional)
Caring	"Everybody was great, of course I am lousy with names I cannot remember names but I think one of them was xxx. I just cannot remember names. And uh, they (lymphedema therapists) were all very great and it was always nice to see them because I felt like I was being cared for, I was special." (ID 1022: caring)
Encouragement	"Yeah. Well I think, it was important to me that xxx (lymphedema therapist) explained to me uh the benefits of what we were going to do, um to encourage me, to do the uh the home part of it…" (ID 1002: encouragement)

Table 6 Negative experiences of lymphedema therapy

Themes	Exemplar quotes from participants
Slow progress	"Oh, maybe 25% (reduction in swelling after the lymphedema therapy) and now it just hangs in there and I wear a compression garment every night." (ID: 1010: slow progress)
Less experienced therapist	"She (patient's lymphedema therapist near home) just wasn't as aggressive. Here I just get a deeper, well no because I am getting the voice therapy too so I could be getting those confused. Um, because I know that I know what they learn in school is basically the same. I know what they learn in school is basically the same, but they just do it so much more frequently here and because I was her (patient's lymphedema therapist near home) very first patient I just feel like she did not have the experience. Because she's good, she's good at what she does, she has the basic knowledge. I just think she does not have the frequency that they see here."(ID: 1020: less experienced therapist)
	"I am not a therapist so I cannot specifically say what the difference is, but as a patient there is just such a difference. I can tell, I can feel it, I see it in the results. They just really know what they are doing here. Um when they use the XXX tape (elastic tape) to tape, my therapist at home did not know about that." (ID: 1020: less experienced therapist)
Therapist demanding	"He (patient's lymphedema therapist) is just very thorough and you are going to do it XXX's (lymphedema therapist) way or you are not going to do it. He was very, this is how we are going to do it. He just had it down pat, what he thought you ought to do and he was very thorough in telling you what to do and, you know, showing you. Making sure I was walking the way he thought I should walk before I left and if I came in two days later for another appointment and I did not have my head up the way he wanted me to have it. You know." (ID: 1004: exact and demanding)
Symptoms not improved	"But so after going to him (patient's lymphedema therapist), you know, for you know for about a month it just, it was nothing was changing." (ID: 1005: symptoms not improved)
	"And I had um two months of therapy, lymphedema therapy, and that helped some but then it still was very, I had a lot of discomfort from it…"(ID: 1010: symptoms not improved).

Discussion

This is the first reported qualitative study to explore the patient's experience with lymphedema therapy after head and neck cancer therapy. Patients' experiences provide clinicians with insights regarding the initiation, completion, impact, timing, and content of lymphedema therapy.

Data from this study indicate that of those patients who initiate lymphedema therapy, 75% will complete the therapy. These numbers show that patients are highly motivated to undergo treatment for this late effect. Findings from this study indicate that compliance with healthcare professional recommendation is a primary reason for initiating lymphedema therapy. Participants specify trust in their healthcare professionals as a strong motivator. Thus, clinicians have an important role in the management of lymphedema; they must not only identify lymphedema early in the disease process, but also provide education and motivation to the patient, emphasizing the importance of lymphedema therapy as a method for optimizing long-term soft tissue function and cosmesis [14–16]. Other factors cited by patients for initiation of lymphedema therapy included fear of living with lymphedema permanently, concerns with cosmetic appearance, and availability of insurance coverage. Since all patients included on this study had received lymphedema therapy, we were not able to investigate reasons for declining lymphedema therapy. This needs further investigation.

One of the most noteworthy results from this study was that a substantial percentage of patients experienced barriers to the completion of lymphedema therapy. Twenty-five percent discontinued therapy due to the encountered barriers. A broad spectrum of barriers were noted including personal factors (e.g., driving concerns/transportation issues, return to work, time constraints, and physical limitations), family factors (e.g., family responsibility required discontinuation of lymphedema therapy), and healthcare accessibility (e.g., insurance coverage and availability of therapy locally). It is critical for clinicians to inquire and assess potential factors that may impede head and neck cancer patients' completion of lymphedema therapy. Supportive strategies need to be considered for assisting patients in completion of lymphedema therapy in a timely manner. The importance of clinician encouragement to complete the recommended treatment sessions cannot be understated.

Most participants in this cohort delineated physical and psychological benefits from lymphedema therapy. This is consistent with results from studies conducted in other patient populations [17–20]. It is important to note that almost all participants experienced immediate, considerable, physical

Table 7 Suggestions to lymphedema therapy

Themes	Exemplar quotes from participants
Need for lymphedema information prior to cancer therapy	"See I am looking back on it and trying to remember, I may have been given the information but looking back now I am thinking well maybe if I had known more about this (lymphedema) I would have taken it more seriously at the time. But, uh but once I saw the results I said oh this this, you know, this really is something." (ID 1015) "Well, maybe to give patients something in writing about it (lymphedema) before it happens. Just to educate them, so that when it occurs they have something to go back and read…Mm hmm, before surgery even. And again, that may be in existence. I do not remember. Yeah. I know there is a lot of information. It would be important information to include." (ID 1001)
Need for personalized education (e.g., show anatomy picture, assist in explaining of surgery with effects)	"If I had it (lymphedema treatment) to do over again? Um I, the only thing maybe would be to um have them show me a picture of myself. Not just like a medical drawing, but a picture of myself and um so that I could actually see the anatomy and understand what was going on. That would have helped me. I did not see that until I saw a live swallow study of myself swallowing and that really helped me understand the whole dynamic of all that. So doing that soon after surgery so that I could actually see what they actually did to me would be helpful." (ID 1001) "Yeah, how it is all related and what the impact of losing 39 lymph nodes is. I did not really have a clear idea of. Even of how many lymph nodes that I have all together. So that would have helped understand a little better." (ID 1001)
Preventative activities/exercises	"I would go back to my radiation. Which gave me my lymphedema basically um and try and start practice of moving and stuff." (ID 1009) "My only suggestion would be to drill it (exercise) up front as much, as best as you can just to get people just to start doing it even before they get it (lymphedema) because they will have a routine going into as oppose to they have another hill to climb. There's plenty of hills to climb and that would be what I would say. It would be a very very good idea." (ID 1009)
Begin lymphedema therapy sooner	"I would have started it (lymphedema therapy) sooner than I started it. I would have started when I first (noticed)…I probably started noticing it in, I would say January and then, like I said, I was here (in March). So it was two months (late)." (ID: 1008) "Especially when you are going to go into physical therapy and have things that happen to you started ahead of time and not. That would be the most important thing that I would have to input if I had any input." (ID 1009)
More discipline for exercise by patient self	"Um I guess, probably one thing in hindsight, even the same thing with the swallowing. I probably well actually I probably would have been more disciplined on you know doing the exercises uh he gave me between the therapies Um. I mean there were some days that I missed and so um and um you know maybe I would have continued to, you know after the therapy is over perhaps would have continued should have continued the therapy or if I had to it over again I might have continued it longer on my own, but, uh…I mean, at the time well I just. Just to improve uh you know, just to improve my uh my good looks (laughs). But uh, you know just the outward appearance as well as um you know just to make sure that there wasn't any reoccurrence or just to make sure there wasn't any ongoing issues there. You know, just be more disciplined about that particular you know exercises." (ID 1011)
Push patient more	"If I was going to have somebody, if I was going to learn it over again I would want to know all of that upfront. You know, we are asking you to do three, but do ten you know, or do three ten times a day or do ten three times a day. And put that stuff, make them try to do more than they need to do without hurting themselves. Just on, in every step of the way because it is only going to be a benefit as long as you do not get to the point where you are hurting yourself." (ID 1009)
Longer treatment time (e.g., need to go for more treatment sessions)	"I would have felt more comfortable probably had went back a couple of more times. Just like a follow-up, maybe if everything looked good then another one and then go okay well we got this under control. But we could tell that things were getting better because his scans were a little bit improving." (ID 1021 patient's wife). "I guess that is one reason why we did not go back. If it had gotten worse or stayed the same we might have made another appointment to go back." (ID 1021)
Group support/treatment	"Let me add this to it. You might, what might be a good idea too. I know you kind of keep your patients separate, but it might not be a bad idea to, if you are doing two or three patients have them do a class together or something. Just To connect the cancer community as well." (ID 1009)
Caregiver education	

Table 7 (continued)

Themes	Exemplar quotes from participants
	"Um I could of, which I did not have anybody, a caregiver go with me and learn it. I probably should have done that just in case. That probably been would have been better if I could have had me and somebody else learn it, you know, because like what if I just felt like I wasn't going to move out of the bed they could have still come in there and helped me out, but I did not do that part of it. That would probably be better." (ID 1013) "Yeah or if she (patient's lymphedema therapist) had just come out and told me what she told you (that would be helpful). Which I know she does not have time to do." (ID 1015 patient's wife)
Alternative therapy should be considered (if conventional therapy does not work)	"I think your lymphedema therapist needs to be looking at some alternative methods of treatment because I got no results. No offense, nothing personal, but it just did not work for me." (ID 1005) "Um, it (lymphedema therapy) just did not (work), maybe eventually it would have if I'd kept doing it, but uh. I just sought an alternative because I wasn't, Um I mean I am in I am in sales and I guess I wanted more than immediate gratification more immediate results and. I mean but after going for a month I did not lose any of the swelling at all." (ID 1005)
Alter therapy when continued improvement stalled	"I guess I probably would have tried something different and recognized sooner that the therapy wasn't, because about halfway through I got to a standstill and I still kept doing it but nothing improved. So I think you have to recognize when the therapy is not no longer helping and the same way with yoga, you know you have to determine when that type of exercise is no longer helping and you have to be willing to help yourself. Um, I learned that you gotta start doing your own manual exercise and I got to where I did it myself every night and that helped just as much as sometimes what the therapy did, what I paid for." (ID 1010) "Well like I said before I would recognize when a certain treatment has gotten to a standstill, where it has done all that it can and go try something else." (ID 1010)
Warmer room	"I cannot think of anything (to change about the patient's experience with the lymphedema therapy but)…Warm the rooms up." (ID: 1017)

benefits from the therapy. The physical benefits were far beyond decreased swelling. They reported other significant benefits, such as increased range of motion, pain relief, increased swallowing function, increased lung function, and improvement in appearance. Clinical trials in the head and neck cancer population investigating the efficacy of lymphedema therapy are lacking. This is in large part due to the absence of objective measures that are reproducible, precise, and feasible [21]. Soft tissue measurement in the head and neck region is fraught with difficulty due to anatomical constraints. In the absence of the ability to garner objective data regarding the efficacy of CDT, patient report becomes critical. Thus, the findings of this study are reassuring for both healthcare providers and patients, underscoring the clinical benefit of CDT. Recognizing the importance of clinical reports in this setting, we have developed a patient report measure to assess the symptom burden associated with head and neck lymphedema [22]. Psychometric testing is ongoing. Should this tool demonstrate validity and reliability, it may become a useful tool for assessing clinical benefit in future trials.

Of note, participants reported psychological benefits from lymphedema therapy. Patients noted decreased psychological distress. Participants also emphasized the importance of therapists' encouragement as a motivating factor for compliance with self-care activities and the ability to help in the establishment of a new routine.

A few participants described unfavorable experiences related to lymphedema therapy. The most common issue was related to efficacy of therapy, including a lack of or slow symptom improvement. Second, patients reported negative experiences with therapists who were either inexperienced or overly demanding. The data point out the importance of effective communication between patients and therapists. Most importantly, therapists must establish realistic expectations regarding outcome. While a high percentage of patients garnered significant clinical benefit, benefit is not guaranteed. Therapists must also ensure that therapeutic interventions are initiated at a pace that the patient can integrate into their practice.

Participants made numerous suggestions regarding lymphedema management that merit discussion. They desired information about lymphedema prior to cancer therapy. Participants also indicated that they would like to be taught preventative activities (e.g., exercises and stretching) at the time of diagnosis. Interestingly, at the study site, healthcare providers have integrated information about lymphedema and fibrosis as well as information on stretches and exercises into a pre-cancer treatment patient educational session. In addition, patients are reminded regularly to conduct routine jaw, neck, and shoulder exercises and to monitor posture. There are a number of potential underlying reasons why patients failed to assimilate this instruction or recognize the relationship between lymphedema/fibrosis and the need for ongoing soft tissue self-care. These include (1) overwhelming amounts of information received from healthcare team prior to cancer treatment; (2) potential issue with information delivery to the patient; (3) other fidelity issues regarding information per se; and (4) impact of disease and/or treatment agents on the patient's capacity to learn and process information. Regardless of the reasons, personalization of information and training needs to be considered to ensure optimal patient outcomes. Clearly, rigorously designed interventional trials are warranted to evaluate the timing and content of educational initiations directed at prevention and management of soft tissue toxicities including lymphedema and fibrosis. Currently, therapists provide the patient with one-on-one lymphedema treatment. Participants indicated that group support and caregiver education may be of value. Thus, different delivery formats for lymphedema management needs to be considered by lymphedema therapists. Participants expressed interest in alternative approaches in the setting of suboptimal response to lymphedema therapy. Through various sources, patients hear about complementary/alternative approaches such as yoga and laser therapy. Unfortunately, the risks and benefits of these approaches are unknown [10]. It should be recognized that approaches and techniques that may exacerbate soft tissue damage should be avoided until data regarding safety is available.

Strengths and limitations

Strengths

This is the first study that the authors are aware of to explore patient experience regarding lymphedema therapy in individuals with head and neck lymphedema. Through semi-structured interviews, the study provided insightful information and shed light on the importance of lymphedema therapy. It provided critical data for future large clinical trials to examine the effectiveness of CDT and compare effectiveness between CDT and other complementary/alternative therapies. Clearly, the study helps in developing hypotheses for future research in this area.

Limitations

There are several limitations within the study. First, the patients in this study received lymphedema therapy; thus, they may not be representative of all patients with head and neck cancer-associated lymphedema. Second, the participants were White and middle-aged adults; thus, the study findings may not be generalizable to minority populations and/or elder adults. Third, the study was conducted at one comprehensive medical center, and the results from this study may not be applicable to facilities in rural areas or any other non-comprehensive medical centers. Further studies are warranted to replicate the findings from this report.

Conclusions

Findings from this study have provided understanding of the importance of lymphedema therapy in clinical management of head and neck lymphedema. Of note, patients describe substantial clinical benefits from therapy. This underscores the importance of self-report in this setting where standardized objective measures are lacking. Barriers to initiation and completion of lymphedema therapy should be addressed with patient at the time of referral. Upon completion of therapy, clinicians must encourage ongoing routine self-care to prevent relapse. Rigorously designed large clinical trials are needed to examine long-term clinical benefit of lymphedema therapy in this population.

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Compliance with ethical standards

The study was approved by the Institutional Review Board at Vanderbilt University and the Scientific Review Committee at the Vanderbilt-Ingram Cancer Center (VICC).

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent

Written informed consent forms were obtained from all participants prior to initiating any study-related research activities

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