

Research

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Home self-management experience of gynaecological tumour patients with lower limb lymphoedema: a qualitative study

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Abstract

Aim: This study aimed to investigate self-management experiences at home among gynaecological cancer patients with lower limb lymphoedema. **Background:** Lower limb lymphoedema is a common complication following gynaecological tumour treatment, causing physical and psychological distress and significantly impacting patients' quality of life. Clinical observations reveal that many patients with lower limb lymphoedema following gynaecological tumour treatment exhibit poor compliance with family self-management, leading to complications such as worsening oedema, cellulitis, or erysipelas. This study seeks to gain insight into patients' actual self-management experiences within their families, offering insights for tailored intervention plans and improved patient self-management compliance in clinical practice. **Methods:** Employing a phenomenological approach in qualitative research, one-on-one semi-structured interviews were conducted to gather face-to-face data from participants. A total of 16 gynaecological cancer patients with lower extremity lymphoedema were selected via purposive sampling from a tertiary cancer hospital. Semi-structured in-depth interviews took place between February and July 2021, with data analysed via the Colaizzi 7-step analysis method. **Findings:** Five key themes emerged: inadequate and uneven availability of medical resources for patients with lymphoedema, limited support for patients, deficient home self-management skills, considerable psychological stress during home management, and variations in self-management behaviours. **Conclusion:** Based on the study findings, increased investment in lymphoedema-related medical care is recommended. Additionally, healthcare professionals can consider promoting family and social support, enhancing patient health education, offering remote psychological counselling, encouraging positive coping behaviours among gynaecological cancer patients with lower limb lymphoedema, and ultimately enhancing their self-management at home.

Introduction

Lower-extremity lymphoedema poses a significant challenge and debilitation among patients undergoing gynaecological cancer treatment. The incidence of lower extremity lymphoedema after gynaecological cancer treatment varies widely, ranging from 7% to 60.1%, with an average of 25%. This variability can be attributed to the absence of standardized diagnostic criteria (Torgbenu *et al.*, 2020). In addition, the incidence of lymphoedema is also subject to treatment regimens. The greater the number of pelvic lymph nodes dissected during surgery, the greater the incidence (Jung *et al.*, 2022; Guliyeva *et al.*, 2020). Lymphoedema arises from the obstruction of lymphatic circulation due to the accumulation of swollen lymphatic tissue outside the cleared region (Grada and Phillips, 2017; de Sire *et al.*, 2022). It is a chronic, progressive condition requiring lifelong management. This can result in recurrent erysipelas, severe fibrosis, including rubbery swelling (Gatt *et al.*, 2017; de Sire *et al.*, 2022), treatment challenges, and physical and psychological distress in patients, significantly affecting their quality of life (Hsu *et al.*, 2023).

Background

Currently, lymphoedema remains incurable. Commonly used therapies include manual lymphatic drainage (MLD), compression bandages and garments, exercise, and skincare, collectively referred to as complete decongestive therapy (CDT). CDT represents the most widely employed and effective treatment approach. On the basis of traditional conservative treatment, in recent years, thanks to the breakthrough of key technologies such as microsurgical technology, high-definition endoscopic system and real-time image navigation, precision surgical treatment programmes have been continuously innovated. Nevertheless, even after

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treatment, patients are required to engage in self-management at home, including stress management, skincare, and functional exercises to maintain treatment effectiveness (Kong and Zhang, 2021). Therefore, to gain an understanding of the self-management experiences at home and offer insights for tailored intervention programmes, in-depth interviews were conducted with these patients.

As an important strategy for chronic disease management, self-management helps control the disease by improving patients' skills and confidence. However, the self-management of patients with gynaecologic tumour-related lower limb lymphoedema faces multiple challenges: the medical level needs to address the complexity of symptoms and treatment, the social role needs to coordinate doctor-patient and family relationships, and the psychological level needs to maintain emotional stability and positive self-perception. Existing programmes are time consuming and lack sustainability, resulting in low patient compliance (Bowman *et al.*, 2021). Current studies have focused mainly on breast cancer-related lymphoedema, which is not specific to gynaecological tumour patients (Shen *et al.*, 2023; Zhao *et al.*, 2021). There is an urgent need for in-depth analysis of self-management barriers in this group and the construction of precise intervention strategies to improve management effectiveness.

The study

Participants

The study employed a purposive sampling method to select patients with lower extremity lymphoedema resulting from gynaecological tumour treatment. Participants were drawn from the patient pool of a tertiary cancer hospital's lymphoedema rehabilitation clinic from February to July 2021. Semi-structured, in-depth interviews were conducted with individuals meeting the following inclusion criteria: (1) had gynaecological cancer patients who had undergone surgery; (2) were diagnosed with stage I-III lower extremity lymphoedema (Executive Committee, 2016); (3) were able to communicate effectively with the researcher; and (4) were willing to provide written informed consent. The exclusion criteria were as follows: 1. Patients with an initial diagnosis of lymphoedema; 2. Patients with renal failure or cardiogenic oedema; 3. Patients with cognitive impairment were diagnosed by physicians. A sample size of 16 participants was determined on the basis of data saturation and was selected to include a range of ages, education levels, occupations, places of residence, tumour types, and degrees of oedema. Detailed information about the interviewees is presented in Table 1.

Design

Determining the interview guideline

The research team consisted of a gynaecological oncologist, three specialized lymphoedema nurses, and a graduate nursing student. The interview guidelines were initially formulated in line with the study's objectives and were informed by a literature review, research group discussions, and consultation with relevant experts. The interview content was refined through preliminary interviews with three cases. The key interview questions included the following: 1. What is the role of home self-management in lymphoedema, in your opinion? 2. How do you manage lymphoedema at home? 3. What are your feelings about self-management of lower limb lymphoedema at home? 4. What kind of assistance and support do you receive for home self-

management (including support from medical institutions, the community, family, workplace, etc.)? What additional assistance and support would you find beneficial?

Data collection

Following the phenomenological methods used in qualitative research, one-on-one semi-structured interviews were conducted to gather face-to-face data from the participants. Prior to the interviews, the interviewees' backgrounds were documented. The purpose and significance of the interviews were explained, and informed consent was obtained. The interviews strictly adhered to confidentiality principles, employed a numbering system, and utilized standardized language. The interviews were conducted in a quiet, private setting. If necessary, the interview content was recorded throughout the process. The interviewer asked questions in accordance with the interview outline's order and respected the language and expressions used by the interviewee, refraining from inducing, interfering, or judging. During our study, none of the 16 respondents lost emotional control or declined to answer the questions. The average interview duration was 35 min.

Ethical considerations

The study adhered to the ethical guidelines outlined in the Declaration of Helsinki and was approved by the Ethics Committee of the hospital (Reference: SBQLL-2020-016). All enrolled patients provided written informed consent before participating in the study.

Data analysis and collation

The interview recordings were transcribed into written documents within 24 h of the interviews. Data analysis was carried out by two researchers following the Colaizzi 7-step analysis method. These steps included the following: 1. A comprehensive review of all collected data; 2. Identification and extraction of significant statements; 3. Encoding and categorization of recurring concepts; 4. Compilation of viewpoints after coding; 5. Provision of detailed descriptions without omission; 6. Exploration of common perspectives and refinement of thematic concepts; 7. The analysis was reviewed and verified to ensure its accuracy (Liu, 2019).

Quality control

The interviewers included a nurse specializing in lymphoedema who held a Ph.D. degree and a master's degree in qualitative research methods, along with extensive interview experience. This nurse was responsible for reviewing all the collected data. After the interviews, the data were continuously and repeatedly analysed, compared, and verified by the two researchers. In cases of disagreement, the research group engaged in discussions to reach a consensus. Following data sorting, the research group offered participants an opportunity to verify the findings without soliciting corrections or additional information from the interviewees.

Results

Inadequate and uneven medical resources for lymphoedema

The interviews highlighted a lack of sufficient medical resources for lymphoedema treatment, especially noticeable disparities between urban and rural areas and variations across different regions. Primary hospitals, particularly those in remote and economically disadvantaged areas, face shortages of medical resources. These facilities lack specialized lymphoedema units, trained medical staff,

Table 1. General information of the interviewees (*n* = 16)

Number	Tumour type	Age (years)	Education level	Career	Occupational residence	Height (cm)	Weight (kg)	Treatment modality	Duration of oedema disease (months)	Oedema level	Oedema latency period (months)
N1	Cervical cancer	47	Primary school	None	Rural	150	80	Surgery + Radiotherapy + Chemotherapy	14	III	3
N2	Cervical cancer	40	High school	None	City	145	53	Surgery + Radiotherapy + Chemotherapy	9	II	9
N3	Cervical cancer	47	Secondary school	Workers	Cities and towns	158	48.5	Surgery + Chemotherapy	15	II	25
N4	Endometrial cancer	46	Master	Teachers	City	157	61	Surgery	1	I	14
N5	Ovarian cancer	63	Primary school	Farmers	Rural	154	60	Surgery + Chemotherapy	26	II	26
N6	Endometrial cancer	54	Undergraduate	Cadres	City	151	68	Surgery + Radiotherapy + Chemotherapy	28	II	15
N7	Cervical cancer	50	Primary school	Individuals	City	155	60	Surgery	39	II	1
N8	Ovarian cancer	55	Junior high school	Farmers	Rural	158	67.5	Surgery + Chemotherapy	13	III	36
N9	Cervical cancer	41	Junior high school	None	Rural	158	56.5	Surgery + Radiotherapy + Chemotherapy	97	II	72
N10	Endometrial cancer	70	Secondary school	None	City	160	85	Surgery + Radiotherapy + Chemotherapy	15	II	2
N11	Cervical cancer	58	High school	Farmers	Rural	159	65	Surgery + Radiotherapy + Chemotherapy	4	II	5
N12	Cervical cancer	34	High school	Individuals	Cities and towns	152	66.5	Chemotherapy + Radiotherapy	1	II	12
N13	Endometrial cancer	45	Junior high school	None	Rural	159	70	Surgery + Radiotherapy + Chemotherapy	6	III	13
N14	Cervical cancer	52	Junior high school	Farmers	Rural	159	52	Surgery + Radiotherapy + Chemotherapy	26	III	49
N15	Cervical cancer	44	Secondary school	Nurses	Cities and towns	158	45	Surgery + Radiotherapy + Chemotherapy	13	II	25
N16	Cervical cancer	57	Junior high school	Freelance	Cities and towns	156	62	Surgery + Radiotherapy + Chemotherapy	27	III	6

and essential lymphoedema treatment supplies, such as stockings, gauze bandages, padding materials, and low-stretch bandages, are lacking. Several interview responses illustrate this issue: N1: “We do not have a dedicated oedema clinic; no one examines me here, and I must travel a long distance for every check-up.” N14: “I developed erysipelas at home once. There were no local specialists for edema. They all thought it was just a common cold and sent me home with cold medicine.” N16: “We did not use compression socks for local lymphoedema. Those are for general edema.” N15: “Swollen legs are manageable, and you can wear compression socks, but I have swelling in my vulva, which is quite challenging. The local hospital currently lacks the necessary treatment supplies, and it would be great if they could obtain them.”

Inadequate support for patients

Insufficient family support

Family support plays a crucial role in the self-management of patients with lower limb lymphoedema at home. It not only provides physical assistance and encouragement but also entails financial and material support. Some interviewees mentioned that their family situations made it challenging for them to engage in self-management at home. Here are a few examples: N11: “My son and daughter-in-law work outside. I handle all the cooking, dishwashing, and house cleaning. I also take care of my grandson.”

Lack of social support

The participants generally hoped for care and support from various sources but reported feeling disappointed and helpless. This disappointment stems primarily from the absence of medical insurance coverage, inadequate workplace support, and prevailing misconceptions and biases in society. Some relevant responses included the following: N3: “Cancer treatment has been costly, and the expenses for oedema treatment and compression socks are not affordable. Unfortunately, health insurance does not cover it, making it quite burdensome.”

Patients lacking home self-management ability

Lack of cognition

Some interviewees had misconceptions about lymphoedema, particularly with respect to the significance of self-management at home. For example, N8: “I am concerned that my tumor might have returned or metastasized, so this lymphedema persists!” N4: “I enjoy soaking my feet in hot water; it is very soothing. I also believe it helps reduce swelling by promoting blood circulation.”

Lack of skills

Most respondents lacked knowledge about how to perform self-management of lymphoedema at home, especially with respect to techniques such as self-drainage, wearing compression socks, and skincare. Here are some of their responses: N2: “I found it a bit challenging. It was easy when I saw the therapist, but I felt confused when I tried it at home.”

Patients facing great psychological pressure during home management

Self-image disorder and inferiority complex

Lymphoedema often leads to progressive worsening, characterized by limb thickening, skin hardening, and visible fibrosis, resulting in an altered limb appearance (Grada and Phillips, 2017; Dessources

et al., 2020). Consequently, respondents frequently experienced negative body image and a sense of inferiority. For instance:

N13: “I feel like a monster with an elephant’s leg.”

Negativity and fear

Since lymphoedema has no known cure, most interviewees expressed a feeling of helplessness regarding the disease’s prognosis. Examples of their responses include the following: N5: “First, I had cancer, and now this edema. Life does not seem to go my way.” N8: “I heard that this swelling cannot be cured. What else can I do? Life appears to be a joke, and everything feels futile.”

Home self-management behaviour presenting polarization

Poor compliance

Some interviewees did not display strong adherence to home self-management and viewed it as disruptive to their daily routines, causing inconvenience. For example, N12: “Functional exercises are too troublesome, and doing them daily takes up a lot of time. I started for a few days initially but eventually gave up.” N13: “I do not wear compression socks daily. I find them inconvenient and only put them on when my legs become uncomfortably swollen.”

Proactive response

Positive Attitude and Behaviour. Several interviewees maintained a positive outlook on home self-management, demonstrating confidence in managing their condition and ameliorating lower limb lymphoedema symptoms through positive actions. Examples include N9: “Since the doctors have assured me that my condition can improve with their treatment and my self-management, I believe I can overcome it.”

Actively ask for help

Certain respondents actively sought support from peers and professional guidance to enhance their home self-management and promote lymphoedema recovery. For example, N1: “When I feel troubled and on the verge of giving up, I reach out to other patients. They often encourage me and share their own treatment successes, which boosts my confidence.”

Discussion

In light of the findings of this study, several measures could be taken to enhance the home self-management experience of patients with gynaecological tumours with lower limb lymphoedema. These measures can be categorized as follows:

Increasing medical investment

Currently, lymphoedema research in China is in its early stages due to a shortage of medical facilities and healthcare professionals specializing in lymphoedema diagnosis and treatment. Furthermore, China’s healthcare policies for rehabilitation support are deficient (Liu *et al.*, 2020). Only a few regions offer reimbursement for lymphoedema treatment. Moreover, many gynaecological cancer patients with lower limb lymphoedema from rural areas face financial constraints. These patients require lifelong rehabilitation management, which places significant psychological stress on them. However, the availability of domestic lymphoedema compression products is limited. Medical institutions exhibit significant disparities, with restricted and limited options (Liu *et al.*, 2021). This not only heightens clinical treatment challenges but also greatly impacts patient compliance with

long-term self-management. Consequently, healthcare decision-makers should increase medical investment in lymphoedema and expand medical insurance coverage for lymphoedema-related services. Furthermore, establishing a comprehensive lymphoedema rehabilitation service system is essential to reduce urban-rural and regional disparities and address practical patient challenges. Additionally, grassroots hospitals should improve their knowledge of the screening, diagnosis, and treatment of lower limb lymphoedema following gynaecological tumour treatment, achieving a standard on par with leading hospitals.

Mobilizing family and social support

Health education and encouragement from patients' families can enhance family support, which is crucial for home self-management. It is advisable to provide health education to patients while encouraging family members to participate in patient networking activities to foster a better understanding of lymphoedema and facilitate family management. This active involvement can contribute to the support of patients in their home self-management. Furthermore, efforts should be made to disseminate lymphoedema education through various channels in communities and families to increase public awareness. For example, knowledge about lymphoedema prevention and rehabilitation can be promoted via telehealth approaches. Some telehealth programmes, such as the UK Cancer Support Network, the Australia Lymphoedema Association, and the American Lymphoedema website, are already available to the public (Woods, 2007). These platforms enable patients to access self-management information for their daily lives and work, which has significant credibility and influence. This not only benefits patients with lymphoedema but also raises public awareness about the topic. In addition to the scattered and sometimes incorrect information available to Chinese patients and the general public online, the hospital community home service chain established by major hospitals has incorporated lymphoedema projects, providing valuable lessons. This approach helps patients with lymphoedema reintegrate into the workforce, participate in community activities, and improve their quality of life.

Strengthening health education

In this study, even though all patients received diagnoses and treatment for lymphoedema, few had a comprehensive understanding of lower limb lymphoedema, family self-management techniques, and the importance of lymphoedema after gynaecological tumour treatment. The analysis suggests that preoperative discussions and postoperative education during clinical hospitalization for patients with gynaecological tumours should primarily emphasize potential complications, even if there is little or no lower limb lymphoedema after discharge. Unfortunately, patients often overlook or disregard postoperative complications, which may be one reason for the lack of information (Zhang and Zhang, 2020). Consequently, lymphoedema-related knowledge should be introduced and explained to patients during their hospitalization through regular lymphoedema lectures conducted in hospitals or related departments. The distribution of a "lymphoedema prevention and treatment manual" can improve patients' and their families' understanding of lymphoedema. Additionally, during the initial diagnosis of lymphoedema, providing thorough explanations of home self-management methods and their significance is vital. The application of educational methods to demonstrate self-lymphatic drainage, the use of compression products, and skin care

is recommended. Furthermore, assessing patients' comprehension and mastery of self-management skills is essential to enhance their home self-management abilities.

Paying attention to psychological counselling

Given that gynaecological tumour patients often experience various degrees of psychological distress (Liu, 2014; Ding *et al.*, 2010), the emergence of lower limb lymphoedema adds to their psychological burden. The American College of Obstetricians and Gynaecologists (Elit and Reade, 2015) suggested screening gynaecological cancer survivors for psychological issues during follow-up appointments to provide psychological support as early as possible and improve their quality of life. In this study, patients exhibited both psychological and behavioural characteristics, including an inferiority complex and fear. While moderate fear can motivate patients to monitor their condition and engage in self-management, prolonged fear can lead to mental and psychological strain, resulting in sleep disturbances and long-lasting stress (Wu *et al.*, 2015; Hinz *et al.*, 2015). Patients with a negative attitude may intentionally neglect self-management of lymphoedema, and their distorted self-image can negatively impact their social interactions, exacerbating their negative emotions. Therefore, healthcare providers should pay attention to the psychological well-being of these patients and consider offering remote psychological counselling through follow-up appointments to increase their confidence in self-management. Psychological interventions, such as motivational interviews (Bao *et al.*, 2014), can be employed to deliver personalized psychological support.

Promoting positive coping behaviour

Some patients with lower limb lymphoedema resulting from gynaecological tumour treatment display positive attitudes and behaviours towards home self-management, which enhances the effectiveness of their self-management efforts. Encouragement from fellow patients and guidance from professionals can also reinforce these positive coping behaviours. Therefore, healthcare professionals should establish communication with patients through platforms such as WeChat to enhance healthcare and facilitate patient communication. Sharing and discussing positive coping strategies among patients can increase their self-management skills, alleviate their symptoms, and improve their overall quality of life.

Limitations

This study was conducted at a single centre because of the impact of COVID-19, which limits the representativeness of the study's findings. In the future, it is advisable to conduct similar research in multiple regions and centres to increase the generalizability and applicability of the results.

Conclusion

This study conducted in-depth interviews to explore the home self-management experiences of gynaecological cancer patients with lower extremity lymphoedema. The study identified five key themes: inadequate and unequal medical resources, insufficient patient support, a lack of home self-management skills, increased psychological pressure during home self-management, and a polarization of self-management behaviour. On the basis of these

findings, increased investment in lymphoedema healthcare is recommended. Additionally, healthcare providers may consider promoting family and social support, strengthening patient health education, offering remote psychological counselling, and encouraging positive coping behaviours among gynaecological cancer patients with lower limb lymphoedema, ultimately enhancing their home self-management ability.

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