

Original article

Suffering of patients developing lymphedema following gynecological cancer surgery

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Abstract

Objective: Lymphedema developing in the lower extremities following gynecological cancer surgery (LE-GCS) produces various kinds of sufferings, including impacts on quality of life (QOL) and body image. This research will serve as a basic resource for the care of patients with this type of lymphedema (LE).

Patients and Methods: A qualitative discursive research method: Thirteen patients suffering from LE-GCS were interviewed in a semi-organized manner. Analysis involved extracting and codifying from transcripts and expressions related to the suffering of LE. Next, these codes were arranged into categories and subcategories under the supervision of qualitative researchers. Furthermore, this study was conducted with the approval of the Research Ethics Review Specialist Committee, which targets individuals affiliated with the public university corporation of Shiga Prefectural University.

Results: Based on the interviews with 13 patients aged 47–79 (median age 62), two core categories were created: 1). Suffering of LE Developing in Lower Extremities (570 codes, seven categories, 23 subcategories); and 2). Supports that Allow Patients to Face Suffering of LE (254 codes, four categories, 14 subcategories).

Conclusion: Patients with LE-GCS live with the fear that LE exacerbation will produce adverse life changes, and this may exceed the fear of cancer itself. The aggravation of their condition results in immense pain as well as reduced mobility, change in appearance, and loss of self-worth. The symptoms fluctuate, and may lead to chronic misery, which does not manifest, but occasionally flares-up because of both, worsening physical disability as well as ordinary events. Additionally, every patient subjectively described the strength they found within themselves to face the suffering. They cited the support of family and friends, existence of compassionate therapists and doctors, acquisition of knowledge, and self-care.

Key words: lymphedema, gynecological cancer surgery, suffering

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Introduction

Lymphedema is a type of swelling caused by dysfunction of the lymphatic vessels. It is a chronic ailment that can be ameliorated, but cannot be reversed or completely cured. In Japan, related statistical information is scarce because national-level investigation into actual numbers of patients has not been conducted. Currently, it is estimated that 100,000–

150,000 patients suffer from lymphedema—approximately 10% are primary cases, and 90% are secondary cases. The majority of secondary cases results from lymph node dissection accompanying extraction of malignant tumors^{1, 2)}. Additionally, the number of latent or potential patients is significant, and annual increases of 6,000 cases have been reported⁴⁾. It is likely to arise as a post-surgical complication particularly in cases of gynecological cancers^{1, 3, 4)}.

This condition results in swelling and increased size of limbs, and consequent limitation of movement. Additionally, if adequate care is not continuously taken, it may also result in a pronounced decrease in quality of life (QOL) because of various significant medical complaints, both physical and mental, due to damage to body image. Moreover, this disease is accompanied by discomfort and pain in many cases. Acute cellulitis inflammation and erysipelas may also ensue, leading to repeated hospitalization and antibiotic dependency⁵⁾.

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Disease treatment depends as much on medical and pathological facts, as the lifestyle of patients, who endure not only physical symptoms and pain, but also suffer psychologically⁶. Suffering is associated with an individual's personality, that is, the self, and constitutes a threat to the overall integrity of the self, which endures the disease. Moreover, it is unpredictable how a person will explain their suffering and its origin. Pain-induced phenomena are patient-specific events because suffering is significantly influenced by circumstances and an individual's level of understanding. To clarify the impact of a disease on a patient, it is necessary to explore the types of sufferings endured by them⁶.

The legs perform the functions of supporting one's weight, as well as walking, running, or jumping—actions where they absorb the impact of many-times a person's actual weight. Additionally, the final point of contact when walking, running, etc. is the floor or ground, and the sensorium of legs must inform the brain about irregularities such as unevenness or inclination; this is when legs perform the significant role of maintaining balance⁷. It is estimated that the irreversible damage caused by lymphedema to legs—a significant body part—causes different types of sufferings in daily life. In a study on the actual situation of lower extremity lymphedema and its impact on QOL among gynecological cancer patients who underwent pelvic lymph node dissection, it was reported that among 200 postoperative lymphedema patients, 38% of them experienced some form of daily life impairment. Specific difficulties related to lower extremity lymphedema in daily life were identified as follows, in order of occurrence: sitting in a traditional Japanese style, engaging in standing work, wearing skirts, wearing underwear, wearing socks and shoes, participating in sports activities, using a Japanese-style toilet, climbing stairs, carrying objects, and walking on slopes⁸.

Patients who develop lymphedema in the lower extremities following gynecological cancer surgery (GCS) experience limitations in various aspects of daily life, and the actions they are unable to perform progressively increase. This kind of chronic life limitation leads to a decrease in QOL. It is evident that many types of sufferings occur when living with lymphedema. However, cogent research could not be found regarding concrete amelioration methods based on psychological and social facets, or any kind of concretization of individual suffering endured by patients as a result of lymphedema-GCS⁹.

In this research, we aim to concretize the suffering of patients who develop lymphedema-GCS and enhance the understanding of nurses. By doing so, we believe that the understanding of the subject will deepen, and it will serve as a foundational resource for nursing care of lymphedema patients.

Patients and Methods

Research design

A qualitative inductive research method was employed, through a research design of element analysis.

Subjects of research

The study included 13 subjects who had received the diagnosis of gynecological cancer (including uterine, cervical, and ovarian cancers) and had undergone treatment by surgery and radiation therapy and/or chemotherapy, and who had presently completed courses of radiation therapy or chemotherapy. Additionally, these subjects were patients recognized, within the classifications of lymphatic disease (ISL), to have lymphedema in the lower extremities in stage 2 or over and were presently receiving appropriate treatment for lymphedema. They had agreed to the motives of this study, and signed affidavits that they would participate in this research.

Term of research

The data collection period was divided into two phases: the first, from December 15, 2011, to the end of March 2013, and the second, from September 27, 2019, to the end of March 2022. During the first phase, lymphedema guidance and management fees were established as medical fees for patients after malignant tumor resection surgery in Japan from 2008. However, it was a difficult period for patients who had undergone surgery before or after 2008 to receive lymphedema care at specialized institutions. The second phase was a period when insurance coverage for lymphedema was expanded with the 2016 revision of reimbursement, and the number of places where patients could receive complex physical therapy increased, mainly at cancer center hospitals nationwide. Therefore, we assumed that the second phase of data collection would provide new insights into the impact of changes in the circumstances surrounding lymphedema care on the suffering of lymphedema patients.

Data collection

Semi-structured interviews were conducted in individual rooms where privacy could be guaranteed. An interview guide was compiled based on significant concepts of suffering found in a general analysis of cancer patients¹⁰, as follows: i) physical suffering; ii) mental suffering; iii) suffering connected with other people and social life; and iv) existential suffering (process of dealing with the disease). Using this interview guide (see below), we interviewed each subject for 30–60 minutes. Subjects were encouraged to respond freely to each question so as to grasp the content of the suffering as comprehensively as possible. With the subjects' permission, we recorded the interview using an IC recorder, and later, compiled a transcript and analyzed the data.

Definition of terms used

“Suffering” implies physical, mental, social (associated with human connections and social life), and existential pain¹⁰. “Gynecological cancer” implies uterine, cervical, ovarian, and vaginal cancers^{3,4}.

Method of analysis

Content related to the suffering experienced by patients with lymphedema-GCS was extracted from the transcripts. The extracted sentences were altered into phrases, without changing the meaning within context. The phrases were analyzed, arranged, and codified based on similarities and differences. Thereafter, the resulting codes, expressed by a brief phrase, were collected by similarity, and converted into abstractions, producing the subcategories of “Types of Concrete Suffering”. These were in turn collected into categories of “Essential Content of Suffering”. Moreover, data analysis was supervised by qualitative researchers, and the legitimacy and reliability of categories and concepts were assured by repeated investigation. Thus, an effort was made to maintain the trustworthiness and legitimacy of analysis.

Ethical considerations

Subjects were explained about the aim and methods of the research, and reassured about their freedom to participate. They were informed that they would not experience any adverse effects if they refused to participate, or after initially agreeing to participate, chose to withdraw.

Additionally, as the interviewees were asked about the nature of “suffering” based on the interview guide, there was a possibility of physical or mental pain resulting from this questioning. Therefore, we carefully observed their facial expressions or words to ascertain any physical or mental discomfort. Moreover, the interviews were conducted in accordance with No. 256 (December 15, 2011) and No. 734 (September 27, 2019) of the findings of the Research Ethics Committee of the University of Shiga Prefecture involving Living Human Participants.

Results

Description of subjects

The subjects included 13 patients aged 47–79 years (median age 62) who were either hospitalized or commuted to hospital or clinics for treatment. Of these, four worked full-time and nine were unemployed (including helping in self-employment enterprises). Their illness history was as follows: seven had cervical cancer, five had uterine cancer, and one suffered from ovarian cancer. All of them had had surgical treatment including lymph node dissection. Additionally, less than two years had elapsed between the first treatment and lymphedema development in the case of all the subjects. The time elapsed since the first appearance of

lymphedema was between four months and 36 years (median six years).

Regarding the treatment situation of lymphedema, six subjects were applying self-care while belonging to a patients’ association. The remaining seven were either applying self-care under the supervision of a doctor or therapist; attending outpatient lymphedema; hospitalized; or were outpatients at a hospital specializing in lymphedema treatment. Furthermore, there were limitations on the number of patients that could be accommodated in lymphedema outpatient clinics and specialized hospitals, resulting in a situation where out of the seven participants, six of them could only have regular check-ups at intervals of approximately two to three months (Table 1).

Core results

Suffering from Lymphedema Experienced in the Lower Extremities by Patients Following Gynecological Cancer Surgery

After the analysis, 824 codes were extracted, which were arranged into 39 subcategories and 11 categories. Additionally, during the interviews, participants shared subjective views about the “strength” they gained by facing the suffering, as well as the essential support in dealing with the suffering. Thus, two core categories were set up (Table 2): *Suffering of lymphedema developing in lower extremities*, and *Ways they found the strength to face the suffering occasioned by lymphedema in lower extremities*. Below, the results will be presented, divided into subcategories and categories.

Suffering of lymphedema developing in lower extremities

Following the analysis, 570 codes, with 23 subcategories and seven categories, were identified under this heading. The seven categories of Suffering of Lymphedema Developing in Lower Extremities were identified by the participants’ narratives: Fear that the swelling of lower extremities would worsen and that heaviness and discomfort noticed after surgery would be irreversible; Fear of recurrence of the pain of cellulitis; Adverse effects resulting from limitation of movement due to swelling in lower extremities; Changes in physical appearance, limitations in choices of clothing, loss of fashion choices; Self-blame because of own inability of early detection and treatment of disease; Necessity for life-long treatment of lymphedema caused feelings of despair; Not being understood; and Inability to talk about suffering produces feelings of isolation. Subcategories and representative narratives of participants in each category are shown in Table 2.

Table 1 Contents of the subject

Item 1	Item 2	# of subjects
Age (years)	40–49	2
	50–59	3
	60–69	3
	70–79	5
Occupation	Full time employee	4
	None (pensioner, housewife, self-employed)	9
Disease	Cervical cancer	7
	Uterine cancer	5
	Ovarian cancer	1
Cancer treatment	Surgery only (including lymph vessel dissection)	6
	Surgery + chemotherapy	6
	Surgery + chemotherapy + radiation therapy	1
LE stage	Early second stage	4
	Late second stage	7
	Third stage	2
LE duration (years)	Less than one	2
	1–5	3
	5–10	2
	Over 10	6
LE treatment	Self care only	6
	Regular outpatient receiving regular care from therapist* ¹	4
	Out- or in-patient at LE specialist hospital dr. or therapist* ²	3
Patients' association	Yes	6
	No	7

*¹therapist: nurse, physical therapist, or masseur with credentials as a lymph drainage therapist.

*²LE: lymphedema.

Table 2 Category/sub-category list 1: suffering of lymphedema developing in lower extremities

Category	Sub-category	Typical narratives
C1. Fear that the swelling of lower extremities would worsen and that heaviness and discomfort noticed after surgery would be irreversible	SCi. Irreversible swelling in legs and labia majora was noticed as well as feelings of discomfort and heaviness / numbness	<i>"I felt that my rear and important womanly parts are sticking out and this naturally causes discomfort", "The skin [of the left thigh] seems to be a different color, and (though it may seem trivial) there is a feeling that something like water has entered between the skin and flesh. It feels like some kind of crisis has occurred in this skin.", "It is heavy, and I'm concerned about wrinkles between ankle and knee."</i>
	SCii. Increasing swelling in legs and fear that this will worsen	<i>"I've noticed on examination that the shape of the thigh has changed and I thought that this was due to swelling in the leg.", "I feel fear. I am afraid because my legs are swelling."</i>
C2. Fear of recurrence of the pain of cellulitis	SCi. Pain and worsening of swelling due to cellulitis	<i>"[When cellulitis occurs] my legs swell up to bursting point. It's so bad that I can't go up and down stairs.", "Because of repeated bouts of cellulitis, my legs are getting fatter all the time", "[hospitalization due to cellulitis] was very bad. It was as tough as the last anti-cancer chemotherapy."</i>
	SCii. Living each day with the fear of the recurrence of cellulitis	<i>"Because of my fear of cellulitis I can never get in the bath again. It will defeat me."</i>
C3. Adverse effects resulting from limitation of movement due to swelling in lower extremities	SCi. Because of leg swelling, limitations in ability to walk or move	<i>"It's hard to move. It's becoming tougher even to stand", "I just feel it would be better to die, as I can't go anywhere"</i>
	SCii. Physical and mental difficulty because of the influence of LE	<i>"I always wear pantsuits to work, but if the condition worsens, they will be too tight. I think other people haven't noticed much, but I don't like it. Naturally at bad times I feel awful.", "When I'm tired -- how shall I say? -- It's so wearying that I feel I have nowhere to go with this body, which used to be myself. I can do less and less in myself."</i>
	SCiii. Difficulty and fear that movement itself will worsen swollen legs	<i>"It's the toughest to feel the increased heaviness after moving." "When I'm invited to go somewhere, I can't go anywhere because I'm frightened because of my legs."</i>
	SCiv. Difficulty of exercise because of pain, and necessity to watch food intake in order to stop weight gain	<i>"I can't do it just by food. The doctor said I should lose 15 kg. At the hospital I was told to develop self-control, but I can't lose any weight."</i>
	SCv. Limitations on hobbies and subsequent loss of enjoyment in life	<i>"I played tennis and lots of other sports, I skied and skated, but now I can't do anything." "I don't have proper footwear for traveling, and I have to carry bandages, so I can't go anywhere."</i>

Table 2 (continue)

Category	Sub-category	Typical narratives
C4. Changes in physical appearance, limitations in choices of clothing, loss of fashion choices	SCi. Difficulty as the outward appearance of legs has changed due to swelling	<i>"My appearance changed, and that was a bit difficult at first.", "I am not fundamentally a fashionable person. I don't like to look at my whole body in the bath mirror, but I still look. I've come to see my legs, especially my right leg, as fat."</i>
	SCii. Clothes and shoes choices are limited, so can't be fashionable	<i>"Shoes are the worst. I have to choose them based on the size of the swollen foot, and the left shoe is then too big. It might seem as if it would be OK if the shoe were long enough, but it isn't. It's the width I need.", "It's really tough because we can't choose the clothes we want, we have to choose from among the clothes that will fit us.", "I really want to wear boots, but I can't wear them unless they are about 27 cm.", "Both winter and summer, I have to wear skirts that are too long and drag on the ground. Really, I can't be fashionable from the hips down."</i>
	SCiii. Having to hide LE with clothing	<i>"Clothing has become a way for me to hide my LE."</i>
C5. Self-blame because of own inability of early detection and treatment of disease	SCi. Developing LE felt like a heavy blow, and self-blame was felt because they were unable to connect this with early diagnosis and treatment	<i>"I was told by the doctor, 'It's swollen, isn't it?' But I didn't think it would be anything like this." "I wonder, why me. I thought, if I had taken better care, maybe it would have cleared up or never developed. I really blamed myself."</i>
	SCii. Couldn't get information or knowledge about LE	<i>"When I developed LE, it was in an era when even the doctors in the hospital didn't know about support socks. There was next to no information about that.", "I had been dealing with LE for 6 whole years. I didn't ask, and because of that, I didn't have any internal sense of what it involved."</i>
C6. Necessity for lifelong treatment of LE caused feelings of despair	SCi. Feelings of resignation and despair toward LE, a disease that will never be cured in this lifetime	<i>"I feel despair since I was told that [LE] was incurable." "When I read a book [about LE], I thought, it can't be! I read that it would be necessary to wear support stockings all my life. What!? was my feeling."</i>
	SCii. Uneasiness from continuation of treatment increases with each passing year	<i>"As I get older, I wonder if this will be with me all my life. I think, what if it becomes difficult even to put on stockings? What shall I do then?" "Even now, I think, can I still [put on stockings] even when I'm an old lady?"</i>
	SCiii. Difficulty of having treatment last all one's life	<i>"It's pretty tough to wear stockings all day long.", "I have to receive care on my legs unendingly.", "If I don't do [self-care], it will swell up even more. I think if it will stay the same with my efforts at self-care and bandaging, that's OK. But I can never stop doing [the self-care].", "My shoulders hurt [since I started putting on the strong support stockings]. When the stockings fall down, I go to the toilet [to fix it], but I feel like I can't pull them up.", "I'm supposed to wrap the bandages for all day, but it moves around, so I have to re-wrap them in the middle of the day."</i>
	SCiv. Financial burden of treatment	<i>"I'm thinking it will get worse after I use up all my money.", "I go to the clinic once a month. Besides the treatment fee, I have to drive myself to the clinic. But it costs about 6,000 yen for each return trip.", "Every time I am hospitalized [for around 2 weeks to 1 month] it costs around 90,000 yen, then when I leave, I have to pay extra for stockings, support socks, etc."</i>
C7. Not being understood; inability to talk about suffering produces feelings of isolation	SCi. Can't make anyone understand about changes in illness or symptoms	<i>"No matter how many times my family says 'Are you OK?' there is pain no one else can understand. If I answer that today I feel particularly bad, a person unconnected may look at my legs and remark, 'They look the same as always' but to the actual sufferer, it's not like that.", "Other people on the bus trip, when we arrived at our destination, said 'Come again when your legs are healed.' That was really a shock to me."</i>
	SCii. Can't make people at the clinic understand about LE	<i>"When I sought help for my condition at the Patients' Association, when they [saw] it might be LE, they said, 'Well, I think it might be good for you to start wearing support stockings immediately.' when I talked to the doctor, he said, 'Oh, you don't have to do that yet.' I felt this implication of, 'There are many others in worse shape than you, so you don't have to make such a fuss.' I felt I wasn't understood.", "I didn't get any explanation from the doctor about LE in connection with the cancer treatment."</i>
	SCiii. Desire not to make trouble for others	<i>"My husband was already deceased when I got cancer, so I had to do everything myself", "I certainly felt bad when everyone kept asking me if I was OK." "LE is something that belongs only to oneself; but as a housewife, I felt obligated to support my family. It was tough when I realized I would have to do everything myself."</i>
	SCiv. Can't mention LE in day-to-day surroundings	<i>"I would mention [the illness] if I felt I was about to fall, but I feel I don't really have to talk about it, because I can always endure a bit more.", "I don't want to mention anything about LE. I don't talk about it at work. I haven't told my boss about it, as he is a man.", "I hide my LE. Somehow I don't want to mention it."</i>
	SCv. Desire to meet friends or go out as before has decreased	<i>"[After developing LE.] of course I don't travel much recently.", "[After developing LE.] I don't go outside unnecessarily. My relationships with friends and acquaintances has gotten more narrow. I don't have so many friends as before."</i>

C: category; SC: sub-category; LE: lymphedema.

Supports that allow patients to face the suffering of lymphedema in lower extremities

Every subject, when speaking about suffering, mentioned the things that supported them as they experienced the suffering. In all the participants' narratives about the factors that empowered them to confront their suffering, the category that stood out was the "Existence of therapists and doctors who would accept, encourage, understand, and treat the patient no matter what the circumstances". This category was mentioned by the participants who have been receiving continuous treatment from doctors, nurses with qualifications in lymphedema drainage, physical therapists, and shiatsu massage therapists in lymphedema outpatient clinics established after the start of reimbursement calculation for lymphedema consultations in 2008.

Following the analysis, 254 codes, 14 subcategories, and four categories were identified under this heading. The four categories of Supports that Allow Patients to Face the Suffering of Lymphedema in Lower Extremities were identified by the participants' narratives: Existence of therapists and doctors who would accept, encourage, understand, and treat patient no matter what the circumstances; During experiences of lymphedema, support and strength were provided by an inner feeling of life's worth and enjoyment; Presence of people close to patient who accepted everything including patient's experience of lymphedema; and, Ability to manage and live with lymphedema with appropriate knowledge and self-care. Subcategories and representative narratives of participants in each category are shown in Table 3.

Discussion

Suffering of lymphedema developing in lower extremities

The 13 lymphedema-GCS patient subjects—already emotionally burdened with the diagnosis of cancer—after concluding surgery, chemotherapy, and radiation therapy, and receiving the news that their cancer treatment had safely concluded, were told that they had developed incurable lymphedema in the lower extremities. Symptoms of lymphedema do not appear in the early stage, but in stage 2 or higher (according to the stage analysis of this disease), light or medium symptoms appear. The lymph vessels may become occluded, causing not only increase in the size of the legs, but also other symptoms such as fatigue, heaviness, and exhaustion³. The interview comments mention heaviness, numbness, and unpleasant sensations, as well as lower extremity swelling, from the onset of lymphedema. Additionally, when identification of lymphedema symptoms was delayed, thoughts about fear of irreversibly worsening swelling were noted. Regarding the delay in the identification of lymphedema symptoms, it should be noted that no hospital in Japan explained the danger of lymphedema following

surgery for malignant tumors of the uterus, related organs, and prostate and lacteal glands (following lymph node dissection treatment in the armpit area) until 2008, when the significance of early treatment and preventive care began to be explained. Treatment fee estimates began in 2008, and doctors as well as nurses and physical therapists supervised by doctors began guiding patients about controlling aggravation of lymphedema during a hospital stay. In 2010, the remuneration was increased to include one session of guidance on how to control aggravation of lymphedema during the month of release from the hospital, and one session during the following month¹¹). In Japan, this low standard of lymphedema treatment was considered a problem, and in 2012, to raise and secure the medical standards, five conferences were held by the following: the Japanese College of Angiology, the Japanese Society for Vascular Surgery, the Japanese Society of Phlebology, the Japanese Society of Lymphology, and the Japanese Society for Foot Care and Podiatric Medicine. Thus, qualifications were established for practitioners of lymphedema treatment. Additionally, a standard price scale was initiated for medical knowledge and technical standards related to lymphedema among persons associated with clinics where multiple courses of treatment were performed, and the title of "Lymphedema Treatment Therapist" was created. Currently, Japan has at least 1,000 of these therapists, and guidance and explanation related to lymphedema after surgery is being established in cancer hospitals. For the past few years, cancer patients have begun receiving guidance and treatment in the early stages of lymphedema following surgery. Consequently, there has recently been little discussion on lymphedema aggravation (because of lack of guidance or treatment). Similarly, patients have reduced discussing about the despair related to lymphedema development or engaging in self-blame for not identifying the disease symptoms early.

Next, the comments of the 13 subjects revealed that they continuously experienced the pain and fear from cellulitis in the lower extremities, which is a factor in the worsening of lymphedema after initial development of symptoms. In the case of lymphedema, circulation worsens, and proteins and fluid accumulate in excess within gaps in tissues. Consequently, once bacteria invades, in howsoever small quantity, it can immediately spread to the entire limb and propagate. If serious inflammation occurs, the space between capillaries expands and proteins and fluids enter the tissues in large quantity, resulting in a sudden increase in swelling¹²). Additionally, fever, chills, and cramps in legs can occur, which can lead to serious, even life-threatening, infection. Moreover, cellulitis induces intense, potentially life-threatening pain, which is one of the limitations placed on the patient's life by worsening lymphedema.

When lymphedema occurs in the lower extremities, it influences the entire range of activities in one's life, includ-

Table 3 Category/sub-category list 2: supports that allow patients to face the suffering of lymphedema in lower extremities

Category	Sub-category	Typical narratives
C8. Existence of therapists and doctors who would accept, encourage, understand, and treat patient no matter what the circumstances	SCi. Existence of therapists and doctors who would accept and treat patient no matter what the circumstances	<i>"When I didn't know if I should be bowling, the doctor said in response to my phone call, 'Ask S [a therapist] about it'. I felt that he had, not exactly given me advice, but pertinent information. He answered my question even though it was trivial -- I am in an environment where I can easily ask about anything.", "Well, I'm always seen by the same therapist each time, and I feel easy because this therapist knows the condition of my legs very well.", "As I get gradually older, I wonder what will happen if I can't ride my bicycle and get [to the clinic]. (Therapist's words: 'If you can't come to the clinic, I will come to you, so don't worry.') I felt so easy when they said that."</i>
	SCii. The best, most enjoyable, worthwhile time is when receiving a massage from the therapist	<i>"(To get a massage from the therapist) is when I feel that life is worth living. To come to the room [clinic] is now my greatest enjoyment."</i>
C9. During experiences of LE, support and strength were provided by an inner feeling of life's worth and enjoyment	SCi. Strength and support comes from the fact of shouldering the burden of this situation	<i>"When they (members of the patients' association who have LE) call me on the phone and I answer, I can feel their relief. I also derive strength from their feeling.", "These legs are very troublesome, but when I go out, I have an enjoyable Relationship with the children. That is very good." "Since I have become this way, I feel myself to be changed, in various ways. Maybe it's my character, but I feel I can do it, so I keep going."</i>
	SCii. Even after developing LE, there is no change in enjoyment, and this is connected to the joy felt in being able to do things	<i>"I derive strength from travelling. There are things which bring me enjoyment, so I feel I'm never going to stop, even if I may want to. It is an incredible support to me, I think. Yes.", "I developed this [LE]. There is nothing else for it. [Pause.] I'm living an ordinary life, going out to meals and karaoke with everyone, having fun, just as before. I talk like this to other people, because I like it."</i>
C10. Presence of people close to patient who accepted everything including patient's experience of LE	SCi. Existence of friends who can take in fact of LE	<i>"Yes, because I love to eat, these days I'm upgrading my cooking. Everyone says, 'Let's at least have good cooking, even if you can't get in the bath.' " "My friends are as important as before. The presence of friends nearby is a very great thing. Yes, very great."</i>
	SCii. Existence of family members who can take in fact of LE	<i>"The first time I went to the Patients' Association, there was a kind of exchange meeting or symposium-like gathering. My family went with me to listen to the talk.", "When I was first discharged from hospital, I was massaged a lot. My daughter and grandchildren would visit as a kind of play-time."</i>
	SCiii. Existence of neighbors and co-workers who can take in fact of LE	<i>"There are various meetings, committee meetings, general meetings etc. When I told them about my condition, they showed proper consideration." "When it was time for fire drills etc., I said I couldn't participate. They all understood, and said voluntarily, 'Well, you be in charge of the phone then'."</i>
	SCiv. Existence of others who also had the same disease, in patients' associations (P.A.) etc.	<i>"I come into contact with other patients as I am working with the P.A. I'm doing telephone consulting from 8 am, but I'm always with someone else. That's why I can continue the treatment.", "Of course they teach me things, and there are lectures. It's quite different when you can meet others in the same situation.", "Developing my illness (LE) was extremely unpleasant, but I felt that one good thing that came of it was getting to know the head of the P.A."</i>
C11. Ability to manage and live with LE with appropriate knowledge and self-care	SCi. Having knowledge and applying self-care makes it possible to guard against worsening (of illness)	<i>"From now on, if I have proper knowledge and if I put on the strong support garments, it won't get any worse. I can state that positively." "I understand that if I control it, it won't get (more terrible). Because of this I have peace of mind." "If I use correctly things that are suitable for me, it won't get worse, so I have an easy feeling."</i>
	SCii. Applying self-care is something that has been incorporated into life	<i>"Taking care not to let the swelling get worse, and feeling good because of this, has become part of my daily life, that's the feeling I have."</i>
	SCiii. Feelings of enjoyment and being fashionable come from care of LE	<i>"I am thinking that I am doing the treatment because I want to be fashionable." "I have become able to wear skirts etc. in summer without fear, because the stockings I have changed to are lighter in color."</i>
	SCiv. Feeling that one can embrace the self that has developed LE	<i>"Because I have been able to recognize within myself, 'I can see that this is not normal, but it's just an illness' through reading books and going to the clinic to get massaged, and that's why I can now talk to people in my surroundings about LE.", "Since I got (cellulitis) 2 or 3 times, from that time I have become able to face it by thinking that I have to be more careful of my body. I know that I don't want to have this difficulty many times, and I've come to feel that the only one who can guard against this is myself."</i>
	SCv. Guarding against the worsening of LE has resulted in this present condition	<i>"With caring for my dog, I've been walking at least an hour and a half in the morning and an hour at night, 2 1/2 hours per day. Only walking, [but] it's been good for my legs too."</i>
	SCvi. The financial burden of outpatient care or hospitalization is at a level that doesn't raise problems with lifestyle	<i>"Right now, I'm getting financial support to buy 2 pairs of stockings per year. The initial outlay was great, but it comes back and thus it is a little cheaper.", "Here I can use the health insurance, and it's closer, so I can come here once a week."</i>

C: category; SC: sub-category; LE: lymphedema.

ing walking; evidently, lymphedema causes hindrances in movement, sitting, and all other essential motions of everyday life⁸). Subjects' comments revealed that they experienced such hindrances in their lives. They particularly expressed fear of the pain of cellulitis inflammation arising from bathing. The changes in bathing habits were noted, including the inability to take baths as they had done prior to the onset of symptoms, and this represented an unavoidable lifestyle change, with a few patients resorting to daily showers all year round.

Lymphedema not only results in limitation of movement due to swelling of the extremities, it also causes many other limitations related to loss of body image, thus lowering one's QOL, both physical and mental⁹). Prior to the onset of lymphedema symptoms in the lower extremities, patients were naturally able to direct their feet wherever they desired; but now patients commented on the difficulty arising from being unable to guard against the worsening of swelling of legs, and they had feelings of heaviness and numbness. Moreover, they could not express themselves sartorially as before, because of the necessity of hiding the swelling under pants or long skirts, or having to wear special size footwear. Often, this prevented them from venturing outside. The sadness of being unfashionable appeared in comments regardless of the subject's age. Being fashionable is a unique way of showing off one's physical form, and is a crucial lifestyle activity¹³). Limitations on such activities induce loss of self-respect. The necessity to hide lymphedema in the lower extremities produces a handicap in one's body image, which may result in an inability to accept transformations in the body, or a feeling that the self no longer includes the body, which are defensive reactions of the unconscious mind¹⁴) to preserve the sense of unity of the self. These defensive reactions are not only for the maintenance of the self-image created by the self, but also for the maintenance of the self-image built by the idea of one's self and body as presented by others. Therefore, it is assumed that an lymphedema patient attempts to not only hide their figure with clothing, but also create an environment where one cannot even mention lymphedema. Thus, as revealed by the subjects' comments, the psychological pain from damage to body image not only decreases the time spent outdoors, but also restricts human relationships.

When relations with other people are no longer harmonious, feelings of isolation and inability to talk may arise, because the subject feels misunderstood by those around them. Subjects' comments reveal the pain of insensitive remarks by surrounding people who did not understand lymphedema, and a sense of anguish arising from the idea that only people going through the same pain could possibly understand their condition. This pain could aggravate, inducing feelings that one was creating trouble for others, thinking that one has no choice but to exist in an atmosphere of mis-

understanding, and a narrowing of human relations. This could eventually result in the stigma of regarding oneself as disabled. When a person becomes disabled halfway through life, as these subjects are, they may at first believe they can return to normalcy; but gradually they realize that they will never again be normal and their disability will forever be a part of their life. They perceive a person with a disability as someone who cannot move normally, and as a person with a stigma, and they erect psychological barriers against others because of this irreversible disability¹⁵). As lymphedema becomes chronic, it transforms into a disability, limiting the movement of the limbs⁵). However, patients gradually learn about lymphedema and self-care, and understand the permanence of the situation. Nevertheless, grasping the situation may be difficult. Circumstances of danger or potential danger may evoke negative urges such as unease or fear. There is a [psychological] system in times of unease or fear, in which an attempted return to a subjective sense of ease occurs through the nearness of certain others¹⁶). Patients with lymphedema of the lower extremities experience limitation of physical activity because of swelling of the legs, and consequently, their non-family contact significantly decreases. Additionally, immobility necessitates human support, and its inadequacy may also cause anguish.

This "suffering of lymphedema developing in lower extremities" largely stems from the fact that this disease can be ameliorated but never completely cured. The subjects had to deal with the shock of realizing its incurability when the symptoms appeared. This shock occurs at the beginning of the process of self-acceptance, leading to acquiescence, and appears as a self-care reaction¹⁵). The shock of realizing that lymphedema is incurable may present as fear that it will aggravate in the future, and self-blame from past inability to seek early treatment may be noted in the comments of subjects who have accepted lymphedema as a part of life. This is experienced as chronic misery, which the subjects call an insurmountable problem. When a physical disability has no end, the resulting chronic misery is deeply felt; it does not always manifest, but may periodically flare-up. These flare-ups can be sparked not only by the aggravation of physical disability, but also ordinary household events¹⁷). Additionally, chronic misery may be accompanied by coping mechanisms, both the type that leads to adjustment to the situation, and that which does not. This proceeds on levels of acceptance, noticing, and recurrence¹⁸).

As lymphedema treatment must continue lifelong, its burden is inestimable. This burden can be roughly divided into two parts: (1) the fact that treatment and self-care for lymphedema must continue throughout life, and (2) the resulting financial burden. In the case of (1), situations of suffering occur in the following instances: shoulder pain from applying self-care using the arms, especially in summer when seasonal considerations arise; difficulty in putting on

bandages and stockings; and being unable to apply methods of self-care, even though one has learned them. Daily self-care, for these subjects, is practiced partly as an escape from the fear that the condition will aggravate. The subjects assiduously apply self-care so that limitations on their lives do not increase, but their incurability does cause immense anguish.

The heaviness of knowing that one will have to bear the burden of lymphedema-GCS all one's life is unimaginable. Even after five, 10, or 20 years, recurrence of lymphedema swelling and cellulitis and the resultant limitations on daily life can trigger frustration because one must bear this alone. This feeling in relation to the recurrence of symptoms may manifest as pain or chronic misery, and facing this kind of suffering requires immense strength.

Supports that allow patients to face the suffering of lymphedema in lower extremities

The main theme of this article is "Suffering from Lymphedema Developing in Patients following Gynecological Cancer Surgery". However, the analysis clarified not only the categories of suffering, but also subjects' coping mechanisms.

People whose physical movement is limited by lymphedema draw the maximum strength from "support from others". Family, friends, and associates are not in a position to administer treatment, but simply remaining by the side of the patient, or assuming the role of an important person for them, can be a source of strength for patients. The three subjects who were receiving continuous treatment at lymphedema specialist facilities mentioned that continuous relations with doctors and therapists was a significant source of support. When faced with the uncertainty about the future experienced by many subjects, that they would not be able to apply self-care or visit a clinic in old age, subjects who were presently receiving continuous care at hospitals or clinics felt immensely reassured by the thought of "the existence of doctors and therapists who will administer care and treatment." By means of the post-operative and post-hospitalization availability of guidance and explanation that became available after 2012, and the increase in outpatient facilities, the attitude toward lymphedema is changing from "an incurable and hard-to-treat illness" to "an illness that can be controlled". A crucial facet of this change in attitude is that now there are places offering continuous appropriate treatment. However, many outpatient clinics and specialty hospitals for lymphedema cannot regularly handle the estimated 100,000–150,000 patients of lymphedema. Therefore, it is necessary to increase the number of qualified doctors and therapists who can treat lymphedema, as well as build more cancer hospitals where lymphedema can be treated on an outpatient basis. Additionally, there should be more lymphedema specialty hospitals offering both inpatient and out-

patient care, and a systems of visiting nurses' stations and shiatsu massage specialists.

"Knowledge and techniques of self-care" also acts as a support for enduring the suffering of lymphedema. Correct knowledge and customized self-care are associated with patients' peace of mind.

Even if the abovementioned supports prove to be sufficient, a few subjects mentioned the suffering emanating from the incurability of lymphedema. In the Corbin–Strauss nursing model, "trace models for chronic disease", the chronic nature of a disease is said to present as a kind of lifelong path, which may significantly change over a period of time¹⁹). Lymphedema, a chronic disease accompanied by long-term disability, significantly impacts the patient's subsequent QOL. As one learns to deal with this suffering, the strength required to face it all should be acknowledged. In addition to understanding the suffering of lymphedema, it is crucial to provide to patients close nursing care that will consider their individual life history.

Conclusion

Regarding the theme of Suffering of Patients Developing Lymphedema Gynecological Cancer Surgery, core category *Suffering of Lymphedema Developing in Lower Extremities*, seven categories were included: Fear that the swelling of lower extremities would worsen and that heaviness and discomfort noticed after surgery would be irreversible; Fear of recurrence of the pain of cellulitis; Adverse effects resulting from limitation of movement due to swelling in lower extremities; Changes in physical appearance, limitations in choices of clothing, and loss of fashion choices; Self-blame because of own inability of early detection and treatment of disease; Necessity for lifelong treatment of lymphedema causes feelings of despair; and Not being understood and inability to talk about suffering produces feelings of isolation.

Regarding the theme of Suffering of Patients Developing Lymphedema Gynecological Cancer Surgery, the nature of the support they received formed the second core category, *Supports that Allow Patients to Face the Suffering of Lymphedema in Lower Extremities*. It included four categories: Existence of therapists and doctors who would accept, encourage, understand, and treat patient under any circumstances; During experiences of lymphedema, support and strength were provided by an inner feeling of life's worth and enjoyment; Presence of loved ones, people close to patient, who accepted everything including patient's experience of lymphedema; and Ability to manage and live with lymphedema with appropriate knowledge and self-care.

Limitations and future tasks

The present research was based on the comments of 13 subjects. However, it is possible that special circumstances,

such as differing policies within Patients' Associations and characteristics of each individual facility, subjects' employment, or lack thereof, etc., may be reflected in the data. When following research subjects with many individual characteristics, it is necessary to consider that other forces may come into play. Additionally, when we interviewed lymphedema-GCS patients in relation to their suffering, all of them emphasized the significance of the support of family, doctors, therapists, other people with the same disease, and knowledge and techniques of lymphedema self-care. These sources of strength or support significantly facilitated the change in attitude from "this is an incurable, difficult-to-treat disease" to "this disease can be controlled". Future research should attempt to clarify these supports, as well

as the suffering of lymphedema itself, to assess the state of continuous nursing care of lymphedema patients.

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