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Research

Health-Related Quality of Life and Coping Style in Patients with Primary and Cancer-Related Lower Limb Lymphedema in an Outpatient Clinic in Japan

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ABSTRACT

AIM : Patients with primary lymphedema have different issues to patients with cancer-related lymphedema because they each have a distinct pathogenesis even though they both display edema in their lower limbs. The purpose of this study was to investigate health related quality of life (HRQOL) and the psychosocial state of primary lymphedema patients by comparing them with cancer-related lymphedema patients.

METHODS : The Medical Outcomes Study 36-Item Short Form Survey (SF-36), the Japanese version of the Hospital Anxiety and Depression Scale (HADS), and a short version of the Coping Orientation to Problems Experienced scale (Brief-COPE) were administered to patients with primary and cancer-related lower limb lymphedema (LLL) in an outpatient clinic. The demographic data and lymphedema conditions were obtained from medical records and physical assessments.

RESULTS : Seventy-eight patients with primary LLL and 63 patients with cancer-related LLL were included in this study. In the SF-36, the primary LLL patients had lower general health than the normative value, but the other health statuses were not lower than the normative value from the Japanese population. Furthermore, significant differences were not found in comparison with cancer-related LLL patients. In the HADS, the proportion of anxiety and depression was not high in patients with primary LLL. The higher active coping and self-blame scores in the Brief-COPE were distinctive in patients with primary LLL after adjusting for age.

CONCLUSIONS : This study found a significant difference in coping styles between patients with primary lymphedema and those with cancer-related lymphedema, while there was no significant difference in HRQOL between the groups.

KEY WORDS : primary congenital lymphedema, coping behavior, anxiety, depression

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Introduction

Primary lymphedema results from an intrinsic abnormality of the lymphatic system¹⁾. According to the time of onset, primary lymphedema is classified into congenital, praecox (initial manifestation before the age of 35), and tarda (initial manifestation after the age of 35), and the most common presentation is at onset of puberty and in females¹⁾. While there are no clear epidemiological investigations into primary lymphedema, the prevalence of primary lymphedema ranges from 6% to 12% according to past studies²⁻⁴⁾. The lower limb is most commonly affected in primary lymphedema⁵⁾.

Although there are many reports of health related quality of life (HRQOL) for secondary lymphedema, few HRQOL studies have been reported for primary lymphedema patients. Previous studies have reported that patients with primary lymphedema suffer from mobility impairment and comorbidity caused by cellulitis⁶⁾. They also experience a long waiting time for referral, poor body image, and clothing issues related to the swollen leg⁷⁾. Consequently, they have not only physical but also psychological impairments. Patients with primary lymphedema have different issues to those with secondary lymphedema, such as cancer-related lymphedema, because primary lymphedema and cancer-related lymphedema have a distinct pathogenesis even though they both display edema in the lower limbs. Equally, there is a possibility of a difference in HRQOL between the two. There is a limited number of studies comparing patients with primary lymphedema and secondary lymphedema, and the distinctiveness of the primary lymphedema patient is not clear. By comparing the HRQOL between the two, we can investigate whether it differs or is the same and the reasons, and can consider the appropriate approach for patients with primary lymphedema.

In addition, the psychosocial aspect of primary lymphedema patients should be examined. It is reported that psychological damage can affect compliance with lymphedema treatment⁸⁾. As one solution, we can prevent them from experiencing a stressful condition by using suitable coping styles⁹⁾. Coping is defined as "cognitive and behavioral efforts to manage specific

external and/or internal demands that are appraised as onerous or exceeding the resources of a person"¹⁰⁾. In other words, coping is a strategy by which people manage stress. When encountering similar stressful events, individuals tend to employ the same coping style¹¹⁾ although coping styles might vary within an individual¹⁰⁾. Previous research into patients' coping ability has been conducted in patients with chronic illness and lymphedema. The results showed that they tend to use emotional-focused coping rather than problem-focused coping techniques¹²⁾¹³⁾. However, most of this research has focused on patients with secondary lymphedema, such as breast cancer-related upper limb lymphedema. Few previous studies have investigated specifically the coping styles of patients with primary lymphedema, and their tendencies for coping strategies are unidentified.

We focused on differences in HRQOL between primary and cancer-related lymphedema patients and psychosocial state due to differences in etiology. We targeted patients with primary lower limb lymphedema (LLL) and patients with cancer-related LLL as a comparison because most patients with secondary lymphedema in Japan have cancer-related lymphedema. The purpose of this study was to investigate HRQOL and the psychosocial state of primary LLL patients in comparison with patients with cancer-related LLL.

Methods

1. Setting and participants

This cross-sectional study was executed at an outpatient clinic for patients with lymphedema in Tokyo from November 2009 to November 2010. This clinic was chosen from medical facilities in Japan dealing with a variety of lymphedema, and the average number of patients seen per week was approximately 150. In the clinic, conservative treatments are used with most patients, including compression garments or bandages, or other management aids, such as manual lymphatic drainage, are provided if necessary.

This study is part of a series of research studies with lymphedema patients. All patients who met the following inclusion criteria were recruited: (1) they were diagnosed with primary lymphedema or can-

cer-related LLL by a physician specializing in lymphedema (i.e., stage I or over of the lymphedema stages of the International Society of Lymphology ; ISL), based on medical history and physical observations ; and (2) they visited the clinic at least twice and underwent conservative treatment. As most of the patients with primary lymphedema have edema in the lower limbs, comparison participants were selected from patients with cancer-related lower limb edema. Patients younger than 16 years of age or those who were unable to fill in the questionnaire on their own were excluded. The Ethics Committee of the Graduate School of Medicine, the University of Tokyo, approved the study protocol (#2763-1). Written informed consent was obtained from all patients.

2. Procedure

After confirming that all participants met the criteria, the data of the patients' demographic details and lymphedema status, including time since onset of edema, edematous sites, and lymphedema stage, were collected from medical records. The participants then completed a self-administered, structured questionnaire within the clinic that included questions related to lymphedema onset, coping style, and states of anxiety and depression. The participants were asked to mail the questionnaire back to the researcher within a week using a prepaid envelope to ensure that participants were given a limited time in which to answer.

3. Measurements

1) Demographics

Age, sex, body mass index, and job status were included in the demographic data.

2) Lymphedema status

The edematous sites were classified as unilateral or bilateral. Edema was categorized using the five lymphedema stages of the ISL as follows : stage 0, where there are sub-clinical conditions despite impaired lymph transport ; stage I, where there is an early accumulation of fluid that subsides with limb elevation ; stage II, where limb elevation alone rarely reduces swelling and pitting is manifest ; late stage II, where there may or may not be pitting as tissue fibrosis supervenes ; and stage III, which encompasses lymphostatic elephantiasis where pitting is absent and trophic skin changes develop, such as acanthosis, fat deposits, and warty

overgrowths¹⁴⁾. The time since onset of edema, suffering from cellulitis within 30 days, history of hospital admission due to cellulitis, support from family, and belonging to the patients' association were evaluated. Self-care comprised of compression garments, bandaging, skincare, self-lymphatic massage, exercise, and intermittent pneumatic compression were also checked.

3) The Medical Outcomes Study 36-Item Short Form Survey

The Medical Outcomes Study 36-Item Short Form Survey (SF-36) was used to assess HRQOL. The SF-36, which was developed to measure the state of general health, consists of eight subscales : physical functioning (PF) ; role-physical (RP) ; bodily pain (BP) ; general health perception (GH) ; vitality (VT) ; social functioning ; role-emotional (RE) ; and mental health (MH)¹⁵⁾. The raw score on each scale ranges from 0 to 100 with a lower score indicating a more severe health status. The Japanese version of the SF-36 was used in this study, which is confirmed for the Japanese general population and lymphedema patients¹⁶⁾¹⁷⁾. First, using the SF-36 manual, the z-scores of each subscale were calculated as a norm based score (NBS) from the Japanese population¹⁸⁾. Then, the scores of the physical component summary (PCS) and mental component summary (MCS) were calculated using factor loadings for the Japanese population¹⁸⁾. The average of the NBS was set at 50, and every 10 points showed 1 SD. The Cronbach's alpha for each subscale and summary score in our study ranged from .88 to .90.

4) Coping Orientation to Problems Experienced scale

A short version of the Coping Orientation to Problems Experienced scale (Brief-COPE) was used to assess coping style¹⁹⁾²⁰⁾. The questionnaire consists of 14 subscales, with two items each, and it measures conceptually differentiable coping reactions. Scores range from 2 to 8 for each subscale, with higher scores representing a greater use of the coping styles. In the Japanese version of the Brief-COPE, criterion-related and construct validity have been confirmed by previous research²¹⁾. The Cronbach's alpha for each subscale in our study ranged from .63 to .7.

5) Hospital Anxiety and Depression Scale

The Japanese version of the Hospital Anxiety and Depression Scale (HADS) was used to assess psycholo-

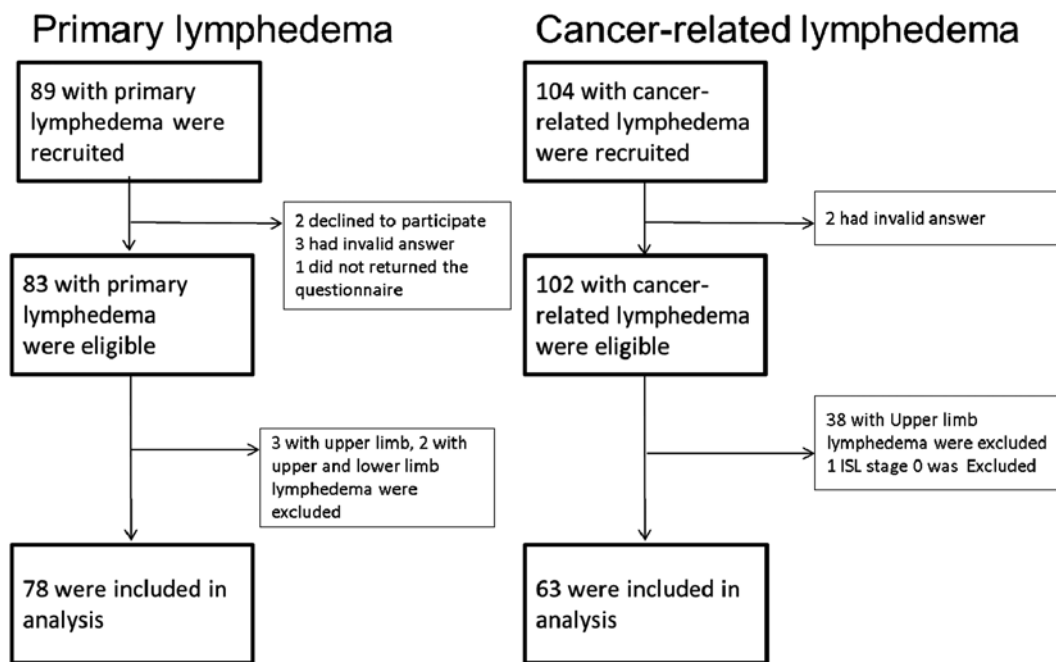


Figure 1 Study Participants

gical state^{22/23}. This consists of seven questions relating to anxiety and seven relating to depression, in which patients rate each item on a four-point scale. Higher scores indicate a greater prevalence of each respective issue. Scores from 0 to 7 are typically thought to indicate no distress, 8 to 10 to indicate doubtful distress, and 11 to 21 to indicate definite distress. Total scores ≥ 8 were taken to be indicative of distress in this study. The Japanese version of the scale has been validated among the Japanese general population²⁴.

4. Data analysis

Descriptive data are expressed as n (%) for categorical variables, and means (SD) or medians (25th and 75th percentiles) for continuous variables. Differences between groups were evaluated using t-tests, χ^2 tests, Fisher’s exact test, or Mann-Whitney U tests. We tested the difference between the NBS of the SF-36 and age- and sex-stratified national norm (ASNN) scores. Analysis of covariance (ANCOVA) for adjusting the effect of age and sex was used to compare the SF-36 scores between patients with primary and cancer-related limb lymphedema. ANCOVA for adjusting the effect of age was used to compare the Brief-COPE scores between the groups. Age-stratified analysis was also conducted where an interaction existed between age and lymphedema classification. Statistical signifi-

cance was set at $p < .05$. All statistical analyses were performed using the Statistical Analysis System software, version 9.2 (SAS Institute Inc., Cary, NC, USA).

Results

1. Recruitment results

Figure 1 summarizes the study participants. A total of 89 patients with primary lymphedema and 104 patients with cancer-related lymphedema were recruited. Regarding primary lymphedema, two patients chose not to participate, one did not return the questionnaire by mail, and three provided invalid answers for more than half of the questionnaire items. In addition, three with upper limb lymphedema, and two with upper and LLL, were excluded. Regarding cancer-related lymphedema, two patients gave invalid answers, and 38 upper limb lymphedema patients and one patient with ISL stage 0 were excluded. A total of 78 patients with primary LLL and 63 patients with cancer-related LLL were subjected to the analyses.

2. Patient characteristics

Demographic characteristics, lymphedema status, and the results of t-tests and χ^2 tests by lymphedema classification are shown in Table 1. The age of patients with primary LLL was 42.5 ± 14.0 years and the age of patients with cancer-related LLL was 61.5 ± 11.9 years

Table 1 Demographics and Lymphedema status of patients

| | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value |
|---|-----------------------|------------------------------|----------------------|
| Characteristics | | | |
| Age (y), mean (SD) | 42.5 (14.0) | 61.5 (11.9) | <0.001 ^{a)} |
| Sex, n (%) | | | |
| Male | 22 (28.2) | 3 (4.8) | <0.001 ^{b)} |
| Female | 56 (71.8) | 60 (95.2) | |
| BMI (kg/m ²), mean (SD) | 21.8 (3.3) | 22.7 (3.5) | 0.115 ^{a)} |
| Time since onset of edema (y), mean (SD) | 14.6 (12.3) | 5.8 (5.3) | <0.001 ^{a)} |
| Unilateral/bilateral edema, n (%) | | | |
| Unilateral | 63 (80.7) | 45 (71.4) | 0.193 ^{b)} |
| Bilateral | 15 (19.3) | 18 (28.6) | |
| ISL lymphedema staging, n (%) | | | 0.017 ^{b)} |
| Stage I | 2 (02.6) | 9 (14.3) | |
| Stage II | 42 (53.8) | 36 (57.1) | |
| Late stage II | 22 (28.2) | 15 (23.8) | |
| Stage III | 12 (15.4) | 3 (04.8) | |
| Cellulitis within 30 days, n (%) | 24 (30.8) | 18 (28.6) | 0.777 ^{a)} |
| History of hospital admission for cellulitis, n (%) | 22 (28.2) | 12 (19.1) | 0.206 ^{a)} |
| Self-care | | | |
| Compression garments, n (%) | 71 (91.3) | 58 (92.1) | 0.826 ^{a)} |
| Bandaging, n (%) | 20 (25.6) | 11 (17.5) | 0.244 ^{a)} |
| Skin care, n (%) | 25 (32.1) | 19 (30.2) | 0.809 ^{a)} |
| Self-lymphatic massage, n (%) | 45 (57.7) | 46 (73.0) | 0.059 ^{a)} |
| Exercise, n (%) | 30 (38.5) | 25 (39.7) | 0.882 ^{a)} |
| Intermittent pneumatic compression, n (%) | 11 (14.1) | 6 (9.5) | 0.407 ^{a)} |
| Having a job, n (%) | 45 (57.7) | 19 (30.2) | 0.001 ^{a)} |
| Support from family, n (%) | 55 (70.5) | 46 (73.0) | 0.743 ^{a)} |
| Belonging to the patients' association of lymphedema, n (%) | 6 (7.7) | 2 (3.2) | 0.298 ^{c)} |

N (%) or mean (SD), a) t-test b) χ^2 test c) Fisher's exact test
 LLL, lower limb lymphedema

($p < .001$). The proportion of females was 71.8% for patients with primary LLL and 95.2% for patients with cancer-related LLL ($p < .001$). Among primary lymphedema patients, the duration of suffering from lymphedema was longer than for patients with cancer-related LLL (14.6 years vs 5.8 years, $p < .001$). More than 80% of patients belonged to the middle stage, such as ISL stage II or late stage II, and there were

significant differences between patients with primary LLL and cancer-related LLL ($p < .017$). Patients with primary LLL were more likely to have job (57.7% vs 30.2%, $p = .001$). There were no significant differences between them in terms of suffering from cellulitis ($p = .777$), self-care (compression garments $p = .826$, bandaging $p = .244$, skin care $p = .809$, self-lymphatic massage $p = .059$, exercise $p = .882$, intermittent pneumatic com-

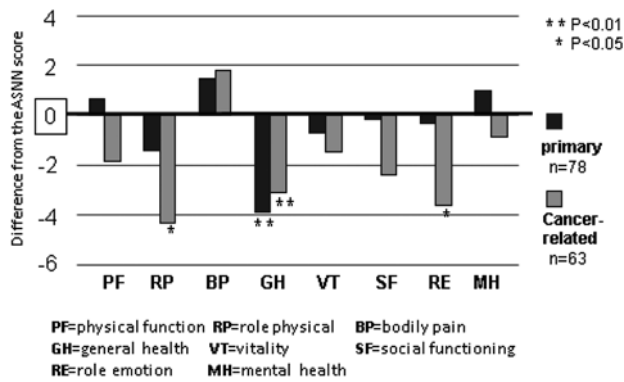


Figure 2 SF-36 scores of patients with primary and cancer-related lower limb lymphedema compared to the ASNN scores

pression $p=.407$), support from family ($p=.743$), or belonging to the patients' lymphedema association ($p=.298$).

3. SF-36 scores

Of the subscales of the SF-36, the mean GH score was lower than the ASNN score, shown as 0, in primary LLL patients ($p<.01$), and not only the GH score ($p<.01$) but also the RP and RE scores ($p<.05$) were significantly lower than the ASNN score in cancer-related LLL patients. There were no significant differences in PF, BP, or MH in primary LLL patients and no significant difference in BP in cancer-related LLL patients, although they had a higher score than the ASNN score (Figure 2). In the comparison of the scores between primary LLL patients and cancer-related LLL patients, all scores except MCS of primary LLL patients were higher than those of cancer-related LLL patients (Table 2). There was a significant difference in PF ($p<.001$), RP ($p<.002$), RE ($p=.011$), and PCS ($p<.001$). However, there was no difference in RP and RE after adjusting for age and sex. There was an interaction between age and classification of lymphedema in PF and age-stratified analyses were conducted. There tended to be a higher PF score for the primary LLL patients (Least Square Means 43.3-52.2) than the cancer-related LLL patients (Least Square Means 39.6-45.6) in the 48 years old and above group ($p=.0071$).

4. HADS scores

A total of 27 (19.1%) patients demonstrated an anxiety score greater than 8, and 15 (10.6%) patients had a depression score greater than 8. In addition, 15

(19.1%) patients with primary LLL and 12 (19.1%) patients with cancer-related lymphedema had anxiety scores ≥ 8 , while 7 (9.0%) and 8 (12.7%) patients had depression scores ≥ 8 . There were no differences in the proportion of patients with anxiety or depression scores of ≥ 8 between patients with primary LLL and those with cancer-related LLL. Although the median scores and 25th and 75th percentiles of both groups' scores were within normal ranges, there was a significant difference in depression score between them. The depression score of patients with cancer-related LLL was higher than those with primary LLL ($p=.026$) (Table 3).

5. Brief-COPE scores

Regarding the comparison of patients with primary LLL and cancer-related LLL for the Brief-COPE, there were significant differences in planning, behavioral disengagement, use of instrumental support, use of emotional support, acceptance, active coping, denial, and self-blame. Planning, use of instrumental support, use of emotional support, acceptance, active coping, and self-blame were higher in patients with primary LLL. Denial and behavioral disengagement were higher in patients with cancer-related LLL. Scores of active coping and self-blame coping styles were higher among primary LLL patients than among those suffering from cancer-related LLL ($p<.001$, $p=.021$) after adjusting for age. Positive reframing coping tended to be more prevalent among patients with primary leg lymphedema ($p=.069$) (Table 4). Since there were interactions between age and classification of lymphedema in planning and acceptance coping styles, age-stratified analyses were conducted. There were higher scores for planning coping and acceptance coping styles for the primary LLL patients in the 48 years old and above group ($p=.004$, $p=.041$) (Table 5).

Discussion

In this research, we compared the HRQOL and coping styles of LLL patients who had a different etiology: primary and cancer-related lymphedema. There were four remarkable findings in this study. First, the primary LLL patients had lower GH than the normative value, but the other health statuses were not lower than the standard value. Second, as for the HRQOL of the

Table 2 Comparison of SF-36 scores in patients with primary and cancer-related lower limb lymphedema

| Variables | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value ^{a)} | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value ^{b)} |
|----------------------------------|-----------------------|------------------------------|-----------------------|-------------------------------|-------------------------------|-----------------------|
| | mean (SD) | mean (SD) | | Least Square Means (95%CI) | Least Square Means (95%CI) | |
| Physical functioning (PF) | 51.7 (8.2) | 42.8 (12.6) | <.0001 | 49.4 (46.9-51.9) | 45.7 (42.8-48.5) | * |
| Role-physical (RP) | 48.9 (10.5) | 42.2 (13.5) | 0.002 | 47.0 (44.0-50.0) | 44.6 (41.2-47.9) | 0.325 |
| Bodily pain (BP) | 51.6 (11.2) | 50.3 (10.1) | 0.452 | 50.8 (48.1-53.5) | 51.3 (48.2-54.3) | 0.849 |
| General health perception (GH) | 46.5 (9.8) | 45.2 (8.0) | 0.394 | 46.6 (44.3-48.8) | 45.2 (42.6-47.8) | 0.491 |
| Vitality (VT) | 48.9 (9.3) | 48.4 (8.0) | 0.774 | 48.4 (46.2-50.6) | 49.0 (46.5-51.5) | 0.755 |
| Social functioning (SF) | 49.6 (10.0) | 46.6 (10.5) | 0.083 | 48.8 (46.2-51.4) | 47.5 (44.6-50.5) | 0.554 |
| Role-emotional (RE) | 49.8 (10.6) | 44.4 (13.6) | 0.011 | 47.6 (44.7-50.6) | 47.0 (43.7-50.4) | 0.809 |
| Mental health (MH) | 50.7 (9.1) | 49.4 (7.8) | 0.383 | 50.0 (47.8-52.1) | 50.3 (47.9-52.7) | 0.849 |
| Physical component summary (PCS) | 50.4 (11.0) | 41.5 (14.3) | <.0001 | 47.9 (44.9-50.9) | 44.6 (41.2-48.1) | 0.208 |
| Mental component summary (MCS) | 49.0 (9.3) | 50.8 (6.8) | 0.201 | 49.3 (47.2-51.3) | 50.5 (48.1-52.8) | 0.502 |

a) t-test b) ANCOVA for adjusting for age and sex *Interaction between age and classification

Table 3 Psychological status of primary and cancer-related lower limb lymphedema patients

| | Total (n=141) | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value |
|--------------------------------------|-----------------------------|-----------------------|------------------------------|---------------------|
| HADS anxiety score (from 0 to 21) | median (P25-P75) 4 (2-6) | 4 (2-7) | 5 (3-6) | 0.275 ^{a)} |
| HADS depression score (from 0 to 21) | median (P25-P75) 3 (2-6) | 3 (1-5) | 4 (3-6) | 0.026 ^{a)} |
| HADS anxiety score ≥ 8 | n (%) 27 (19.1) | 15 (19.2) | 12 (19.0) | 0.478 ^{b)} |
| HADS depression score ≥ 8 | n (%) 15 (10.6) | 7 (9.0) | 8 (12.7) | 0.476 ^{b)} |

a) χ^2 test b) Mann-Whitney U test
HADS, Hospital Anxiety and Depression Scale.

primary LLL patients, significant differences were not identified in comparison with cancer-related LLL patients after adjusting for age and sex. Third, we revealed the psychological status of primary LLL patients for the first time using the HADS, and the proportion of anxiety and depression was not high in patients with primary LLL. Finally, there was a significant difference in the Brief-COPE between primary LLL and cancer-related LLL patients. The higher active coping and self-blame scores in the Brief-COPE were distinctive in patients with primary lymphedema after adjusting for age. Additionally, the

higher scores of planning and acceptance coping were also distinctive in patients over 48 years old.

Only GH was significantly lower for patients with primary LLL than the normative value and there were no statistical differences in the other dimensions of the SF-36. A low GH in the SF-36 means the “recognition of not being in good health and gradually worsening.”¹⁸⁾ As lymphedema is a chronic condition with no cure at the moment, its progress is unavoidable if it is neglected²⁵⁾. In a study by Huggenberger et al.²⁶⁾, which studied the HRQOL of primary LLL patients, there were no significant differences compared to normative data

Table 4 Brief-COPE scores between patients with primary and cancer-related lower limb lymphedema

| Variables | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value ^{a)} | Primary LLL (n=78) | Cancer-related LLL (n=63) | P-value ^{b)} |
|-----------------------------|--------------------|---------------------------|-----------------------|----------------------------|----------------------------|-----------------------|
| | Mean (SD) | Mean (SD) | | Least Square Means (95%CI) | Least Square Means (95%CI) | |
| Subscale of the Brief-COPE | | | | | | |
| Self-distraction | 5.2 (1.1) | 5.0 (1.1) | 0.173 | 5.2 (5.0-5.5) | 5.0 (4.7-5.3) | 0.246 |
| Active coping | 6.0 (1.0) | 5.6 (1.0) | 0.014 | 6.2 (5.9-6.4) | 5.3 (5.1-5.6) | <0.001 |
| Denial | 3.4 (1.3) | 4.0 (1.3) | 0.020 | 3.7 (3.4-4.0) | 3.7 (3.3-4.0) | 0.993 |
| Substance use | 3.2 (1.5) | 3.0 (1.5) | 0.466 | 3.3 (2.9-3.6) | 2.9 (2.5-3.4) | 0.331 |
| Use of emotional support | 5.4 (1.2) | 4.8 (1.4) | 0.012 | 5.3 (5.0-5.6) | 4.9 (4.6-5.3) | 0.201 |
| Use of instrumental support | 5.3 (1.2) | 4.8 (1.3) | 0.009 | 5.2 (4.9-5.6) | 4.9 (4.6-5.3) | 0.236 |
| Behavioral disengagement | 3.8 (1.0) | 4.3 (1.2) | 0.005 | 3.9 (3.7-4.2) | 4.1 (3.8-4.4) | 0.509 |
| Venting | 4.6 (1.3) | 4.4 (1.1) | 0.456 | 4.5 (4.2-4.8) | 4.6 (4.3-5.0) | 0.495 |
| Positive reframing | 5.6 (1.2) | 5.4 (1.3) | 0.455 | 5.7 (5.4-6.1) | 5.3 (4.9-5.6) | 0.069 |
| Planning | 6.0 (1.1) | 5.4 (1.4) | 0.003 | – | – | * |
| Humor | 4.3 (1.3) | 4.3 (1.2) | 0.831 | 4.3 (4.0-4.7) | 4.2 (3.8-4.6) | 0.57 |
| Acceptance | 6.0 (0.9) | 5.6 (1.2) | 0.013 | – | – | * |
| Religion | 3.6 (1.4) | 3.7 (1.6) | 0.750 | 3.8 (3.5-4.2) | 3.4 (3.0-3.8) | 0.175 |
| Self-blame | 4.8 (1.2) | 4.4 (1.2) | 0.038 | 4.9 (4.6-5.2) | 4.3 (4.0-4.7) | 0.021 |

a) t-test b) ANCOVA for adjusting for age *Interaction between age and classification

Table 5 Age-stratified analyses of subscales of the Brief-COPE

| | <48 years old | | | ≥48 years old | | |
|------------|--------------------|---------------------------|-----------------------|--------------------|---------------------------|-----------------------|
| | Primary LLL (n=52) | Cancer-related LLL (n=10) | P-value ^{a)} | Primary LLL (n=26) | Cancer-related LLL (n=53) | P-value ^{a)} |
| Planning | 5.9 (5.6-6.2) | 6.2 (5.4-6.9) | 0.514 | 6.2 (5.7-6.7) | 5.2 (4.9-5.6) | 0.004 |
| Acceptance | 6.0 (5.7-6.3) | 6.5 (5.9-7.1) | 0.158 | 6.0 (5.6-6.5) | 5.4 (5.1-5.8) | 0.041 |

Least Square Means (95%CI). a) P-value adjusted for age

although the proportion of ISL stage III patients in the study was higher than in the present study (38.5% vs 15.4%). From these findings, although physical state has been relatively preserved and the degree of lymphedema is in the moderate stage in this study's primary LLL patients, they might have fears about their edema becoming worse associated with a change in appearance. In this study, the SF-36 scores, except for GH, were relatively high in primary LLL patients. Research that has compared the HRQOL of lymphedema patients before and after treatment showed an improvement in physical activity, pain, and vitality²⁷⁾. In our study, as participants visited the clinic at least twice,

we assumed that appropriate care including obtaining diagnosis and adequate information in the clinic had an effect on the HRQOL.

The HRQOL of patients with primary LLL was not significantly different from that of patients with cancer-related LLL after adjusting for age and sex. In this study, we controlled age and sex, which were considered to have an impact on the HRQOL, and tried to find that the difference in the etiology influenced the HRQOL. As a result, it was found that there was no difference in the outcomes of the HRQOL. Even though the etiology is different, when the patient's feeling of burden to the symptoms of lymphedema does not

change, the difference would not be observed in the HRQOL, especially regarding the physical aspects. The research by Huggenberger et al. concluded that the VT of patients with secondary LLL was lower than that of the patients with primary LLL but a clear reason was not mentioned²⁶⁾.

Focusing on the mental aspect of the primary LLL patients, the percentage of patients with anxiety or depression in the HADS was not low compared with the results of investigations of depression in lower leg ulcer patients²⁸⁾. As such, it can be said that the psychological state of primary lymphedema patients is relatively stable. It is reported that physical factors, such as pain or the smell, are related to the psychological distress of leg ulcer patients. The score of BP in the SF-36 was above the standard in the primary LLL patients in this study. This specific feature of lymphedema influenced the HADS score. The difference of depression score between patients with primary and cancer-related LLL is supported by the study that cancer-survivors show a high prevalence of depression²⁹⁾.

The patients with primary lymphedema used more active coping and self-blame than the cancer-related LLL patients in the Brief-COPE. Active coping refers to taking a proactive approach in solution finding²⁰⁾. As many primary lymphedema patients spend a long time on a waiting list before a consultation in the hospital and receiving a diagnosis³⁰⁾, the feeling of relief after beginning appropriate care might be related to their positive behavior. This conclusion is in line with the findings of another study that investigated patients who had just received comprehensive information and had feelings of being supported and motivated in the treatment after referral⁷⁾. Although the self-blame score was not very high among the Brief-COPE scores, the reason why the self-blame score in primary LLL patients was higher than that of cancer-related LLL may be the unknown cause of the impairment, and primary LLL patients may be attributing the cause to themselves. Previous studies showed that self-blame is associated with psychological distress³¹⁾³²⁾. Regarding that the planning and acceptance scores of patients with primary LLL were higher than those of cancer-related LLL patients over 48 years old, we assume that coping strategies might be more established due to the duration

of the disease compared to that of the cancer-related LLL patients who were thought to have suffered from the disease in middle age or later. This is consistent with a case study of primary LLL patients by Symvoulakis⁶⁾.

In this study, we found that coping styles differed between the groups. We need to be aware of their different coping styles and to use specific physical and mental approaches to achieve a desirable coping style as well as HRQOL. In one study in our series, we reported that approaching coping was positively associated with the mental component summary (MCS) score and distractive coping was negatively associated with the MCS score in the SF-36³³⁾. Thus, coping affects HRQOL, especially psychological status. Considering the coping property of primary LLL patients that was revealed in this study, sharing information and encouraging patients to develop an understanding of lymphedema are important factors that lead to a feeling of relief and support approaching coping strategies, including active coping, planning, and acceptance. Moreover, the approval of patients' efforts to self-manage is important for avoiding self-blame coping. The provision of care to improve general health is necessary for patients in the moderate stage of primary LLL, whose decrease in body function is not noticeable. Hence, physical self-management, such as the prevention of cellulitis that causes difficulty in working or everyday life, must be undertaken so as not to let the existing edema deteriorate.

There are limitations to this study. As the SF-36 is a general HRQOL scale, there is a possibility that physical function and physical role peculiar to the LLL patients have not been reflected. In addition, as we conducted a cross-sectional study, we cannot infer cause and effect and grasp the changes over time. This study focused on the participants after referral to the clinic. However, the HRQOL of patients with primary LLL before referral or first admission to the clinic might be lower than found in this study when the characteristic of primary lymphedema patients is considered. As we measured the differences and tendencies of coping styles for patients with primary and cancer-related lymphedema, we were unable to investigate intrapersonal changes in coping style for primary lymphedema patients from the early onset of the condition to its maturity. Future research needs to pay more attention to the intrapersonal

changes in HRQOL and coping style to discover the specific psychosocial aspects of primary LLL patients.

Conclusion

This study found a significant difference in coping styles between patients with primary lymphedema and those with cancer-related lymphedema while there was no significant difference in HRQOL between the groups. Our study highlights the importance of providing proper support according to their coping disposition, which leads to the maintenance of HRQOL. Sharing information about lymphedema and enhancing physical self-management is necessary for patients with primary LLL.

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原発性下肢リンパ浮腫患者とがん関連下肢リンパ浮腫患者における健康関連 QOL とコーピングスタイルの比較

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要旨

背景：原発性リンパ浮腫患者とがん関連リンパ浮腫患者では疾患の成り立ちやその背景の違いから健康関連 QOL (HRQOL) やコーピングスタイルが異なることが予測される。本研究は、原発性下肢リンパ浮腫患者とがん関連下肢リンパ浮腫患者を比較することにより、原発性リンパ浮腫患者の HRQOL とコーピングスタイルを明らかにすることを目的とする。

方法：HRQOL を測定するスケールとして SF-36 日本語版、日本語版 HAD 尺度 (HADS) を用い、コーピングスタイルの測定には日本語版 Brief-COPE を用いた。基本属性、リンパ浮腫の状態は診療録、フィジカルアセスメントより情報を得た。

結果：原発性下肢リンパ浮腫患者 78 名、がん関連下肢リンパ浮腫患者 63 名が対象となった。年齢、性別をマッチングさせた国民標準値と比較すると原発性下肢リンパ浮腫患者における HRQOL は全般的健康感 (GH) のみ低い結果であった。さらに、共分散分析を用い年齢、性別を調整した両群の HRQOL の比較においては、有意差は認められなかった。HADS では、不安、抑うつともに点数 8 (不安、抑うつの疑いのあるスコア) 以上の患者の割合は低い結果であった。Brief-COPE の項目では、原発性下肢リンパ浮腫患者における積極的コーピングと自己非難の得点が、がん関連下肢リンパ浮腫患者よりも高い結果であった。

結論：原発性下肢リンパ浮腫患者とがん関連下肢リンパ浮腫患者の HRQOL の違いは確認されなかったが、コーピングスタイルの違いが明らかとなった。

キーワード：先天性リンパ浮腫、ストレス対処行動、不安、抑うつ

Research

Risk Factors for Lymphoedema in Breast Cancer Survivors

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ABSTRACT

OBJECTIVE : To clarify the risk factors for lymphedema (LE) in postoperative breast cancer patients.

METHODS : This cross-sectional study involved postoperative breast cancer patients (age, ≥ 20 years) living in Tohoku and Hokkaido, Japan, who were not undergoing adjuvant therapy at the time of the study. Between October 2013 and June 2014, patients with and without LE completed self-administered questionnaires contained patient characteristics, therapeutic regimens, postoperative complications, discharge instructions, concern regarding the affected limb, and the Type A Behavior Pattern Scale.

Descriptive statistics were applied to all variables. After performing univariate analysis with the presence or absence of LE as the dependent variable, significant independent variables were subjected to multiple logistic regression to determine the odds ratios (ORs).

RESULTS : A total of 318 of the 472 questionnaires were returned. Numbers of patients at each LE stage were as follows : 0, n=225 (70.8%) ; I, n=36 (11.3%) ; IIa, n=47 (14.8%) ; IIb, n=9 (2.8%) ; and III, n=1 (0.3%). Mean LE onset was at postoperative 47.2 months (SD 69.3). Related ORs determined using forced entry were as follows : Axilla lymph node dissection (ALND), 12.1 ($p=0.002$) ; cellulitis, 7.3 ($p=0.001$) ; postoperative difficulty moving arm, 2.3 ($p=0.031$) ; changes around the time of swelling onset, 2.1 ($p=0.035$) ; and being too busy to worry about the affected limb, 0.5 ($p=0.030$). The regression coefficient (B value) for being too busy to worry about the affected limb was -0.8 , indicating that this was a factor related to prevention rather than onset.

DISCUSSION : The present findings suggest for prevention of LE onset, including : ongoing follow-up even after LE onset, detailed information collection regarding parameters such as physical, mental, and lifestyle changes around the time of swelling onset, and encouraging appropriate movement of the affected limb without excessive worry.

KEY WORDS : lymphoedema, breast cancer, risk factors

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Introduction

Lymphoedema [LE] occurs after the treatment of cancer. The incidence of lymphoedema after postoperative breast cancer patients was 10% and 25% in gynecologic cancer¹⁾. In previous study²⁾, it was noted onset of lymphoedema within 3 years after the operation. Outpatient LE care reduces limb circumference, many patients still experience exacerbated edema or recurrent inflammation even with ongoing care. It is necessary to identify risk factors for not only LE onset but also progression to stage II. Some LE risk factors were identified by a literature review³⁾. There were LE risk factors related to patient characteristics (including body mass index [BMI], age, and airplane travel), treatment (including years of follow-up, medical history, axillary lymph node dissection [ALND], type of surgery, radiotherapy, chemotherapy, and anti-hormone therapy), and postoperative symptoms (including infection, sensory impairment, pain, and limited range of motion [ROM]).

No studies in Japan have investigated risk factors concerning lifestyle and treatment after breast cancer surgery. An interview study of factors related to LE onset in postoperative breast cancer patients in Japan⁴⁾ supported the findings regarding patient characteristics and treatment risk factors reported in overseas literature. The patients in this study had varied lifestyle habits and regional cultures, particularly with regard to activity-related factors such as use of the arms and hands, women's roles, assisting with local events, and economic issues, and psychological factors such as the will to not develop LE, type A behavior patterns, and not worrying about the affected limb. The state of LE instruction also varied. However, these findings suggested that risk factors related to regions and lifestyle habits except treatment remained to be clarified for LE in postoperative breast cancer patients in Japan, and no studies to date have investigated exacerbating factors.

The purposes of this study were to examine the risk factor [RF] for developing and deteriorating factors of LE in breast cancer survivors, and to describe the how activity level and developing and deteriorating behavior influence of daily life.

The findings will hopefully enable prediction of

lifestyles that may cause LE developing (onset) and thus be useful for preventing onset and exacerbation. The risk factors for LE onset are presented in this report.

Methods

1. Study design

Retrospective, cross-sectional study was used.

2. Subjects

1) Selection criteria

The subjects were female postoperative breast cancer patients (age, ≥ 20 years) living in Tohoku and Hokkaido, Japan. Inclusion and exclusion criteria were as follows.

Inclusion criteria :

a) Able to communicate, understand questionnaire content, and complete the questionnaire by hand.

b) Able to understand the study objective and significance and voluntarily decide to participate or withdraw.

2) Exclusion criteria :

Undergoing chemotherapy or radiotherapy at the time of the study.

3. Measurement tools

Measurement tools were made based on previous studies⁵⁾⁶⁾ comprised two questionnaires : 'Stages I-III Questionnaire' for LE patients and 'Stage 0 Questionnaire' for non-LE patients.

1) Questionnaire content

(1) Stages I-III Questionnaire

The Stages I-III questionnaire covered 88 items divided into 9 sections : 1) patient demographics, 2) personality traits, comprising the Type A Behavior Pattern Scale⁷⁾. This 6-point Likert scale (from 1 'does not apply at all' to 6 'applies completely') is divided into three main sections (I. Hostility, II. Perfectionism, and III. Japanese workaholism) and 30 subsections. Scale reliability (Cronbach's $\alpha = 0.81-0.85$) and validity have been confirmed. Permission to use the scale was obtained from the copyright holder, Professor Masahiro Seto of Kanagawa University Faculty of Human Sciences ; 3) therapeutic status, comprising duration of hospital stay, age at LE onset, affected limb, and changes around the time swelling was noticed, type of surgery, so on ; 4) postoperative complications, comprising pain,

Visual Analog Scale (VAS) (score, 0-100), cellulitis, wound dehiscence, so on ; 5) discharge instruction, 6) hospital visits, 7) concern regarding the affected limb, comprising prioritizing work over the fear of developing LE and absence of LE for the following reasons, 8) daily activities, and 9) preventive behavior of LE.

(2) Stage 0 Questionnaire

All items were the same as for the Stage I-III Questionnaire except for questions pertaining to changes around the time swelling was noticed.

(3) Face validity

Under the supervision of the LE therapist, questionnaire contents was repeatedly investigated regarding 1) applicability to LE (Stages I-III) and non-LE (Stage 0) postoperative breast cancer patients ; 2) usage of jargon ; and 3) usage of leading or loaded questions.

Next, 1 non-LE and 2 LE postoperative breast cancer patients were asked to complete the survey. The mean time required for completion was 35 min. The patients reported that the questions were “mostly comprehensible” with regard to terminology and difficulty of expressions, “there were no incomprehensible areas” regarding how to answer the questions, and that the font size was “just right”.

4. Data collection

1) Procedures and methods

(1) Location

Since post-discharge lifestyle was expected to affect LE onset and exacerbation, data collection was limited to Tohoku and Hokkaido as two regions of Japan with comparable conditions such as seasons and regional customs.

(2) Requests for participation

① Facilities and patients' associations

The directors of nursing and outpatient nursing were firstly explained verbally and in writing details of the study such as the purpose and methods. A written request for study participation was then explained to the hospital director of each facility, and informed consent was obtained.

Where present, the nurse/LE therapist at each facility was asked to act as a research associate and assist with the study by selecting subjects and determining LE stage⁸⁾, distributing questionnaires, and responding to patients' concerns and questions regarding aspects

such as LE care methods. They were also asked to provide patients who were found through the questionnaire to have LE of stage I or higher with instruction regarding self-care methods and to introduce outpatient LE care services. Therapists were given manuals to ensure that patient selection, study explanations, and questionnaire distribution methods were consistent between facilities.

Author got signature about consent forms of all patients' association representatives for participation after receiving a written explanation of the study aims, methods, and patient explanation process, and seeing a copy of the questionnaires.

Patients were asked to complete the questionnaire at home and then return it by post within 10 days. Consent for participation was implied by return of the questionnaire.

② Determining LE stage

Patients were given the questionnaire that corresponded to their LE stage, determined by the author or nurse/LE therapist as 0 for non-LE patients and I-III for LE patients.

2) Study period

October 2013-June 2014

5. Data analysis

1) Descriptive statistics (all variables)

Frequency, mean, standard deviation (SD), minimum, maximum, and median values for each variable were tabulated to provide an overview of the data. Free responses were summarized based on content.

2) Univariate analysis

With presence (LE stage, $\geq I$) and absence (LE stage, 0) of LE as the dependent variables, chi-square test (χ^2 or Fisher's exact test) was performed for independent variables comprising two values (present [1] or absent [0]) or ordinal scales. With regard to Type A Behavior Pattern Scale (6-point scale) scores or continuous variables, normality was confirmed, and independent-samples t-tests or Mann-Whitney U tests were performed for two-group comparison and Kruskal-Wallis or one-way analysis of variance was performed for three-group comparisons.

3) Multivariate analysis

Forced-entry multiple logistic regression analysis was performed with LE stages 0 (0) and $\geq I$ (1) as the

dependent variables. Data organization and confirmation in preparation for multiple logistic regression⁹⁾ included confirming the sample size and number of independent variables, multicollinearity, and outliers.

Goodness-of-fit was determined using the Hosmer-Lemeshow test and the true rate. Statistical analysis was performed using IBM SPSS ver. 22.0J for Windows. Significance was set at $p < 0.05$ (power, 0.80; effect size, 0.40).

6. Ethical considerations

Patient's consent for study participation was implied by return of the self-administered questionnaire. The author and research associates at all facilities were prohibited from using language or attitudes suggesting that participation was mandatory, and questionnaire return was neither confirmed nor encouraged.

Treatment, LE care, and involvement in patients' association activities were wholly unaffected by and no penalty arose from patient refusal to participate or non-return of the questionnaire. This was clearly stated on the study participation request form and explained verbally. The questionnaires were anonymous, preventing individual identification. Approval by the Ethical Review Board of each facility that indicated such approval was necessary was obtained following submission of the necessary documents. Approval was also obtained from the Ethical Review Board of St. Luke's International University (Approval No.13-041).

Results

As stated 7 sections in questionnaire were reported in this results.

A total of 472 questionnaires were distributed to six facilities across A Prefecture (n=4), K Prefecture (n=1), and H Prefecture (n=1) and nine patients' associations across A Prefecture (n=6), I Prefecture (n=1), and H Prefecture (n=2). All responses from the 318 returned questionnaires (collection rate, 67.4%) were tabulated and analyzed. LE was present (stages I-III) in 93 (29.2%) patients and absent (stage 0) in 225 (70.8%) patients. The incidence was therefore 29.2%. LE stages were as follows: 0, n=225 (70.8%); I, n=36 (11.3%); IIa, n=47 (14.8%); IIb; n=9 (2.8%); and III, n=1 (0.3%). Mean LE onset was at postoperative 47.2 months (SD 69.3; equivalent to 3 years 9

mon, median 24.0, min 2, max 480). Affected limbs were as follows: left arm, n=46 (50.5%); right arm, n=41 (44.1%); bilateral arms, n=4 (4.3%); and unknown, n=1 (1.1%).

1. Difference between LE and non-LE patients

1) Patient demographics: LE vs. non-LE patients

Mean ages at surgery for LE and non-LE patients were 53.00 y (SD 11.16 y) and 54.72 y (SD 11.62 y), respectively, while BMIs at surgery were 23.07 (SD 3.29) kg/m² and 22.96 (SD 3.09) kg/m², respectively. BMI at LE onset was 24.11 (SD 4.86) kg/m². A total of 77 (82.8%) LE patients and 182 (80.9%) non-LE patients had jobs (including housework). According to their free responses, patients' jobs included administrator, caregiver, hairdresser, *koto* (Japanese harp) teacher, farmer, fisherman, *kimono* seamstress, registered dietician, and yoga instructor so on. Little difference was observed between LE and non-LE patients with regard to mean working hours per day at 416.0 min (SD 169.9 min; approximately 6.8 h and 400.9 min SD 140.2 min; approximately 6.7 h, $p = .485$ Mann-Whitney U test). Times between hospital discharge and returning to work for LE and non-LE patients were 7.02 mo (SD 11.46 mo) and 6.65 mo (SD 12.53 mo), respectively. LE and non-LE patients gave one or more of the following reasons for returning to work: 'end of sick leave' (9% vs. 10%), 'asked to return' (5% vs. 7.0%), 'wanted to work' (27% vs. 17.6%), 'financial reasons' (16.9% vs. 13.7%), and 'other' (18.2% vs. 11.5%).

2) Personality traits: LE vs. non-LE patients

With regard to personality traits, mean total Type A Behavior Pattern Scale scores (range, 30-180) in LE and non-LE patients were 92.3 (SD 19.9) vs. 91.5 (SD 19.4). Mean subscale scores were as follows: hostility, 22.5 (SD 8.1) vs. 22.3 (SD 8.2); perfectionism, 35.5 (SD 9.4) vs. 35.4 (SD 9.4); and Japanese workaholism, 34.3 (SD 9.8) and 33.9 (SD 9.0).

Cronbach's α reliability coefficient values confirming the internal validity of the Type A Behavior Pattern Scale results were 0.87 for all 30 items and 0.88, 0.88, and 0.83 for hostility, perfectionism, and Japanese workaholism, respectively.

There is no significantly variables between LE and

non-LE patients on demographics and personality traits.

3) Therapeutic regimen

Hospital stay was significantly longer for LE compared to non-LE patients by a mean of 6 days (24.0 days [SD 26.9 days] vs. 18.2 days [SD 18.8 days] ; Mann-Whitney U test, $p=.005$).

Mean LE onset was at postoperative 47.2 mo (SD 69.3 mo ; equivalent to 3 y 9 mo ; range, 2-480 mo). Significant differences were observed in proportions of LE patients who experienced changes around the time of swelling onset (LE) or to date (non-LE) (45.2% [n=42] vs. 32.9% [n=74] ; $\chi^2=6.092$, degrees of freedom [df]=1, $p=0.014$). Changes around the time of swelling onset in LE patients included weight gain (most common response), mental fatigue, family member requiring care, travel pulling a suitcase, quitting work, and extended working hours. Changes to date in non-LE patients similarly comprised weight gain for many patients, as well as impaired wound healing. All LE patients underwent either lumpectomy (46.2% [n=43]) or mastectomy (51.6% [n=48]). In non-LE patients, lumpectomies were significantly more prevalent than mastectomies (60.0% [n=135] vs. 35.1% [n=79] ; $\chi^2=6.6$, df=1, $p=0.010$). Drain use was significantly more common in LE than non-LE patients (76.3% [n=71] vs. 65.3% [n=147] ; $\chi^2=4.0$, df=1, $p=0.045$). A significant difference was also observed for ALND, with almost all LE patients undergoing ALND (93.5% [n=87] vs. 65.3% [n=147] ; $\chi^2=25.6$, df=1, $p=0.000$). A smaller proportion of LE than non-LE patients underwent sentinel lymph node biopsy [SLNB] (33.3% [n=31] vs. 44.0% [n=99]). The use of adjuvant therapies in LE and non-LE patients was as follows : radiotherapy, 61.3% (n=57) vs. 51.6% (n=116) ; chemotherapy, 58.1% (n=54) vs. 47.6% (n=107). The use of anti-hormone therapy was more common in non-LE patients (73.8% [n=166] vs. 66.7% [n=62]). The incidence of cancer recurrence in LE and non-LE patients was 3.2% (n=3) vs. 3.6% (n=8). Follow-up durations among LE compared to non-LE patients were as follows : ≥ 6 y, 44.1% (n=41) vs. 36.9% (n=83) ; 5.9-5.0 years 15.1% (n=14) vs. 8.4% (n=19), 4.9-4.0 years, 10.8% (n=10) vs. 16.0% (n=36) ; and 3.9-3.0 years, 3.2% (n=3) vs. 5.3% (n=12). A significant difference was observed between

LE and non-LE patients regarding the proportion of patients attending hospital follow-up for 5 years or more (60% vs. 45% ; $\chi^2=8.7$, df=1, $p=0.046$).

4) Postoperative complications

Pain was experienced by 55.9% (n=52) LE and 55.1% (n=124) non-LE patients. Pain intensity was higher for LE patients (mean VAS scores), 21.8 [SD 25.4] vs. 14.91 [SD 18.4]). The incidence of cellulitis was around 5 times higher in LE than non-LE patients, a significant difference (25.8% [n=24] vs. 5.8% [n=13] ; $\chi^2=23.9$, df=1, $p=0.000$). The incidence of wound dehiscence was 7.5% (n=7) in LE and 4.0% (n=9) in non-LE patients, while periwound swelling was 17.2% (n=16) and 18.7% (n=42). The incidence of periwound induration was lower in LE than in non-LE patients (39.8% [n=37] vs. 44.9% [n=101]). A higher proportion of LE than non-LE patients experienced periwound hypoesthesia (60.2% [n=56] vs. 56.9% [n=128]), while a significantly higher proportion of LE patients experienced postoperative difficulty moving arm(s) (63.4% [n=59] vs. 49.8% [n=112] ; $\chi^2=4.5$, df=1, $p=0.035$).

5) Discharge instructions

No significant difference was observed for discharge instructions, which was received by 71.0% (n=66) LE and 70.7% (n=159) non-LE patients. LE and non-LE patients received discharge instructions from one or more of the following people : nurse, n=22 vs. 50 ; doctor, n=11 vs. 28 ; physical therapist, n=5 vs. 10 ; and others, n=5 vs. 14.

Discharge instructions covering one or more of the following aspects of LE was received by LE and non-LE patients as follows : development process, n=15 vs. 30 ; symptoms, n=26 vs. 53 ; treatment methods, n=17 vs. 25 ; importance of self-care, n=18 vs. 34 ; prevention and improvement methods, n=28 vs. 54 ; precautions during daily life, n=35 vs. 63 ; methods of managing infection, n=8 vs. 10 ; and 'other' content, n=4 vs. 0. The most common instruction for both LE and non-LE patients related to precautions during daily life. Discharge instructions for LE and non-LE patients was delivered verbally (n=27 vs. 57), using pamphlets (n=34 vs. 54), by video (n=6 vs. 11), and by 'other' methods (n=2 vs. 3). No significant difference was observed in instruction methods between LE and

non-LE patients. A significantly higher proportion of LE than non-LE patients received post-discharge outpatient instructions (29.0% [n=27] vs. 10.7% [n=24]; $\chi^2=4.0$, df=1, p=0.045).

6) The time required to hospital

The time required to hospital for LE and non-LE patients were as follows: ≤ 30 min, 61.3% (n=57) vs. 60.9% (n=137); 31-60 min, 19.4% (n=18) vs. 24.9% (n=56); 61-90 min, 11.8% (n=11) vs. 7.6% (n=17); and ≥ 91 min, 5.4% (n=5) vs. 4.0% (n=9). Around 80% of both LE and non-LE patients had the time required to hospital of ≤ 60 min.

7) Concern regarding affected limb

A significantly higher proportion of non-LE than LE patients responded that they were too busy to worry about the affected limb (56.5% [n=127] vs. 44.1% [n=41]; $\chi^2=6.5$, df=1, p=0.011), demonstrating that around half of non-LE patients were unconcerned about the affected limb. Frequency of unconcerned about the affected limb in LE and non-LE patients was as follows: always, 41.5% (n=17) vs. 23.6% (n=27); sometimes, 36.6% (n=15) vs. 53.5% (n=68); and occasionally, 21.9% (n=9) vs. 25.2% (n=32). Lack of awareness regarding right or left was reported by 41 (44.1%) LE and 117 (52.0%) non-LE patients. Frequency of not favoring right or left arm in LE and non-LE patients was as follows: always, 26.0% (n=11) vs. 17.9% (n=21); sometimes, 39.1% (n=16) vs. 47.0% (n=55); and occasionally, 34.1% (n=14) vs. 35.1% (n=41). LE and non-LE patients believed they would not develop LE because they were not taking anti-cancer drugs or undergoing radiotherapy (2.2% [n=2] vs. 1.8% [n=4]; undergoing regular checkups (19.4% [n=18] vs. 15.1% [n=34]); and only working (studying, engaging in hobbies) a little (14.0% [n=13] vs. 11.6% [n=26]). Among the 259 employed patients, 36.3% (n=28) LE and 21.4% (n=39) non-LE patients prioritized work over the fear of developing LE.

2. Odds ratio of Risk factors for LE

Forced-entry multiple logistic regression analysis performed on the variables that showed significance (Table 2) generated the following odds ratios (ORs): ALND, 12.1 (p=0.002); cellulitis, 7.3 (p=0.001); postoperative difficulty moving arm(s), 2.3 (p=0.031); changes around time of swelling, 2.1

(p=0.035); and being too busy to worry about the affected limb, 0.5 (p=0.030). The regression coefficient (B value) for being too busy to worry about the affected limb was -0.8, indicating that this was a factor for LE prevention rather than onset (Table 3).

Discussion

The present risk factors, including changes around the time of swelling (weight gain), duration of hospital stay, type of surgery, drain use, ALND, duration of follow-up, cellulitis, and postoperative difficulty moving arm(s), have also been reported in previous studies overseas. This indicates that LE risk factors in patients outside Japan are similar to those in patients in Hokkaido and 3 prefectures in Tohoku.

The main change at the time of swelling onset was weight gain (OR $\times 2.1$). However, non-physical changes relating to family and working life, such as a family member requiring care, mental fatigue, and quitting work, were also reported in the free response section. We must consider their family as well as their own lifestyle needs. These findings show that prevention methods need to consider and respond appropriately to not only weight gain but also anything else that is troubling the patient. Weight gain may be due to increased subcutaneous fat or the LE-related lymph congestion itself. Mean BMIs at surgery were within the normal range (18.5-25.0 kg/m²) at around 23 kg/m² for both LE and non-LE patients. Many breast cancer patients undergo pre- and/or postoperative chemotherapy. Increased capillary permeability and subsequent edema have been reported with taxane⁽¹⁰⁾⁽¹¹⁾, while persistent edema following swelling due to anti-cancer drugs has also been experienced in clinical practice. Many literature reviews have presented the risk of LE onset with chemotherapy⁽¹²⁻¹⁸⁾. Postoperative anti-hormone therapy also causes weight gain, triggering LE⁽¹⁹⁻²²⁾.

Theoretically, with increased capillary permeability arising from drug side effects, excessive tissue fluid builds up in the tissues and, through osmosis, either returns to the veins or enters the lymph capillaries where it is transported as lymph fluid to the venous angle and enters the venous blood system. Thus, swelling does not arise. However, in postoperative

Table 1 Demographics and personality traits of patients

| Characteristics | LE (n=93) | non-LE (n=225) | p value |
|---|---------------|----------------|---------|
| Age at surgery, mean (SD) | 53.0 (11.2) | 54.7 (11.6) | .226 |
| BMI (kg/m ²) at surgery, mean (SD) | 23.1 (3.3) | 23.0 (3.1) | .888 |
| BMI (kg/m ²) at LE onset, mean (SD) | 24.1 (4.9) | | |
| Jobs (including housework), N (%) | 77 (82.8) | 182 (80.9) | .616 |
| Working hours per day, mean (SD) | 416.0 (169.9) | 400.9 (140.2) | .485 |
| Times between hospital and returning to work : month, mean (SD) | 7.0 (11.5) | 6.7 (12.6) | .452 |
| Reasons for returning to work (multiple replies allowed), N (%) § | | | |
| End of sick leave | 7 (9.0) | 18 (9.9) | .451 |
| Asked for return | 4 (5.2) | 13 (7.1) | .223 |
| Wanted to work | 21 (27.2) | 32 (17.6) | .292 |
| Financial reasons | 13 (16.9) | 25 (13.7) | .976 |
| others | 14 (18.2) | 21 (11.5) | .411 |
| Marital statuses, N (%) | | | .229 |
| Married | 73 (78.5) | 169 (75.1) | |
| Unmarried | 12 (12.9) | 22 (9.8) | |
| In a relationship | 2 (2.2) | 3 (1.3) | |
| Others | 3 (3.2) | 16 (7.1) | |
| unknown | 3 (3.2) | 15 (6.7) | |
| Highest education level, N (%) | | | .197 |
| Elementary school | 0 – | 4 (1.8) | |
| Junior high school | 12 (12.9) | 19 (8.4) | |
| High school | 57 (61.2) | 127 (56.5) | |
| University/postgraduate | 14 (15.1) | 47 (20.9) | |
| unknown | 10 (10.8) | 28 (12.4) | |
| Household income, N (%) | | | .194 |
| 5.01 million yen/y | 21 (22.6) | 50 (22.2) | |
| 301-500 million yen/y | 9 (9.7) | 39 (17.3) | |
| 151-300 million yen/y | 51 (54.8) | 97 (43.2) | |
| 150 million yen/y | 11 (11.8) | 32 (14.2) | |
| unknown | 1 (1.1) | 7 (3.1) | |
| Concurrent diseasres (multiple replies allowed), N (%) | 48 (51.6) | 127 (56.4) | .431 |
| Hypertension | 23 – | 45 – | .349 |
| Orthopedic disorder | 15 – | 30 – | .515 |
| Cardiovascular disease | 8 – | 10 – | .144 |
| Diabetes mellitus | 3 – | 20 – | .056 |
| Gynecological disorders | 3 – | 11 – | .375 |
| Cranial nerve disease | 2 – | 11 – | .214 |
| Respiratory disease | 1 – | 6 – | .343 |
| Others | 12 – | 49 – | .067 |
| Type A Behavior Pattern Scale : range, 30-180, mean (SD) | | | |
| Total : 30 items | 92.3 (19.9) | 91.5 (19.4) | .417 |
| Hostility : 10 items | 22.5 (8.1) | 22.3 (8.2) | .825 |
| Perfectionism : 10 items | 35.5 (9.4) | 35.4 (9.4) | .864 |
| Japanese workaholism : 10 itmes | 34.3 (9.8) | 33.8 (9.0) | .680 |

note : § N of Jobs (LE=77, non-LE=182). LE : Lymphoedema, SD : standard deviation, Body mass index : BMI, : Chi-square test, Fisher's exact test, Mann-Whitney test, Student's t-test

Table 2 Variables with a significant difference between LE and non-LE patients

| | LE (n=93) | | Non-LE (n=225) | | p value | Pearson's χ^2 |
|--|---------------|-----------|----------------|--------|---------|--------------------|
| Duration of hospital stay (days), mean (SD) | 24.0 (27.0) | | 18.2 (18.8) | | .005* | |
| Changes around time of swelling onset (LE)/changes to date (non-LE), N (%) | | | | | .014* | 6.1 |
| | Yes | 42 (45.2) | 74 | (32.9) | | |
| | No | 37 (39.8) | 126 | (56.0) | | |
| Type of surgery, N (%) | | | | | .010* | 6.6 |
| | Mastectomy | 48 (51.6) | 79 | (35.1) | | |
| | Lumpectomy | 43 (46.2) | 135 | (60.0) | | |
| Drain use, N (%) | | | | | .045* | 4.0 |
| | Yes | 71 (76.3) | 147 | (65.3) | | |
| | No | 14 (15.1) | 56 | (24.9) | | |
| Axillary lymph node dissection, N (%) | | | | | .000* | 25.8 |
| | Yes | 87 (93.5) | 147 | (65.3) | | |
| | No | 2 (2.2) | 57 | (25.3) | | |
| Duration of follow-up (years), N (%) | | | | | .046* | 8.6 |
| | None | 0 – | 1 | (0.4) | | |
| | ≤ 1 year | 6 (6.5) | 29 | (12.9) | | |
| | 1.0-1.9 years | 7 (7.5) | 18 | (8.0) | | |
| | 2.0-2.9 years | 10 (10.8) | 20 | (8.9) | | |
| | 3.0-3.9 years | 3 (3.2) | 12 | (5.3) | | |
| | 4.0-4.9 years | 10 (10.8) | 36 | (16.0) | | |
| | 5.0-5.9 years | 14 (15.1) | 19 | (8.4) | | |
| | ≥ 6 years | 41 (44.1) | 83 | (36.9) | | |
| Cellulitis, N (%) | | | | | .000* | 23.9 |
| | Yes | 24 (25.8) | 13 | (5.8) | | |
| | No | 66 (71.0) | 194 | (86.2) | | |
| Postoperative difficulty moving arm(s), N (%) | | | | | .035* | 4.5 |
| | Yes | 59 (63.4) | 112 | (49.8) | | |
| | No | 30 (32.3) | 99 | (44.0) | | |
| Provision of post-discharge outpatient instructions, N (%) | | | | | .045* | 4.0 |
| | Yes | 27 (29.0) | 24 | (10.7) | | |
| | No | 57 (61.3) | 97 | (43.1) | | |
| Concern regarding affected limb : too busy to worry about the affected arm(s), N (%) | | | | | .011* | 6.5 |
| | Yes | 41 (44.1) | 127 | (56.5) | | |
| | No | 44 (47.3) | 70 | (31.1) | | |

note : Chi-square test, Fisher's exact test, Mann-Whitney test

*p<0.05

patients, normal lymphatic flow via the lymph vessels is disrupted and lymph congestion occurs. Swelling is avoided if the lymph fluid is rerouted at the lymph capillary level, but if the transport capacity of the lymph vessels is exceeded, LE will develop.

While studies in Europe and America have reported BMI ≥30 kg/m² as a risk factor for LE onset²³⁾²⁴⁾, a study

in Hong Kong and South Korea by Park et al²⁵⁾ found the cutoff to be 23–25 kg/m². Meanwhile, although Aonuma et al.²⁶⁾ reported no significant difference between the mean BMI of LE (23 kg/m² ; n=27) and non-LE patients (24 kg/m² ; n=16), a significant difference was found in another study (24 [SD 3.8] kg/m², n=16 vs. 22.6 [SD 3.0] kg/m², n=31 ; p<0.05)²⁷⁾. These find-

Table 3 Risk factor odds ratios for LE onset

| Variable | B | P-value | Exp (B) | Exp(B) 95% CI | |
|--|------|---------|---------|---------------|-------------|
| | | | | Lower limit | Upper limit |
| Axillary lymph node dissection | 2.5 | .002* | 12.1 | 2.5 | 59.2 |
| Drain use | -0.5 | .325 | 0.6 | 0.3 | 1.6 |
| Cellulitis | 2.0 | .000* | 7.3 | 2.3 | 22.5 |
| Postoperative difficulty moving arm(s) | 0.8 | .031* | 2.3 | 1.1 | 4.7 |
| Changes around time of swelling onset | 0.7 | .035* | 2.1 | 1.1 | 4.1 |
| Too busy to worry about the affected limb | -0.8 | .030* | 0.5 | 0.2 | 0.9 |
| Constant | -3.2 | .000 | 0.0 | | |
| Omnibus test of model coefficient: p value | .000 | | | | |
| Hosmer-Lemeshow test | .830 | | | | |
| True rate | 73.0 | | | | |

B=regression coefficient, Exp(B)=odds ratio, CI=Confidence Interval

*p<0.05

ings reaffirm the importance of not simply including BMI in discharge instruction based on values stated in previous literature, but considering the origin and characteristics of the patients from whom these values were obtained.

In addition to measuring weight (BMI), other screening is necessary to identify potential risk factors in postoperative patients. Creating an observation chart containing screening items related to LE onset such as duration of hospital stay (≥ 24 days), duration of follow-up (4-5 years), type of surgery, SLNB, ALND (OR $\times 12.1$), drain use, postoperative difficulty moving arm(s) (OR $\times 2.3$), and cellulitis (OR $\times 7.3$) to be used pre- and post-discharge would enable any health worker to assess patient status.

With regard to postoperative difficulty moving arm(s) and cellulitis, it is necessary to go beyond simply confirming their presence or absence and understand the details of the situation. The present study only asked whether patients had postoperative difficulty moving arm(s) and did not generate details such as differences in symptom duration and range and types of motion. When assessing ROM of affected arm, it is necessary to confirm : the ranges of abduction, flexion, and extension with the shoulder as the pivot ; which motions are difficult and to what degree ; and if any other motions triggers twitches, as well as assessing any associated

pain. Similarly, with regard to cellulitis, recurrent inflammation causes increased arm circumference, high fever, and exacerbated fibrosis. Therefore, it is important to clarify what the patient was doing before onset in addition to simply checking for inflammation in order to avoid repeating the action that induced the inflammation. The OR $\times 7.3$ for cellulitis suggests that patients should be particularly warned about behaviors linked to infection.

LE patients were three times more likely than non-LE patients to receive post-discharge outpatient instruction (29.0% [n=27] vs. 10.7% [n=24] ; p<0.05). However, no differences were observed between the two groups with regard to instruction content or products used during instruction. Although the present results found no difference in instruction content, the difference in frequency between the two groups calls into question the effectiveness of the instruction received by patients who went on to develop LE, and further investigation is urgently required.

Concern regarding affected limb (being too busy to worry about the affected limb) had an OR $\times 0.5$ and a regression coefficient (B value) of -0.8. This variable was based on risk factor categories identified by Kimura²⁸⁾ of “working without awareness regarding the affected arm” and “prioritizing work over concerns regarding swelling”. Working hard without concern for

the risk of developing LE was expected to place a burden on the arm on the operated-on side. However, the negative coefficient resulting from multiple logistic regression analysis indicated that this is a preventive factor rather than an onset risk factor. While postoperative difficulty moving arm(s) and limited ROM were found to be onset risk factors, worrying about and not moving the arm(s) similarly appeared to be actually linked to onset. The collecting lymphatic vessel walls contain smooth muscle; however, subepithelial lymph capillaries are not capable of peristaltic contraction. Moving the arms and trunk entails movement of the muscles and diaphragm, and blood vessel pulsation, thereby stimulating flow of congested lymph fluid. Appropriate physical movement is therefore linked to LE prevention.

LE and non-LE patients were compared using the Type A Behavior Pattern Scale to investigate whether this typically Japanese attitude and serious-mindedness may be risk factors for onset; however, no differences were observed. Mean scores for hostility, perfectionism, and Japanese workaholism in different subject groups at scale development²⁹⁾ were as follows: ischemic heart disease patients (n=13) 30.62 (SD 5.12), 42.62 (SD 5.80), and 38.92 (SD 5.63), respectively; general managers (n=148) 29.91 (SD 7.32), 41.73 (SD 6.59), and 40.10 (SD 6.56), respectively; and healthy women (n=296) 28.14 (SD 7.49), 38.31 (SD 6.76), and 35.63 (SD 7.73). The mean scores in the present study were lower than all scores at scale development apart from Japanese workaholism in healthy women. These findings indicate that the subjects in the present study (n=318) tended toward hostile behavior less than the average for healthy women and were neither perfectionists nor prone to Japanese workaholism.

These findings indicate that, in addition to giving specific instructions such as "limit activities to this level, avoid being bitten by insects to prevent infection, and rest if tired", in most cases, encouraging patients to feel that it is better not to constantly worry about the affected limb may contribute to LE prevention. Many postoperative patients avoid moving due to pain and worry that they will never be cancer-free. Pain relief, gradual rehabilitation, and not being overly nervous may help to prevent onset.

Conclusion

The present questionnaire surveyed 472 postoperative breast cancer patients. Responses were obtained from 318 patients. Univariate analysis with the presence or absence of LE as the dependent variable identified 10 variables with significant differences: type of surgery, duration of hospitalization (≥ 24 days), ALND, drain use, cellulitis, postoperative difficulty moving arm(s), post-discharge outpatient instruction, duration of follow-up, changes at the time of swelling, and being too busy to worry about the affected limb. Forced-entry multiple logistic regression on these variables generated the following OR: ALND, 12.1 ($p=0.002$); cellulitis, 7.3 ($p=0.001$); postoperative difficulty moving arm(s), 2.3 ($p=0.031$); changes at the time of swelling, 2.1 ($p=0.035$); and being too busy to worry about the affected limb, 0.5 ($p=0.030$). The regression coefficient (B value) value for being too busy to worry about the affected limb was -0.8 , indicating that this is a factor related to prevention rather than onset.

Limitations

Participants in this study were not all breast cancer survivors after operation in the Hokkaido and Tohoku area. So, the RFs of LE are a part of them. Next step would be carried out prospective research using RFs of this study.

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乳がん術後患者のリンパ浮腫のリスクファクターに関する研究

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要 旨

目的：乳がん術後患者のリンパ浮腫（以下LE）発症に関与するリスクファクター（以下RF）を明らかにする。

研究方法：研究デザインは自記式質問紙を用いた横断調査である。研究対象は東北・北海道に居住する20歳以上で、補助療法中でない乳がん術後患者とした。調査期間は平成25年10月～平成26年6月。質問紙は、属性・治療内容・術後合併症・退院指導・患肢への関心・タイプA行動パターン尺度を含む。分析は全変数の記述統計を行い、LEの有無を従属変数とし単変量解析後、有意であった変数を用いて多重ロジスティック回帰分析を行いオッズ比を求めた。

結果：施設は6施設、患者会は9団体で、配布総数472件のうち、回収は318（67.4%）件だった。病期は、0期225人（70.8%）、Ⅰ期36人（11.3%）、Ⅱa期47人（14.8%）、Ⅱb期9人（2.8%）、Ⅲ期1人（0.3%）で、LEの発症は術後平均47.2ヶ月（SD 69.3）だった。

単変量解析後、オッズ比（強制投入）を求めると、腋窩リンパ節郭清（odds：12.1 p=.002）、術後蜂窩織炎（odds：7.3 p=.001）、患肢の動きにくさ（odds：2.3 p=.031）、むくんだ頃の変化（odds：2.1 p=.035）、多忙で患肢を気にしない（odds：0.5 p=.030 回帰係数-0.8）だった。多忙で患肢を気にしないは、係数がマイナスということから、発症ではなく予防に向いていた。

考察：結果から、術後から継続的なフォローアップをする、むくんだ頃の心身や生活の変化等の詳細な情報収集をする、患肢をあまり気にせず適度に動く等のLE発症予防に関する示唆を得た。

キーワード：リンパ浮腫，乳がん，リスクファクター

Research

Characteristics of Nursing Care for Patients with Lymphedema after Cancer Surgery

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ABSTRACT

OBJECTIVE : To clarify the characteristics of nursing care to support patients with lymphedema after cancer surgery, who need to perform long-term self-care as part of symptom control.

METHODS : Semi-structured interviews were conducted with 8 nurses engaged in lymphedema care for patients after cancer surgery, whose consent had been obtained. Data were collected to extract those regarding the characteristics of the above-mentioned nursing care, and analyze them, focusing on their contents, as well as similarities and differences among them.

RESULTS : Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>. The care delivery system consisted of 8 components : <arrangement of the form>, <securing of place>, <securing of time>, <team structure and the patient in charge system>, <the number of outpatients>, <management of medical articles>, <instructional materials>, <the presence of a supervisor and mentor>.

KEY WORDS : lymphedema after cancer surgery, self-care support, outpatient lymphedema treatment

Introduction

Methods to completely cure lymphedema after cancer surgery have not yet been established, and the first-choice treatment approach combines skin care, compression, therapeutic exercise under compression,

and lymphatic drainage. Once the disorder occurs, it is necessary to prevent it from deteriorating and control its symptoms by continuing such treatment. In conventional oncological services, mainly aiming to kill cancer cells, the level of interest in treatment-related complications and inconvenience to patients has been low¹⁾.

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According to data, some patients suffering from postoperative lymphedema are told by their doctors : 'Now that you are free from cancer, you should endure the swelling²⁾. As a consequence of this attitude, the activities of groups organized by patients themselves to enhance awareness of symptom control³⁾, efforts and positive outcomes achieved by clinicians continuously engaged in medical and nursing services for patients with lymphedema⁴⁻⁷⁾, and findings of basic and clinical studies on the disorder⁸⁻¹⁴⁾ have been favorably evaluated, leading to a revision of medical fees in 2008, and consequently enhancing recognition of lymphedema in medical fields.

In Japan, the insurance coverage of lymphedema treatment started in 2008 when 100 points were allocated to lymphedema guidance and management, and 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.

Professionals qualified to calculate combined lymphedema treatment fees are limited to doctors, nurses, physical/occupational therapists, and masseurs (there are some conditions for masseurs to perform such calculations). Currently, there are 180 facilities, in which nurses provide outpatient care for patients with lymphedema as private practice¹⁵⁾. Now that combined lymphedema treatment is insurance-covered, the number of facilities that adopt systems to perform it is likely to rapidly increase. The insurance coverage entitles all Japanese people suffering from lymphedema to receive high-quality, combined treatment approaches, while placing medical institutions and professionals providing such medical services under the obligation of ensuring their sufficient quality. 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.

Objective

To clarify the characteristics of nursing care to support patients with lymphedema after cancer surgery, who need to perform long-term self-care as part of symptom control, this study examined nurses with experience of actually caring for patients with the disorder in departments performing outpatient lymphedema treatment, with the aim of obtaining basic data for the development of a model of such nursing care.

Methods

1. Subjects

Eight nurses engaged in lymphedema care in departments performing outpatient lymphedema treatment were studied with their consent (**Table 1**).

2. Period and method of data collection

Data were collected within the period between July and December 2015 through semi-structured interviews, focusing on the following items : the detailed contents of care being actually provided, systems to provide lymphedema care (the pattern of nurse assignment, service provision frequency, number of staff members, and others). During the interviews, the nurses freely answered questions regarding their patient allocation systems, experiences related to the management of, difficult patients, and others. Each interview session was held in a private room, and its duration was 60 to 90 (mean : 65) minutes. With the nurses' agreement, the contents of the interviews were recorded, while data regarding their basic attributes, such as the age and years of experience, were previously collected from them.

3. Method of data analysis

Narrative records were created for each of the nurses. Subsequently, data related to the contents of care, systems to provide lymphedema care (the pattern of nurse assignment, service provision frequency, number of staff members, and others), patient allocation, and experiences related to the management of difficult patients were extracted, classified, and analyzed through comparison. Also, for each stage in the process

Table 1 Subject Outline

| Subject | Age | Sex | Qualification | Duration of nursing experience (years) | Duration of lymphedema care provision (years) | Educational background |
|---------|-----|-----|---------------|--|---|---|
| A | 30s | F | Nurse | 15 | 10 | Nursing junior college |
| B | 40s | F | Nurse | 23 | 8 | Nursing college |
| C | 40s | F | Nurse | 25 | 15 | Nursing graduate school (master course) |
| D | 40s | F | Nurse | 19 | 7 | Nursing junior college |
| E | 40s | F | Nurse | 24 | 7 | Nursing college |
| F | 40s | F | Nurse | 18 | 6 | Nursing college |
| G | 30s | F | Nurse | 17 | 6 | Nursing graduate school (master course) |
| H | 30s | F | Nurse | 10 | 5 | Nursing college |

of analysis, researchers had a meeting in an effort to increase the validity.

4. Ethical considerations

Prior to the study, the approval of ethics committees of the institutions the researchers belonged to was obtained. The nurses were introduced after showing the study plan to the directors and head nurses of the relevant facilities, and obtaining their agreement. The nurses were provided with written explanations of the study content, voluntary participation, and protection of participants' rights to obtain their consent.

Results

1. Subject outline

Table 1 outlines the 8 nurses' attributes. All of them were female, and their mean age was 40. The mean durations of nursing experience and lymphedema care provision were 19 and 8 years, respectively. They received specialized nursing education at : nursing colleges : 4 ; nursing junior colleges : 2 ; and nursing graduate schools (master courses) : 2. All were licensed ; 2 and 1 were certified nurses and certified nurse specialist, respectively. All of them had also completed lymphedema training programs.

2. Factors related to the provision of care for patients with lymphedema after cancer surgery

1) Systems to provide lymphedema care in hospitals (1) Patterns of nurse assignment

Systems to provide lymphedema care (the patterns of nurse assignment) in hospitals were classified into 3 patterns. Pattern A, in which the nurses in charge of

lymphedema care were assigned to wards on the days of outpatient lymphedema treatment, was the most common : 6, followed by Pattern B, in which ward nurses collaborated with doctors of outpatient medical departments to perform and operate outpatient lymphedema treatment : 1, and Pattern C, in which the nurses in charge were exclusively engaged in outpatient lymphedema treatment : 1.

(2) Spatial arrangements

Patterns A and C ensured locations exclusively for the provision of specialized outpatient services. In Pattern B, such services were provided simultaneously with outpatient medical services.

(3) Temporal arrangements

In the most common Pattern A, outpatient lymphedema treatment was performed twice per week : 4 or once per week : 2. In all cases, the nurses in charge were engaged in specialized outpatient services for patients with lymphedema throughout service hours on the days of such treatment. In Pattern B : 1, the treatment was performed once weekly. In contrast, in Pattern C : 1, it was performed daily and managed by the nurse working the day shift. In all patterns, the operation and rest times were determined by contracts.

(4) Teamwork and patient allocation

In both Patterns A and B, a special team was organized on the days of outpatient lymphedema treatment. In most of the facilities, in which outpatient lymphedema treatment was performed by nurses, such a team was made up of those nurses combined or not combined with physical therapists. In all patterns, each

Table 2 Characteristics of Nursing Care for Patients with Lymphedema after Cancer Surgery

| Category | Sub-category |
|--|--|
| Improving acute-stage symptoms | Assessment (symptoms, knowledge, abilities, and motivation) |
| | Showing examples of care |
| | Demonstrating early improvements |
| Preventing complications | Assessment (environments, working condition, and life pattern) |
| | Knowledge acquisition in accordance with lifestyles |
| Supporting continuous self-care | Clarifying factors preventing self-care through assessment (the working condition, life pattern, personality, and sense of values) |
| | Motivating individual patients appropriately to continue performing self-care |
| | Showing points of the continuation of self-care (without seeking perfection) |
| Guiding toward healthier life patterns | Identifying problems preventing lymphedema from improving through assessment (daily, weekly, monthly, and annual life patterns) |
| | Guiding patients toward the development of feasible and favorable habits |
| | Making arrangements to improve the relationships with other family members or key persons |
| Providing information regarding social resources | Providing information to improve symptoms and resolve life-related problems |
| | Presenting the latest reports on lymphedema treatment |
| | Providing information regarding national policies on lymphedema treatment |
| | Introducing patient support groups, as necessary |

team member was basically in charge of specific patients.

(5) Number of patients receiving outpatient lymphedema treatment

In Pattern A, the daily number of patients ranged from 10 to 30, while it exceeded 30 in Patterns B and C.

(6) Supplies management

In all patterns, budget inclusion for necessary supplies was performed, and the management of such supplies was performed by the person in charge.

(7) Education materials

In all patterns, patient education materials were originally developed and created.

(8) Presence of supervisors/advisors

Systems to provide technical support for nurses engaged in outpatient lymphedema treatment were established in 2 out of the 8 cases : staff members who were well-versed in lymphedema care were present within the facility in one, and external supervisors were used in the other case. In the 6 remaining cases, official support systems were not available, so the nurses consulted their personal advisors.

2) Characteristics of nursing care for patients with lymphedema after cancer surgery

Based on the nurses’ free statements, nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources> (**Table 2**). The following sections describe each of the 5 categories : < > : categories ; { } : sub-categories ; and “ ” : the nurses’ statements during interviews, () : include of subject :

(1) <Improving acute-stage symptoms>

This category represented the improvement of the main symptoms causing distress in patients through nursing care, consisting of the following sub-categories : {assessment (symptoms, knowledge, abilities, and motivation)}, {showing examples of care}, and {demonstrating early improvements}. In relation to these, the nurses mainly stated as follows : “In severe cases, the presence of elephantiasis occasionally leads to a difficult situation, but the most important point is achieving improvements in the most marked symptoms.

This is effective not only for patients' comfort, but also to establish trust-based relationships with them (C)" and "When dealing with patients who had been suffering from symptoms for a long period, it is pointless to blame them for the acute deterioration, because such deterioration would not have occurred if management had been appropriate. It is more important to help them realize reduced swelling (A)".

(2) <Preventing complications>

Regarding phlegmon and lymphorrhea as the most common events faced by patients with lymphedema, the nurses mainly stated as follows: "I remember a patient, who sighed over the development of lymphedema despite all her arrangements to prevent it after being provided with explanations of the disorder prior to surgery, such as having her bamboo forest behind deforested and leaving her pet cat in others' care (B)" and "Some patients with untreated lymphorrhea do not seek outpatient treatment. We cannot do anything for them without their access to our department (C)". The sub-categories of this category were: {assessment (environments, working conditions, and life patterns)} and {knowledge acquisition in accordance with lifestyles}.

(3) <Supporting continuous self-care>

Difficulty in supporting continuous self-care by patients was the most common problem faced by the nurses, and the following statements were observed: "Sometimes I consider patients who do not visit our outpatient department, regarding them as having decided not to do it as their own responsibility. On the other occasions, I consider them more positively, thinking that they may have adapted to their own current physical conditions favorably, so they do not need to visit us (C)", "It is necessary to motivate patients to appropriately perform self-care, but actually all we can do is teach them how to apply bandages. We cannot advance to the next step unless this is cleared (D)", "Bandage application by nurses → symptom improvement → withdrawal from outpatient treatment → deterioration after some years; some patients repeat this cycle, causing a dilemma (G)", "Excessive efforts may result in poor adherence to self-care, possibly due to fatigue (F)", "In the case of patients who are busy working, they tend to withdraw from self-care, as they

also seek perfection in such care despite their limited time for it (E)", and "I cannot help blaming myself for patients' poor adherence to self-care, considering that this indicates poor outcomes of both treatment and patient satisfaction (A)"; some nurses also mentioned the significance of their own existence. This category consisted of the following sub-categories: {clarifying factors preventing self-care through assessment (the working condition, life pattern, personality, and sense of values)}, {motivating individual patients appropriately to continue performing self-care}, and {showing points of the continuation of self-care (without seeking perfection)}.

(4) <Guiding toward healthier life patterns>

This category represented the nurses' deeper insight into patients, compared with <supporting continuous self-care>, and nursing approaches to lead them to review their life patterns as part of symptom improvement and deterioration prevention. Its sub-categories were illustrated by the following statements: {identifying problems preventing lymphedema from improving through assessment (daily, weekly, monthly, and annual life patterns)}: "While performing the treatment procedure, I take sufficient time to listen to patients to confirm their living environments and daily activities (F)" and "On the initial consultation, we interview patients using an instructed format (D)"; {guiding patients toward the development of feasible and favorable habits}: "Even if their poor dressing and grooming suggest a disturbance of daily life, we do not know how patients themselves see this (G)" and "Habits should not be forced (E)"; and {making arrangements to improve the relationships with other family members or key persons}: "There was a patient who was simultaneously engaged in housekeeping and work with her markedly swollen legs. In this case, it was necessary to also provide guidance for other family members (H)".

(5) <Providing information regarding social resources>

This category consisted of the following sub-categories: {providing information to improve symptoms and resolve life-related problems}, {presenting the latest reports on lymphedema treatment}, {providing information regarding national policies on lymphedema

treatment}, and {introducing patient support groups, as necessary}. They were mainly described by the nurses as follows: “I frequently show examples of self-management performed by other patients with similar symptoms (G)”, “Patients actively communicate and exchange information with each other. We occasionally participate in their conversations to confirm the accuracy of the information provided by them (A)”, “I remember that when the cost of compression materials became insurance-covered, patients asked me a number of questions (B)”, and “Communication among patients is very important. I saw even a patient in a depressive state become cheerful after making friends with other patient support group members (D)”.

Discussion

This study aimed to clarify the characteristics of nursing care for patients with lymphedema, based on the experiences of 8 nurses who had provided pioneering nursing approaches in this area.

1. Appropriateness of subjects

In Japan, conservative therapy for patients with lymphedema started around 1995, and it has gradually expanded since 2000¹⁶⁾. Considering such a background, the subjects of the present study, nurses with long-term experience, may be regarded as professionals who had been engaged in pioneering nursing approaches for such patients from the early stages, and are therefore appropriate for a study aiming to obtain findings on systems to provide lymphedema care and their contents, which are useful to address the current situation.

2. Factors related to the provision of care for patients with lymphedema after cancer surgery

1) Systems to provide lymphedema care in hospitals

From the nurses' statements, the following items were extracted as components of systems to provide lymphedema care in hospitals: the patterns of nurse assignment; spatial arrangements; temporal arrangements; teamwork and patient allocation; number of patients receiving outpatient lymphedema treatment; supplies management; education materials; and presence of supervisors/advisors.

Lymphedema care was provided by the nurses as private practice in hospitals in 3 patterns in accordance with the characteristics of each facility: being assigned

to wards as part of outpatient service arrangements (concurrent duty); through collaboration with doctors of outpatient medical departments (concurrent duty); and being exclusively engaged in outpatient lymphedema treatment. In all patterns, the nurses in charge were engaged in specialized outpatient services for patients with lymphedema throughout service hours on the days of such treatment as a member of a team mainly made up of nurses. In a study by Higuchi et al.¹⁷⁾, insufficient human resources and in-hospital systems for lymphedema care, such as the absence of therapists with specialized knowledge and skills and dependence on individual nurses' and wards' judgments, respectively, were noted as challenges of such care. As a future perspective, marketing, including estimating the number of patients and confirming the presence/absence of similar service providers in surrounding areas, as well as outpatient service arrangements, such as the pattern of assigning nurses, their number for teamwork, and scheduling for service provision on fixed days, may be useful when organizing facilities to provide outpatient lymphedema treatment performed by nurses. Education materials were originally developed and created in most cases, while technical support tended to be obtained from personal advisors. It is desirable for such materials to contain appropriate contents with the newest information, and approaches to maintain and improve technical skills are needed to perform optimal techniques for patients. Therefore, outpatient lymphedema treatment systems should be operated in consideration of the necessity of supporting knowledge and technical skills. From these viewpoints, the results of the present study are likely to provide basic information for nursing departments of medical institutions to organize and operate lymphedema treatment systems.

2) Characteristics of nursing care for patients with lymphedema after cancer surgery

Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories: <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>.

<Improving acute-stage symptoms> outlines nursing care to promptly improve distress due to dermatitis

or other symptoms in the early stages of lymphedema and when it suddenly deteriorates. A reduction in distress not only enhances patients' QOL, but also motivates them to perform self-care more actively to alleviate their symptoms. The probability of a person performing a behavior increases when he expects a favorable outcome of the behavior (outcome expectancies), and perceives that he is capable of successfully performing it (self-efficacy)¹⁸⁾. <Improving acute-stage symptoms> may promote the former outcome expectancies. <Supporting continuous self-care> refers to the examination of factors related to the continuation of self-care by patients and approaches to support it. The sub-scales {motivating individual patients appropriately to continue performing self-care} and {showing points of the continuation of self-care (without seeking perfection)} outline approaches to enhance patients' self-efficacy. In these respects, the initiation and continuation of self-care for lymphedema by patients may be supported by <improving acute-stage symptoms> and <supporting continuous self-care>.

<Preventing complications> also refers to assessment and knowledge provision for approaches to prevent the complications of lymphedema. It has been reported that approximately 20% of patients with lymphedema have a history of phlegmon as the most common complication, which is recurrent in the majority of these cases¹⁹⁾, highlighting the importance of prevention, early identification, and management. Such management may be covered by the sub-categories of this category, {assessment (environments, working conditions, and life patterns)} and {knowledge acquisition in accordance with lifestyles}.

<Guiding toward healthier life patterns> represents approaches to improve patients' life patterns as a basis for the continuation of self-care. As housekeeping duties and lifestyles are closely associated with risk factors in patients with lymphedema after breast cancer surgery²⁰⁾, such approaches may be necessary to prevent the development and deterioration of symptoms, and maintain a favorable condition.

<Providing information regarding social resources> refers to the provision of information regarding social resources, such as living environments, medical ser-

vices, national policies, and support systems, in accordance with patients' conditions. Kudo, et al.²¹⁾ revealed that patients after breast or other gynecologic cancer surgery tend to face sociopsychological distress, in addition to financial burdens, due to limited access to information in the presence of lymphedema. Patients' level of need for information regarding social resources is also high at this point, and <providing information regarding social resources> may represent approaches to accommodate such a need.

In short, the 5 categories representing nursing care for patients with lymphedema after cancer surgery explain support approaches for patients to perform safe, comfortable, and independent lymphedema management through continuous self-care. Among these categories, 4, excluding <providing information regarding social resources>, consisted of sub-categories covering assessment, confirming that care was being provided based on the results of assessment related to each category.

From the point of view of the development of clinical knowledge, Benner focused on the specific knowledge types of nurses in nursing practice. Benner identified 7 domains of nursing care: the helping role; teaching-coaching function; diagnostic and patient monitoring function; effective management of rapidly changing situations; administering and monitoring therapeutic interventions and regimens; monitoring and ensuring the quality of healthcare practices; and organizational work role competencies. Along with the identification of these domains, she noted 5 stages of skill acquisition to practice such nursing, from novice to expert²²⁾. Some of the 5 categories representing the characteristics of nursing care for patients with lymphedema after cancer surgery extracted in the present study are consistent with the 7 domains identified by Benner, but none covered 'effective management of rapidly changing situations', possibly due to the characteristics of the disorder and nursing setting. Furthermore, although some of the nurses' statements referred to the domain 'organizational work role competencies', they were finally summarized into 'systems to provide lymphedema care', based on the results of analysis. Except for that provided as part of nursing during educational hospitalization, lym-

lymphedema care is completed by performing a 60- to 90-minute combined treatment procedure. Therefore, it may be characterized by the process of establishing patient-nurse relationships, and developing nursing practice needed by individual patients, while repeating such a therapeutic session. 5 items are considered relationships, orderliness and mutual are encapsulated. Future issues using quantitative research methods to address the structural mechanism verification of the features of lymphedema care.

Conclusion

Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>. Each category consisted of multiple sub-categories.

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がん術後リンパ浮腫看護の特徴

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要 旨

目的：がん術後リンパ浮腫患者に特有である長期にわたるセルフケアによる症状コントロールを支える看護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ケアに従事する同意の得られた看護師 8 名を対象に半構造化インタビューを行った。収集したデータからリンパ浮腫看護の特徴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への看護の特徴として、1. 「急性期症状の改善」 2. 「合併症の予防を図る」 3. 「セルフケアの継続を支える」 4. 「生活パターンの健全化を方向付ける」 5. 「社会資源の情報提供を行う」の 5 項目を見出すことができた。また、ケア提供システムについては、1. 配置形態, 2. 場所の確保, 3. 時間の確保, 4. チーム体制と患者担当制, 5. 受診患者数, 6. 物品管理, 7. 指導教材, 8. スーパーバイザー・相談相手の存在が構成要素として見出された。

キーワード：がん術後リンパ浮腫, セルフケア支援, リンパ浮腫外来

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 surgery¹⁻⁴⁾, and from 20.0 to 51.9% in those targeting lower limbs after uterine cancer surgery⁵⁻⁸⁾; these values are similar to those reported

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in advanced and Asian countries⁹⁾¹⁰⁾. The number of cancer patients, which is currently estimated at 100,000 to 120,000¹¹⁾¹²⁾, 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”¹³⁾.

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 approaches¹⁴⁾¹⁵⁾, patient QOL¹⁶⁾¹⁷⁾, and the effects of combined physical therapy¹⁸⁾¹⁹⁾, 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 | | | |

vously 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’²⁰⁾. 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.²¹⁾ 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

寄稿

WUWHS 学会紀行 5th World Union Wound Healing Society に参加して

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「創傷治癒の学会にこんなにリンパ浮腫のセッションがある!!!」学会参加前、事前プログラムを見た私は、とても驚きました。2016年9月25日から9月29日までイタリア・フィレンツェにて開催された5th World Union Wound Healing Society (写真1、2)のプログラムに、リンパ浮腫のセッションが複数設けられたからです。というのも、World Union Wound Healing Society (以下、WUWHS)は、全世界の医師や看護師などのコメディカルが参加する世界で一番大きな創傷治癒の学会であり、これまでリンパ浮腫はこの学会ではクローズアップされてこなかったからです。WUWHSの取り組みは、創傷治癒に関するBiology、Pathologyなどの基礎的なメカニズムの解明、褥瘡や糖尿病性足潰瘍、手術部位感染などの様々な種類の創傷に関する治療、ケア、リスクアセスメントなどであり、それらの発展に非常に大きな役割を果たしてきました。その中に、リンパ浮腫の領域が追加され、今後、皮膚領域においても、リンパ浮腫の治療やケアに積極的に取り組んでいこうという流れを感じることができました。

WUWHSでのリンパ浮腫に関する演題は、関連学会であるInternational Compression Clubの圧迫療法に関するシンポジウムが学会初日に行われました。ここでは、圧迫圧の測定法、リンパ浮腫における圧迫法の利点、効果的な圧迫を行うための工夫や包帯の種類に関する演題がありました。学会4日目には、ILF、LYMPRINT

の活動とリンパ浮腫の病態と現状、スキンケアなどについてのシンポジウム、5日目は、リンパ浮腫患者のQOLに関するシンポジウムが行われました。私は、今春からリンパ浮腫の病態解明の基礎研究に取り組んでおり、まだまだリンパ浮腫に関する知識は浅いです。このシンポジウムで、現在のリンパ浮腫治療やケアの状況、さらには疫学や病態まで幅広く、世界のトップの専門家から知識を得ることができ、とても有益な時間を過ごすことができました。このことは同時に、リンパ浮腫治療やケアの今後の課題の多さを学ぶことにもなりましたが、研究の重要性を再認識することにもなりました。そして、それを明確に表したのが、学会賞です。WUWHSでは、数種類の学会賞が設けられていました。そのうちの一つのJWC-WUWHS AWARDSをNottingham大学のChristine Moffatt先生が受賞しました(写真3)。この賞は、Journal of wound care協賛の学会賞であり、Moffatt先生のリンパ浮腫研究に対するこれまでの功績が世界的に認められたことを意味します。以前は、認知度の低かったリンパ浮腫という疾患が、日に日に脚光を浴び、世界的に関心が強くなっていることを確信しました。これは、これまで地道にリンパ浮腫研究に取り組んできたMoffatt先生をはじめとする全ての研究者の功績によるものでしょう。この成果は、今後のリンパ浮腫研究を更に加速させていくものと思います。

WUWHS全体のプログラムに関しては、外科医師が

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参加者の大半を占めるため、治療に関する演題が多いです。新たなデバイス開発とその評価、各研究分野のこれまでのレビューと現状などの教育的なシンポジウム、SSI などの難治性創傷への陰圧閉鎖療法の効果などの内容が特徴的でした。実際に演題中で使用されたデバイスも展示されており、演題を聞いた後に機器に触れ、体感するという経験もできました。最新の技術と知識に間近に触れることができ、本当に心躍る日々でした。

今回、WUWHS に参加して、世界の各々の分野の研究の動向、それらと照らし合わせた自身の研究の立ち位置を学び、英語で研究を発信していく事の大切さを再認識しました。WUWHS での学びを生かすべく、現在は今年 12 月に開催される第 46 回日本創傷治癒学会において、英語セッションでマウスリンパ浮腫モデルの作製に関する演題発表を予定しています。今回の日本創傷治癒

学会は、本研究協議会の理事長である真田弘美先生が大会長を務めます。リンパ浮腫に関する演題も複数あります。創傷治癒学会は、会員の多くが医師であるため、リンパ浮腫に関する演題は基礎研究が主であり、リンパ浮腫を主とする学会の演題とは視点が少し異なる研究かもしれません。ご興味のある方は、是非参加してみたいかがでしょうか。私はまだ学生であり、自分に出来ることは限られています。しかし、WUWHS に参加し、世界の素晴らしい研究に触れたことで、自分も少しでも多く、少しでも早く、臨床へ成果を還元できるような研究者になりたいと奮起させられました。現在の患者さん、未来の患者さんのために、自分に今出来ることは何か、何をすべきかを常に考え、今後も研究に邁進したいと思います。



写真 1



写真 2


News • WUWHSdaily

WUWHS and JWC Awards: recognition of the wonders of the wound care world

Last night, in the fabulous Scherma Hall in the Fortezza de Basso, the inaugural JWC/WUWHS awards were held. Those attending included the nobility of the wound care world—JWC Editorial board members along with the heads of numerous sister and collaborating societies, and WUWHS president Marco Romanelli. The shortlisted nominees came from all over the world from the US to Taiwan, Australia to Israel. The standard of the entries received was phenomenal, giving the judges a really difficult time; in some cases, one mark separated two different results, meaning all those shortlisted had produced some amazing work over the past 4 years.

Following a buffet dinner as the sun set on a warm Florence evening, people retired inside for the ceremony itself. The atmosphere was electric. After the welcome by MA Healthcare global publishing director, Anthony Kerr, and the evening's host, Stuart Flanagan, resident doctor on BBC Radio 1's Surgery, the JWC WUWHS Rising Stars opened the evening. Our three candidates, Chih Sheng Lai, Alicja Krejmer and Francesca Papadia, were invited to give presentations, on their work; the results were announced at the end of the evening.

The Lifetime Achievement award was presented to Christine Moffat, University of Nottingham. A testimonial to her work stated:



Lifetime achievement: Christine Moffat

'Her research into methods of compression has been instrumental in developing and validating three new compression systems, one of which is used in the treatment of lymphoedema. Her engagement, knowledge, integrity and her ability to always find new ways for the wellbeing of the patients inspire everybody who works with her from professionals and patients to industry. It is very important to her that knowledge is shared and she never puts herself first'. Christine is highly respected by colleagues all over the world in her professional work but also for her kind, open and giving personality. Huge congratulations go to Christine, all the winners and those who made it to the shortlist!

Full details of all the winners can be found on the website: <http://jwcworldunion.com/>

*As this category was voted on at the event, the result had not been announced as we went to press

Winners of the inaugural JWC/WUWHS 2016 awards


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|---|---|--|--|
| <p>Innovation in Wound Care (sponsor: L&R)</p> <ol style="list-style-type: none"> Andrew Baird Charmaine Childs Expert Centre in Wound Care | <p>Cost-effective Wound Management (sponsor: Advancia)</p> <ol style="list-style-type: none"> Julian Guest Pawel Jan Stanrowski, Magdalena Bizo, Anna Kociszewska, Krzysztof Cendrowski and Włodzimierz Sawicki Leanne Atkin and Joy Tickle | <p>Outstanding Achievement in Patient Care (sponsor: Zorflex)</p> <ol style="list-style-type: none"> Paul Glat Helena Vicente, Dara Franco, Margarida Rafael, Ligia Ferreira, Elza Antunes and Eliazete Rosa Miguel Angel Barbas Monjo | <p>Most Progressive Society (sponsor: WUWHS)</p> <ol style="list-style-type: none"> International Skin Tear Advisory Panel (ISTAP) Association for the Advancement of Wound Care and Wound Healing Society AISLeC—Associazione Infermieristica per lo studio delle lesioni cutanee |
| <p>Contribution to Education in Wound Care (sponsor: Leg Club Foundation)</p> <ol style="list-style-type: none"> University of Huddersfield Kimberly LeBlanc William Li | <p>Most Innovative Dressing (sponsor: JWC)</p> <ol style="list-style-type: none"> Aquacel Ag+ Extra Zorflex HydroClean plus | <p>Most Innovative Product (sponsor: WC4H)</p> <ol style="list-style-type: none"> Circoid juxtacures Adtec SherFlo gas plasma technology Debrisoft | <p>Advances in Pressure Care (sponsor: L&R)</p> <ol style="list-style-type: none"> Amit Gefen Nick Santamaria Zero Pressure Ulcer Campaign |
| <p>Infection and Biofilm (sponsor: Zorflex)</p> <ol style="list-style-type: none"> Philip Bowler, Daniel Metcalf and Jennifer Hurlow Gregory Schultz Thomas Bjarnsholt | <p>Contribution to Clinical or Preclinical Research (sponsor: Advancia)</p> <ol style="list-style-type: none"> Allison Cowin Nelson Pinto, Marc Quiryssen and Yelka Zamora Teresa Oranges |  | |

写真 3