

Research

## Characteristics of Self-care Performed by Patients with Lymphedema to Manage Their Physical Conditions after Cancer Surgery

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### ABSTRACT

**OBJECTIVE** : To clarify the characteristics of physical condition management performed by patients with lymphedema in their daily lives after cancer surgery.

**METHODS** : Sixteen patients, diagnosed with lymphedema after cancer surgery and currently receiving related treatment, were studied with their consent. Data were collected through semi-structured interviews to extract and qualitatively analyze those related to daily self-care as part of physical condition management, focusing on their semantic contents, as well as similarities and differences among them.

**RESULTS AND DISCUSSION** : The characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery were represented by 6 categories : <accepting the reality that the previous physical condition cannot be restored, and deciding to make efforts for the prevention of deterioration>, <understanding that discomfort from refractory edema and recurrent phlegmon can be controlled>, <devising personalized methods to alleviate the symptoms of lymphedema>, <incorporating personalized methods devised to alleviate the symptoms of lymphedema into daily life>, <playing a role in the family, community, and society>, and <developing future perspectives on the course of lymphedema>.

**CONCLUSION** : The characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery were represented in 6 categories. Each category consisted of multiple sub-categories related to attitudes and actions.

**KEY WORDS** : lymphedema after cancer surgery, symptom control, self-care

### Introduction

The incidence of lymphedema in Japanese patients after cancer surgery ranged from 5.1 to 51% in studies

examining upper limbs or other areas of the body after breast cancer surgery<sup>1-4)</sup>, and from 20.0 to 51.9% in those targeting lower limbs after uterine cancer surgery<sup>5-8)</sup>; these values are similar to those reported

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in advanced and Asian countries<sup>9)10)</sup>. The number of cancer patients, which is currently estimated at 100,000 to 120,000<sup>11)12)</sup>, is likely to further increase with the aging of the Japanese population. To date, the level of interest in lymphedema related to oncological treatment has been low in medical fields, as the disorder does not directly influence life, and this has forced patients to bear their uncovered distress for a long period, convincing themselves : “Now that I am relieved from cancer, I should endure the swelling”<sup>13)</sup>.

Under these circumstances, the treatment of lymphedema after cancer surgery began to be targeted for medical fee calculations in 2008, when medical fees were revised, and 100 points were allocated to lymphedema guidance and management before and after each surgery for specific cancers (breast, uterine, ovarian, and prostate cancers) in Japan. This was followed by the allocation of subsidies for elastic clothing and other items for the treatment of limb lymphedema. In 2010, the number of medical fee calculations for lymphedema guidance and management was reviewed, leading to a revision of the requirements of such calculations (to enable insurance-covered medical institutions providing outpatient services for postoperative patients in communities, in addition to those performing surgery, to also provide patient education after discharge in consideration of patients' consultation-seeking behavior) in 2012. In line with these movements, combined lymphedema treatment fees became insurance-covered in 2016 when medical fees were revised again, establishing systems to treat patients with lymphedema after cancer surgery.

Up to the present, studies on nursing care for such patients have developed while examining physiological approaches<sup>14)15)</sup>, patient QOL<sup>16)17)</sup>, and the effects of combined physical therapy<sup>18)19)</sup>, in this area. In the future, it is necessary to discuss appropriate methods to ensure the quality of care for them, using extensive findings obtained through these studies and practices. Therefore, as an urgent issue, it may be necessary to develop an appropriate model of nursing care for patients with lymphedema after cancer surgery, and use it as a standard for quality assurance to calculate insurance-covered combined lymphedema treatment fees.

## Objective

To clarify the characteristics of physical condition management performed by patients with lymphedema after cancer surgery in their daily lives, based on symptom control through long-term self-care that is specific to such patients.

## Definition of Terms

### 1. Physical condition management

Actions adopted by patients with lymphedema in their daily lives to maintain/improve their mental and physical conditions, with a view to preventing symptom deterioration.

### 2. Self-care

Part of symptom control performed by patients with lymphedema independently to prevent symptom deterioration through combined treatment approaches (skin care, compression, therapeutic exercise under compression, lymphatic drainage, and adherence to daily precautions).

### 3. Attitude

A settled way of thinking or feeling about someone or something, typically one that is reflected in a person's behavior (The thought process behind any subsequent action).

### 4. Action

The fact or process of doing something, typically to achieve an aim (The kind of action taken as a result of the proceeding thought process (the attitude)).

## Methods

### 1. Subjects

The study involved 16 inpatients diagnosed with lymphedema after cancer surgery, who consented after being provided with written explanations of its content (Table 1).

### 2. Period and method of data collection

Semi-structured interviews were conducted with the patients within the period between July and December 2015 to collect their free statements regarding the following items : changes in the body, symptoms, and emotions after the onset of lymphedema ; the details of physical condition management performed in daily life ; and relationships with other family members, commun-

**Table 1 Subject Outline**

Subject	Age	Sex	Site of lymphedema	Primary disease and related treatment	Time between primary disease treatment and the onset of lymphedema(months)	Time between the onset of lymphedema and the initiation of treatment	Duration of lymphedema
A	30s	F	Right lower limb	Uterine cancer Surgery, chemotherapy	12	1	36
B	50s	F	Left and right limb	Uterine cancer Surgery	36	36	156
C	50s	F	Right lower limb	Ovarian cancer Surgery	60	24	60
D	60s	F	Left lower limb	Ovarian cancer Surgery	24	15	84
E	30s	F	Right lower limb	Uterine cancer Surgery, chemotherapy	8	0	2
F	60s	F	Left lower limb	Uterine cancer Surgery	72	32	132
G	70s	F	Left and right limb	Uterine cancer Surgery	168	13	36
H	40s	F	Left and right limb, Genital area	Ovarian cancer Surgery	2	12	96
I	80s	F	Left and right limb	Uterine cancer Surgery, chemotherapy	120	144	276
J	70s	F	Left lower limb	Breast cancer Surgery, chemotherapy	24	96	156
K	40s	F	Left and right limb	Uterine cancer Surgery	1	13	36
L	80s	F	Left and right limb	Uterine cancer Surgery	192	84	204
M	50s	F	Left and right limb, Genital area	Uterine cancer Surgery	48	16	60
N	70s	F	Left and right limb	Uterine cancer Surgery	96	48	144
O	40s	F	Left and right limb	Uterine cancer Surgery	48	12	96
P	30s	F	Left and right limb	Uterine cancer Surgery, chemotherapy	3	2	24

ity residents, and co-workers. Each patient underwent an interview session that lasted for 20 to 50 (mean : 45) minutes in a private room using an independently created interview guide. With their agreement, the contents of the interviews were recorded, while data regarding the age, primary disease and related treatment, and lymphedema treatment were collected from medical records.

### 3. Method of data analysis

Narrative records were created for each of the patients. Subsequently, data related to self-care as part of physical condition management performed in daily life were extracted, classified, and qualitatively analyzed, focusing on their semantic contents, as well as similarities and differences among them. In addition, in order to ensure the reliability and validity, the researchers of the meeting performed multiple interviews.

Convinced by the theoretical saturation, it was thought that no increase in the number of interviews required to complete the analysis were needed.

#### 4. Ethical considerations

Prior to the study, the approval of ethics committees of the institutions the researchers belonged to was obtained. The patients were introduced after showing the study plan to the directors of the relevant facilities, and obtaining their agreement. The patients were provided with written explanations of the study content, voluntary participation, and protection of participants' rights to obtain their consent. The interviews with them were conducted while confirming their physical and psychological burdens.

### Results

#### 1. Subject outline

Table 1 outlines the patients' attributes. All of them were female, and their mean age was 58. The primary disease was : uterine cancer : 12 ; ovarian cancer : 3 ; and breast cancer : 1. The length of time between primary disease treatment and the onset of lymphedema varied, as the disorder developed immediately to 16 years after surgery. The time between the onset of lymphedema and the initiation of lymphedema treatment also varied from immediately to 12 years after. The lengths of these times were shorter in recent cases, revealing that an accurate diagnosis was not provided even in the presence of the symptoms of lymphedema, leading to delays in the initiation of treatment.

#### 2. Characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery

Based on the patients' free statements, 6 categories representing the characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery were created : <accepting the reality that the previous physical condition cannot be restored, and deciding to make efforts for the prevention of deterioration>, <understanding that discomfort from refractory edema and recurrent phlegmon can be controlled>, <devising personalized methods to alleviate the symptoms of lymphedema>, <incorporating personalized methods devised to alleviate the symptoms of lymphedema into

daily life>, <playing a role in the family, community, and society>, and <developing future perspectives on the course of lymphedema>. These categories consisted of sub-categories mainly classified into : {attitudes} toward and {actions} for self-care as part of physical condition management. It revealed that past {attitudes} to reach {actions} were not designed in a special analytical methods (Table 2). The following sections describe each of the 6 categories representing the characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery : < > : categories ; { } : sub-categories ; and “ ” : the patients' statements during interviews.

1) <Accepting the reality that the previous physical condition cannot be restored, and deciding to make efforts for the prevention of deterioration>

This category outlined the patients' process of recognizing lymphedema as an incurable disorder, accepting changes in the body, and deciding to make efforts to prevent the disorder from deteriorating.

In line with this, 2 sub-categories related to attitudes were extracted from the following statements : {regarding the current situation as unavoidable and accepting it} : “I have convinced myself : ‘This is the way I am’, rather than having got used to my condition. I have no other choice (A)”, “I have not become familiar with self-care. I have just resigned myself to my current situation. Resignation is important (B)”, and “I know that there are many people with severer conditions than mine, but sometimes I cannot help sighing over my situation... although it is useless to complain about it. After all, there is no one but me who should take care of myself (J)” ; and {becoming aware of the importance of maintaining other healthy areas of the body} : “I am going to adhere to the care approaches they taught me (D)” and “I thought that my leg became non-human. I was frightened. So, I decided to prevent it from getting worse (L)”.

The category also consisted of the following action-related sub-categories and statements : {regarding the changed body as ‘natural me’ and accepting it} : “As I was initially told that lymphedema cannot be cured, I persuaded myself to continue performing self-care with rests throughout my life (K)” and “Although I pre-

**Table 2 The characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery**

Characteristics	Attitudes	Actions	
Accepting the reality that the previous physical condition cannot be restored	Regarding the current situation as unavoidable and accepting it	Accepting changes in the body	
	Becoming aware of the importance of maintaining other healthy areas of the body	Maintaining other healthy areas of the body	
		Observing the affected limb	
	Measuring and recording the circumference of the affected limb		
Knowing it gets worse if efforts are not made	Deciding to make efforts for the prevention of deterioration		
Understanding that discomfort from refractory edema and recurrent phlegmon can be controlled	Recognizing one's weaknesses, and avoiding possible dangers	Paying attention to the affected limb to protect it	
		Avoiding possible infection	
Devising personalized methods to alleviate the symptoms of lymphedema	Calming oneself	Mastering mental approaches to control one's physical condition	
		Paying attention to body movements and preventive self-care	Clarifying habitual postures
			Clarifying body movements possibly leading to swelling, and appropriate methods to apply bandages and wear stockings
			Continuously evaluating the effectiveness of approaches, such as applying bandages and wearing stockings, to prevent swelling
Incorporating personalized methods devised to alleviate the symptoms of lymphedema into daily life	Considering the physical condition and mood, and avoiding excessive burdens	Developing a life pattern with preventive self-care incorporated	
		Performing physical activities when the physical condition is good	
		Avoiding making excessive efforts to meet other family members' demands	
	Considering the physical condition and mood, and avoiding excessive burdens	Permitting oneself to skip preventive self-care on some days	
		Not seeking perfection and cutting corners	
Playing a role in the family, community, and society	Seeking opportunities for social participation	Working in accordance with the physical condition	
		Taking charge of household affairs	
		Enjoying sharing time with friends and other family members	
Developing future perspectives on the course of lymphedema	Actively seeking information	Achieving knowledge from the experience of other patients	
		Understanding that some can appropriately adopt preventive actions and the others cannot—learning from other patients facing difficulty	
		Effectively using experts	
		Staying in hospitals periodically to receive treatment and education	
	Becoming active	Obtaining detailed information from publishers or broadcast stations when interested in topics presented by books or TV programs	
		Actively speaking about the symptoms to get inspiration from many people	
	Developing realistic thoughts	Developing an uncompromising, but optimistic view of reality	
Enjoying leading a positive life			

viously heard that I might have swollen legs after surgery, I could not figure edema out. I understood what incurable edema is only after its progression to the current condition (P)”; {maintaining other healthy areas of the body} : “I was desperate to learn self-care methods during the initial 2-week hospitalization. I

purchased stockings and all other necessary products through the hospital (O)” and “I put on stockings for both legs, as I heard that this is more effective to prevent the normal leg from swelling (C)”; {observing the affected limb} : “After bathing, I stand in front of a mirror, and look closely at my whole body (C)”;

{measuring and recording the circumference of the affected limb} : “I do not want to have my leg more swollen than it is now. So, I measure the most markedly swollen area, and record the results in a notebook (E)” ; and {deciding to make efforts for the prevention of deterioration} : “I never fail to apply bandages even when I become reluctant, because I worry about deterioration (P)”.

2) <Understanding that discomfort from refractory edema and recurrent phlegmon can be controlled>

This category explained the patients’ process of initially recognizing the sudden onset of lymphedema, delays in the initiation of treatment, and distress due to recurrent phlegmon as unfortunate experiences, and subsequently convincing themselves to overcome such difficulties on a step-by-step basis.

It consisted of the following attitude-related sub-categories and statements ; {recognizing one’s weaknesses, and avoiding possible dangers} : “Other healthy people tell me to do this and that as I previously did, but now I cannot. They may be thinking that I can do everything, as I look healthy, except for my swollen legs. No one knows that I suffer from fatigue due to excessive burdens whenever walking or running (A)” ; and {calming oneself} : “After the onset of swelling, I underwent the initial consultation provided by a plastic surgeon, who told me to take nutritionally-balanced meals and bed rest while avoiding exercise. I was surprised when I was instructed to perform exercise by a lymphedema specialist later (G)”, “In the hospital where I underwent surgery, the Department of Surgery prescribed diuretics at all times to promote urination. I took them, and went to the toilet all too often, but swelling did not improve (N)”, “This is a matter of course. Inconvenience is normal. This is the way I live (A)”, “There was no doctor providing a diagnosis of lymphedema 14 or 15 years ago. I had to visit various medical departments, such as the Department of the Circulatory System, and undergo various types of examination, but no one told me that this was lymphedema. Persistent complications disturbed me. My long-term patience is now rewarded, as understanding of lymphedema is being promoted (B)”, and “I suffered from phlegmon during this year’s Golden Week

in May, and called emergency hospitals. Four hospitals refused me when I told them that I had phlegmon derived from lymphedema, and the fifth admitted and treated me with 1-week drip infusion. If I tell the truth, they refuse me, and if not, I cannot receive appropriate treatment...But I must resign myself to this, because I am inevitably depending on hospitals services (G)”.

The action-related sub-categories of this category were described as follows ; {paying attention to the affected limb to protect it} : “As a care-giver, I went out by bicycle to provide care daily, and this may have led to the development of lymphedema. After the onset, I began to avoid riding on a bicycle or similar movements (J)” ; {avoiding possible infection} : “I wanted to go swimming to lose weight, but I was told that this was not a good idea, because I was still vulnerable to bacterial infection (C)” ; and {mastering mental approaches to control one’s physical condition} : “I measure and record the sizes of 4 areas of the body every night. When I succeeded in reducing 15 cm in 3 months, I rewarded myself with a trip to a spa. After staying there while caring for myself with simplified bandaging for 3 days and 2 nights, I regained the 15 cm. It was too bad. But I said to myself : ‘I have the next opportunity’ (C)” and “Although I wish to recover soon, it is meaningless to be impatient if the disorder is incurable. Impatience causes irritation, so I control myself through step-by-step approaches (K)”.

3) <Devising personalized methods to alleviate the symptoms of lymphedema>

This category summarized the patients’ process of devising appropriate methods for them to alleviate the symptoms of lymphedema, in order to fulfill their lives while coping with the disorder.

It consisted of ; {paying attention to body movements and preventive self-care} as an attitude-related sub-category, explained by the following statements : “I aimed to do it perfectly in the beginning, but I changed my mind to take it easy, because I have to get along with it throughout my life (K)”, “Actually, I can find changes by myself, checking my whole body in a mirror. Nevertheless, it is important to undergo examination by experts regularly, because I may underestimate such changes (H)”, and “Bandages are

heavy, and they affect my posture. I tend to tilt my body when standing (P)".

There were also 2 action-related sub-categories, illustrated by the following statements ; {clarifying habitual postures} : "Basically, I am a lazy person, who is reluctant to walk, and fond of taking a nap (M)" and "Being a housewife, I mostly work while standing (N)", "I am not good at Japanese traditional-style sitting. It causes pain. I just noticed that I unconsciously avoid sitting in such a way (F)" ; {clarifying body movements possibly leading to swelling, and appropriate methods to apply bandages and wear stockings} : "Whenever I skip some of the instructed care procedures, I have to pay for this later. Then, I realize their necessity and correctness (K)", "When I wish to take a shower on hot days, I find it burdensome to take off stockings, and put on them again. Sometimes I feel like not using them (E)" ; and {continuously evaluating the effectiveness of approaches, such as applying bandages and wearing stockings, to prevent swelling} : "I occasionally cut corners when I perform drainage, but I have never failed to apply bandages over the past 10 years. When I find my legs slightly more swollen, I apply an increased number of bandages (F)", "First, I will try to soften the genital area with more marked swelling, and apply bandages to my legs. As the next step, I will change these to stockings. Wearing stockings, I will be able to lead a more comfortable daily life (H)", and "Having tried to remove bandages only when I bathe, I could further improve my leg condition, and they praised me for this (I)".

4) <Incorporating personalized methods devised to alleviate the symptoms of lymphedema into daily life>

This category clarified the patients' process of incorporating personalized methods devised to alleviate the symptoms of lymphedema into their daily activities, and fulfill their lives while coping with the disorder through trial and error.

It consisted 2 attitude-related sub-categories, explained by the following statements ; {giving priority to the alleviation of lymphedema in daily life} : "I should give importance to this, because I cannot do anything without addressing my legs (E)" ; and {considering the physical condition and mood, and avoiding excessive

burdens} : "I have to get along with the disorder throughout my life. Impatience does not benefit me (P)" and "Unlike other patients living with or close to other family members, those living alone like me easily become depressed. I try not to take my situation too seriously (J)".

Regarding actions, 5 sub-categories were extracted from the following statements ; {developing a life pattern with preventive self-care incorporated} : "These stockings cannot be put on in a usual manner, so I place a smoother in them beforehand (N)", "I used to spend a lot of time bandaging at home. It took me 40 minutes to apply a bandage. So, I slept without bandages at night, and applied them in the morning after bathing (N)", and "In the morning, I start my household chores with a bandage I applied the previous night. When they are finished, around 10 o'clock, I remove the bandage, and wear stockings (G)" ; {performing physical activities when the physical condition is good} : "As housework forces me to work while standing all the time, I tend to have marked swelling in the evening. This is why I try to finish my housework in the morning (I)" ; {avoiding making excessive efforts to meet other family members' demands} : "I decided not to react even when my husband calls and asks me to meet his needs. Now he stops calling me if I do not answer, guessing that I am busy with my bandages. He may be regarding such a situation as unavoidable (N)" and "I take a bath first, and then, see to my husband. I have convinced him to accept this as a countermeasure against prevention (I)" ; {permitting oneself to skip preventive self-care on some days} : "I used to apply bandages at night, and wear stockings during the daytime. I made all efforts for bandaging. Gradually becoming tired of this unfamiliar, burdensome procedure, I began to skip it on some occasions. Now I try not to make excessive efforts (O)" and "Sometimes I become reluctant to perform this daily. When I am sleepy or busy, and do not have time for it although I know that it is necessary, I permit myself to go to bed without bandages (N)" ; and {not seeking perfection and cutting corners} : "I cannot do it perfectly, but I try to do it generally well. I have been told that my method of bandaging is good for 2 years. I feel much more comfortable ever since they told me that I am doing it well (O)".

5) <Playing a role in the family, community, and society>

This category indicated a harmony between leading a daily life while controlling lymphedema and playing a role in the family, community, and society without isolation.

It comprised {seeking opportunities for social participation} as an attitude-related sub-category based on the following statement: "I can enjoy chats with other people in the hospital...Without such a place, I might have been depressed (J)".

There were also the following sub-categories and statements related to actions; {working in accordance with the physical condition}: "I try to reduce my burden by teaching my husband housework (N)" and "I asked my supervisor in the workplace to assign me to desk work (E)"; {taking charge of household affairs}: "My son works overtime and comes back home late every night. I cannot help taking care of him and preparing dinner for him, so I go to bed at midnight. Next morning, he has to leave at 6:30, so I wake up at 5:30 to prepare breakfast for him and all...A lack of sleep is the cause of my fatigue. Or should I say it is my character. I cannot leave him alone (J)"; and {enjoying sharing time with friends and other family members}: "Enjoying nearby hot springs for a couple of days with my elder sister is my recent favorite activity (A)" and "Considering my condition and my husband's age, my younger brother and his wife living nearby bring me some dishes for dinner (I)".

6) <Developing future perspectives on the course of lymphedema>

This category highlighted the patients' intention to develop future perspectives on the course of lymphedema symptoms after the onset by obtaining information using various measures, and interpreting and effectively using it to clarify recent trends in treatment.

It consisted of the following attitude-related sub-categories and statements; {actively seeking information}: "I continuously use outpatient services provided by the hospital where I underwent surgery, but even the director of the Department of Surgery did not know that I was suffering from lymphedema. Under these

circumstances, I should access all necessary information by myself (J)", "They did not show me even the methods to apply bandages, so I had to seek books explaining them (J)"; {becoming active}: "It is important to actively speak about everything concerning lymphedema (E)"; and {developing realistic thoughts}: "The reality differs from the ideal, and I am different from others (A)".

The action-related sub-categories of this category were described as follows; {achieving knowledge from other patients}: "It is useful to listen to other patients who have coped with lymphedema for a long period (G)" and "My friends with long-term lymphedema I met in the hospital have useful information regarding daily life, and teach me precautions to be adopted daily (H)"; {understanding that some can appropriately adopt preventive actions and the others cannot-learning from the experience of other patients}: "I realize that the condition of lymphedema varies among patients (J)" and "When I saw her, I braced myself, thinking that I should be more careful to prevent my condition from progressing to that level (E)"; {effectively using experts}: "When I read a book, I write to the author to ask questions (J)", "Hospital staff show me bandages, stockings, and other new products (A)" and "I make efforts to be praised by the doctors in charge of lymphedema treatment. Praise from them makes me happy, and motivates me to continue performing self-care (C)"; {staying in hospitals periodically to receive treatment and education}: "I prefer stockings to bandages. These are custom-made, and cause less pain (G)", "I have rough skin of the instep as a cutaneous symptom, which may be aggravated by commercially available stockings. So, I am using those made of plain knitted cloth (N)", and "I stay in the hospital twice a year to receive treatment and patient education. I feel good when staff praise me for improvements in my condition on my next visit (I)"; {obtaining detailed information from publishers or broadcast stations when interested in topics presented by books or TV programs}: "One day, after seeing a doctor of my acquaintance appear on a TV program, and talk about lymphedema, I called NHK (Japan Broadcasting Corporation) by telephone (J)"; {actively speaking about the symptoms to get inspiration from



many people} : “When I showed my body to a stylist who helped me wear a kimono for my mother’s funeral, she said : ‘My mother has the same condition’, and introduced this hospital to me, because her mother was receiving treatment there (M)” ; {developing an uncompromising, but optimistic view of reality} : “Being already elderly, I doubt that I will still be able to care for myself independently when I am 100 years old. Well, even so, the situation will be somehow managed (L)”, “Without care, my legs may rapidly swell, involving severe rough skin. I should prevent deterioration, but in an easy-going way (D)” ; and {enjoying leading a positive life} : “It is incredible that there are no methods to effectively treat lymphedema yet. This means that there may be a great discovery before my death (H)” and “Someday in the future, someone will develop thin, soft, but sufficiently tight bandages for us (A)”.

## Discussion

The objective of this study was to clarify the characteristics of physical condition management performed by patients with lymphedema in their daily lives after cancer surgery. Schematized and model building due to the results are not envisioned.

- 1) <Accepting the reality that the previous physical condition cannot be restored, and deciding to make efforts for the prevention of deterioration>

The experience of patients who have suffered from lymphedema for a long period may be more specific, compared with that of patients with recent onset. In the present study, the former had to wait a long time for diagnosis, try various hospitals, and undergo inappropriate treatment on some occasions. In the meanwhile, they faced changes in their appearances, and inconvenience in their daily lives. In such a situation, they began to adopt actions for physical condition management such as {regarding the current situation as unavoidable and accepting it} and {becoming aware of the importance of maintaining other healthy areas of the body}. In these cases, the long duration of the disease may have led them to recognize the inevitable necessity of accepting their unfortunate experience and changes in their bodies. Becoming aware of a close association between inappropriate life patterns and repeated symptom

deterioration, they may have succeeded in strengthening their intention to prevent such deterioration, as indicated by {deciding to make efforts for the prevention of deterioration}.

- 2) <Understanding that discomfort from refractory edema and recurrent phlegmon can be controlled

The patients were shocked by changes in their appearances, and had suffered from severe complications that intensified their sense of irritation for a long period until they began to receive appropriate treatment using effective methods. On the other hand, they obtained practical information regarding daily life such as {recognizing one’s weaknesses, and avoiding possible dangers} and {calming oneself}. They also successfully learned approaches such as {mastering mental approaches to control one’s physical condition}. In Oriental medicine, the body and mind are regarded as one, and importance is given to ‘mind-body unity’<sup>20)</sup>. Although the subjects of the present study did not rely on Oriental medicine, they aimed to control their irritation through mental approaches. Such approaches may be called a strategy to overcome physical weaknesses with mental strength.

- 3) <Devising personalized methods to alleviate the symptoms of lymphedema>

The patients devised appropriate methods for them to alleviate the symptoms of lymphedema based on their own coping experiences. In this process, they redefined themselves to personalize such methods. It was characteristic that they devised approaches that were applicable to their bodies, minds, daily lives, and seasons after learning basic treatment methods to prevent deterioration.

- 4) <Incorporating personalized methods devised to alleviate the symptoms of lymphedema into daily life>

When incorporating personalized methods devised to alleviate the symptoms of lymphedema into their daily lives, the patients repeated trials and errors, and examined the effectiveness of these methods based on feedback. Such trials were supported by the following attitude : {considering the physical condition and mood,

and avoiding excessive burdens}. From the experience of facing repeated symptom alleviation and deterioration, the majority of the patients learned that impatience was pointless. They also successfully incorporated preventive self-care into their life rhythms. If strictly egotistical behavior appeared to be useful to prevent symptom deterioration, they adopted it without hesitation or consideration for other family members. These tendencies represented their characteristic ideals for daily life to control lymphedema as a chronic disorder.

5 ) <Playing a role in the family, community, and society>

Strause AL et al.<sup>21)</sup> noted that opportunities for patients with a chronic disease and their families to participate in society are reduced by the presence of the disease, as well as the necessity of managing it. In the present study involving patients with lymphedema, a harmony between leading a daily life while controlling lymphedema and playing a role in the family, community, and society without isolation was observed. The patients' active communication with other family members, co-workers, and other patients with the same disorder was represented by the following attitude : {seeking opportunities for social participation}. It was characteristic that they intended to enhance recognition of their coping with the disorder among close people to avoid isolation and ensure safe environments for themselves.

6 ) <Developing future perspectives on the course of lymphedema>

The sixth characteristic of self-care as part of physical condition management performed by patients with lymphedema was represented by the category : <developing future perspectives on the course of lymphedema>. This highlighted the patients' intention to develop future perspectives on the course of lymphedema symptoms after the onset by obtaining information using various measures, and interpreting and effectively using it to clarify recent trends in treatment. Furthermore, such an intention manifested as the following attitudes : {becoming active} and {developing realistic thoughts}. They developed an uncompromising, realistic view of their situations as a basis for the collection of useful information. The ability to fulfill

one's life while coping with lymphedema for a long period depends on the continuation of favorable symptom control. Therefore, these tendencies may be regarded as a positive characteristic of the patients who had got through changes in their appearances and long-term inconvenience prior to the initiation of treatment.

Background of patients on the status of attributes and lymphedema were diverse. This analysis aimed at finding the characteristics of the physical condition management beyond the diversity.

### Limitations

The sample size of this study was small so it's difficult to know how representative the data is.

Researchers focused on female participants with problems following surgery for specific cancer types. As such the study did not investigate gender differences or other factors involves in the diversity of post-operative problems.

### Conclusion

The characteristics of self-care as part of physical condition management performed by patients with lymphedema after cancer surgery were represented by 6 categories : <accepting the reality that the previous physical condition cannot be restored, and deciding to make efforts for the prevention of deterioration>, <understanding that discomfort from refractory edema and recurrent phlegmon can be controlled>, <devising personalized methods to alleviate the symptoms of lymphedema>, <incorporating personalized methods devised to alleviate the symptoms of lymphedema into daily life>, <playing a role in the family, community, and society>, and <developing future perspectives on the course of lymphedema>. Each category consisted of multiple sub-categories related to attitudes and actions.

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## がん術後リンパ浮腫患者の体調管理セルフケアの特徴

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### 要 旨

目的：がん術後リンパ浮腫患者の日常生活における体調管理の特徴を明らかにすることを目的とした。

方法：がん術後リンパ浮腫と診断され、リンパ浮腫治療中の患者で、同意の得られた16名を対象とした。対象者に半構造化インタビューを行い、収集したデータから、日常生活の中での体調管理セルフケアに関連するデータを取り出し、それぞれの意味と類似性、差異を比較検討しながら質的に分析を行った。

結果：がん術後リンパ浮腫患者の体調管理セルフケアの特徴として、1. 「発症前の身体を取り戻すことはできないことを引き受け、悪化を防ぐ意思を持つ」2. 「改善しない浮腫・繰り返す蜂窩織炎にいらだちを覚えるが自分次第だということを納得する」3. 「浮腫症状を軽減させるために自分に合った方法を編み出す」4. 「浮腫症状を軽減させるために編み出した方法を生活の中に取り入れる」5. 「家族・地域・社会の中で役割を果たす」6. 「自分のリンパ浮腫の成り行きを見通す」の6項目を見出すことができた。

**キーワード**：がん術後リンパ浮腫，症状管理，セルフケア