

ORIGINAL RESEARCH

Relationship between self-care continuation and self-efficacy in patients with secondary lower extremity lymphedema: A questionnaire survey

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ABSTRACT

Objective: Complex physical therapy (CPT) has recently become the therapeutic focus for managing secondary lymphedema. Although it is advisable to perform CPT every day, only a few of our patients with lymphedema currently maintain this regimen. The aims of our study were to (1) assess the self-care practices that were employed by our patients with secondary lower extremity lymphedema, and to (2) determine the relationship between self-care continuation and self-efficacy in these patients.

Methods: This cross-sectional study was conducted at Kyoto University Hospital's Consultation Room for Women's Mental and Physical Health, and evaluated patients with secondary lower extremity lymphedema. A total of 118 patients were invited to anonymously complete a self-administered questionnaire regarding their demographic information, current self-care habits for manual lymphatic drainage and compression therapy, and self-efficacy rating. We used this data to compile descriptive statistics and compare the differences in the respondents self-efficacy scale scores, according to their continuation of self-care status.

Results: Approximately 64% of the invited patients returned the questionnaires, and 30% of these patients reported not continuing self-care, mainly because of the "cumbersome" and "time-consuming" procedures and the belief that self-care "did not result in much improvement". There was no significant difference in the self-efficacy scale scores between the groups that did or did not continue self-care, although the scores tended to be higher in the groups that continued self-care.

Conclusions: These findings indicate that patients with lymphedema should be educated regarding the benefits of self-care, as a large percentage of these patients ultimately discontinued self-care. Therefore, these patients should be informed that only minor apparent changes in lymphedema state are expected, in order to better understand the effects of daily self-care.

Key Words: Compression therapy, Cross-sectional study, Lymphedema, Manual lymphatic drainage, Self-care, Self-efficacy

1. INTRODUCTION

The annual worldwide number of patients who require surgery because of uterine and breast cancer has recently exhibited annual increases.^[1,2] Approximately 25%-40% of these patients report swelling in their legs after surgery, and 10%-20% of these patients are clinically diagnosed with

lower limb lymphedema.^[3,4] Furthermore, 10%-65% of the patients who undergo surgery for breast cancer also report experiencing lymphedema after surgery.^[5-7] In Japan, lymphedema develops in 10% and 25% of the patients who undergo surgery for uterine and breast cancer, respectively.^[8]

Previous studies have reported that cancer survivors expe-

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rience pain, fatigue, peripheral neuropathy, lymphedema, gastrointestinal complications, sleep disturbance, bladder dysfunction, and menopause.^[9] Among these conditions, lymphedema is thought to be specific to patients who survive breast and gynecological cancers.^[9,10] Furthermore, the Sociology of Cancer research group surveyed the concerns and burdens of 7,885 Japanese cancer survivors, and reported that swelling (edema) due to secondary lymphedema was the foremost concern of patients who survived uterine cancer.^[11]

In recent years, the focus of treatment for secondary lymphedema has shifted to complex physical therapy (CPT),^[12–16] which combines appropriate skin care, manual lymphatic drainage (MLD), compression therapy (bandage or elastic stockings; CB) and exercise. Although it is advisable to perform CPT every day,^[13,17,18] only a few of our patients with lymphedema maintain this regimen, and many patients ultimately discontinue MLD and CB. Furthermore, these procedures are central components of CPT, and the techniques that are used for these procedures are specialized and time-consuming, which may explain why patients stop using them. Nevertheless, the motivations for discontinuation of MLD and CB have not been reported in previous studies.

Self-efficacy has become an important consideration in several areas of human performance, including health behavior modification,^[19] where it describes a sense of personal control over desired changes or a belief that an individual can accomplish a specific behavior.^[20] Although previous studies have demonstrated that self-efficacy could be associated with the self-care for chronic disease,^[21–24] little is known regarding the relationship between self-care and self-efficacy in patients with lymphedema. Therefore, the present study evaluated the self-care status of patients with secondary lymphedema in their lower extremities, and explored the relationship between self-care continuation and self-efficacy in these patients.

2. METHODS

2.1 Study design and duration

Data for this cross-sectional study were gathered during January and February 2011.

2.2 Setting

This study was conducted at Kyoto University Hospital's Consultation Room for Women's Mental and Physical Health. This national university hospital in Japan has 21 departments, in addition to the Consultation Room, and different specialists provide daily consultations to women with health-related issues. In addition, a nurse who specializes in lymphedema provides weekly consultations and treatment to patients with

lymphedema. This nurse provides guidance regarding self-care, including skin care and exercise, and educates the patients regarding CB (compression garments or bandaging) and MLD (self-massage) when necessary.

2.3 Participants and survey methods

We invited all patients with secondary lymphedema in their lower extremities who visited the Consultation Room for Women's Mental and Physical Health to enroll in this study. Patients were excluded if their native language was not Japanese or if they suffered from dementia. A total of 118 women with secondary lymphedema in their lower extremities were enrolled; each patient was mailed an anonymous self-administered questionnaire, which they were asked to complete and return to the research group via mail.

2.4 Questionnaire items

2.4.1 Demographic variables

Demographic data included information regarding the year of the patient's surgery, time since the surgery, time of lymphedema onset (years since the surgery), state of the edema, age, and information regarding the person who provided support for self-care at home (*e.g.*, husband, wife, daughter).

2.4.2 Self-care status

The self-care practices that we assessed were MLD and CB. The questionnaire included the following items: continuation status for MLD and/or CB after visiting our institution, average number of times per week that MLD and/or CB were performed, the MLD areas (for subjects who continually performed MLD), the technique for performing CB (for subjects who continually performed CB), and reasons for discontinuing MLD and/or CB (for subjects who discontinued self-care).

2.4.3 Self-efficacy

We used the Japanese version of the generalized self-efficacy scale (SE scale).^[25] This scale consists of 23 items, and was established by translating the original SE scale.^[26] The scores for the translated SE scale range from 23 to 115, and this scale is known to be reliable (a Cronbach's α -coefficient of 0.88).^[25] Furthermore, the translated SE scale has been confirmed to be valid using its correlation with the Bem Sex-Role Inventory and the Center for Epidemiologic Studies Depression Scale.^[25]

2.5 Data analysis

After analyzing the questionnaires, we compiled descriptive statistics, and then grouped and compared the SE scale scores, based on the respondents' continuation status for MLD and CB (continuing group *vs.* discontinued group). We also compared the scores for 3 subgroups: subgroup 1 continued with

MLD and CB, subgroup 2 continued with MLD or CB, and subgroup 3 discontinued self-care. Inter-group differences in categorical variables were evaluated using the chi-square test, the Mann-Whitney U test was used for normally distributed continuous variables, and the Kruskal-Wallis test was used for non-normally distributed continuous variables. Differences with a *P*-value of < .05 were considered significantly different. SPSS software (version 17.0J for Windows, SPSS Inc., Chicago, IL, USA) was used for all analyses.

2.6 Ethical considerations

A letter explaining the purpose of the study and that the participants' privacy and personal information would be protected was included with the questionnaire, and all questionnaires were collected anonymously. The return of a completed questionnaire was considered consent for participation. The study protocol was approved by the institutional review board of the Kyoto University Graduate School of Medicine.

3. RESULTS

3.1 Participant characteristics

The recovery rate for the questionnaires was 64.4% (*n* = 76). We excluded questionnaires that were < 50% complete, and questionnaires that did not have answers regarding the status of self-care and the self-efficacy scale questions. Based on these exclusions, data from 56 women was included in our analysis. Table 1 shows the participant characteristic. The average age of the participants was 58.3 ± 10.0 years, the average number of years since their surgery was 8.9 ± 7.1 years, and the average onset of lymphedema was 2.5 ± 3.4 years after their surgery. Only 17 (30.4%) of the participants reported having a person who helped them perform their self-care routine. No significant differences were observed when we compared the demographic characteristics of the patients who did and did not continue self-care.

Table 1. Participant characteristics

Variable		Age (years)		Time elapsed since surgery (years)		Time since the onset of lymphedema (years)		Does a person support your self-care?			
		N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	Yes	No	N	%
MLD	Continuing	N	39	N	39	N	39	N	14	N	25
		Mean (SD)	58.7 (9.9)	Mean (SD)	8.3 (6.6)	Mean (SD)	2.5 (3.3)	%	35.9	%	64.1
	Discontinued	N	17	N	17	N	16	N	3	N	14
		Mean (SD)	57.5 (10.5)	Mean (SD)	10.2 (8.1)	Mean (SD)	2.5 (3.8)	%	17.6	%	82.4
	<i>P</i> -value	.68*		.42**		.90**		.22*****			
CB	Continuing	N	40	N	40	N	39	N	12	N	28
		Mean (SD)	58.6 (10.4)	Mean (SD)	9.4 (7.8)	Mean (SD)	2.5 (3.3)	%	30.0	%	70.0
	Discontinued	N	16	N	16	N	16	N	5	N	11
		Mean (SD)	57.7 (9.2)	Mean (SD)	7.6 (4.8)	Mean (SD)	2.5 (3.8)	%	31.2	%	68.8
	<i>P</i> -value	.77*		.79**		.70**		1.00*****			
Self-care	Continuing both MLD and CB	N	31	N	31	N	31	N	10	N	21
		Mean (SD)	58.3 (10.0)	Mean (SD)	9.2 (7.0)	Mean (SD)	2.7 (3.5)	%	32.3	%	67.7
	Continuing either MLD or CB	N	17	N	17	N	16	N	6	N	11
		Mean (SD)	59.8 (10.9)	Mean (SD)	7.7 (8.2)	Mean (SD)	1.7 (2.1)	%	35.3	%	64.7
Discontinued	N	8	N	8	N	8	N	1	N	7	
	Mean (SD)	55.3 (8.3)	Mean (SD)	10.3 (4.8)	Mean (SD)	3.2 (5.0)	%	12.5	%	87.5	
	<i>P</i> -value	.44***		.24***		.81***		.61*****			
Total	N	56		56		55		17		39	
	Mean (SD)	58.3 (10.0)		8.9 (7.1)		2.5 (3.4)					
	%							30.4		69.6	

Note. MLD, manual lymphatic drainage; CB, compression therapy; N, number; SD, standard deviation; * *t*-test; ** Mann-Whitney U test; *** Kruskal-Wallis test; **** chi-square test; ***** Fisher's exact test

3.2 Self-care continuation

Our findings regarding self-care continuation were that 39 patients (69.6%) reported that they continued to perform MLD, 40 patients (71.4%) continued to perform CB, 31 patients (55.4%) continued to perform both MLD and CB (see Table

2). Among the 39 patients who reported continuing MLD, 26 patients (66.7%) only performed drainage for some of the sites that are required for effective MLD. More than 80% of the patients reported performing MLD at the following sites: "the axillary fossa on the same side as the swollen leg",

“the thigh”, “the lower extremities”, “shoulder rotation”, and “abdominal respiration”. However, only 40%–65% of the patients reported performing MLD at “the side of the body”, “the dorsum of the foot”, and “the fingers”. Among the patients who reported continuing CB, 6 patients (15%) used both bandages and elastic stockings, 33 patients (82.5%) used only elastic stockings, and 1 patient (2.5%) only used a bandage.

The most commonly reported reasons for discontinuing MLD were that it was “cumbersome” ($n = 10, 58.8\%$), “did not result in much improvement” ($n = 6, 35.3\%$), “hands could not reach the lower leg” ($n = 6, 35.3\%$), and “was not possible alone” ($n = 6, 35.3\%$). The most commonly reported reason for discontinuing CB was that it was “time-consuming” ($n = 4, 25.0\%$); other reasons included “bandages and elastic stockings are uncomfortable to wear on a hot day” and “bandages and elastic stockings are uncomfortable to wear because they exert strong pressure”.

Table 2. Self-care status ($N = 56$)

Groups	N	%
MLD		
Continuing	39	69.6
Discontinued	17	30.4
CB		
Continuing	40	71.4
Discontinued	16	28.6
Self-care		
Continuing both MLD and CB	31	55.4
Continuing either MLD or CB	17	30.4
Discontinued	8	14.3

Note. MLD: manual lymphatic drainage; CB: compression therapy

3.3 The relationship between SE scale scores and self-care continuation

The mean SE scale score was 78.0 ± 12.7 . There was no difference in the SE scale scores when we compared the groups that did or did not continue MLD or CB ($P = .23$ and $P = .63$, respectively). In addition, no difference was observed when we compared the 3 subgroups for self-care continuation ($P = .56$) (see Table 3). Nevertheless, the SE scale scores for the groups that continued MLD and/or CB tended to be higher than those for the groups that discontinued self-care.

4. DISCUSSION

4.1 Self-care status

Our results revealed that approximately 30% of the patients who returned our questionnaires reported discontinuing MLD or CB self-care. In addition, only approximately half of the

patients who reported continuing MLD also reported completing the entire lymphatic drainage routine. Furthermore, numerous patients reported that they did not perform MLD “on the side of the body”, despite this being an important lymphatic drainage site. Moreover, our findings highlighted that commonly reported reasons for discontinuing self-care were that the patients found it to be “cumbersome” and “time-consuming”.

In cases of secondary lymphedema in the lower extremities, MLD should be performed on the visibly swollen leg, as well as on the remaining areas of the body, beginning at the supraclavicular area on the affected side, then moving towards the corresponding axillary fossa, and proceeding to the thigh on the same side of the body.^[17] Therefore, it takes 30-40 min to carefully and slowly perform MLD. In addition, patients must learn to tie several bandages (5-6) for CB, and several patients reported discontinuing CB because it was time consuming. Furthermore, elastic stockings were considered difficult to wear, because of the pressure that they exert on the limbs. Moreover, self-care must be performed daily to be effective,^[17,18] rather than every other day or two, because gravity causes blood circulation to stagnate in the lower extremities during the daytime. Therefore, we presume that all of these factors contributed to our patients reporting that MLD and CB were cumbersome and time-consuming.

Interestingly, our participants did not report experiencing the beneficial effects of self-care. This lack of a perceived benefit may be related to the fact that a comparison of the limbs before and after lymphedema treatment is needed to observe the effects of self-care. However, patients typically compare the condition of their lower limbs after self-care with the state of their limbs before the onset of lymphedema. In addition, the beneficial effects of self-care are not immediately visible, and improvements in lymphedema are typically assessed by measuring lower limb circumference, with changes of several millimeters being within the expected measurement error range.^[27] Therefore, it is difficult for patients to visualize the changes, which may explain the lack of perceived benefits for self-care.

4.2 The relationship between SE scale scores and self-care continuation

Although there were no differences in the SE scale scores for the groups that did and did not continue self-care, the SE scale scores tended to be higher in the groups that continued self-care. Thus, these findings suggest that self-efficacy might be associated with self-care continuation. In studies of chronic disease, improvements in self-efficacy were associated with improvements in exercise, eating behaviors, and physical activity;^[28-30] all of these changes can be con-

sidered self-care. Furthermore, the use of blood glucose self-monitoring devices motivates diabetes patients to continue practicing self-care.^[31] Therefore, it may be possible to improve self-care continuation in patients with lymphedema if the patients are provided with measuring instruments to

monitor their progress, which may also improve their sense of self-efficacy. Thus, developing devices that visually indicate the effects of self-care may motivate patients to continue self-care therapy.

Table 3. Comparing self-efficacy scale scores according to self-care continuation status

Groups	N	Mean ± SD	Median (range)	P-value
MLD*				
Continuing	39	79.1 ± 13.0	78.0 (54-111)	.23
Discontinued	17	75.6 ± 12.1	74.0 (62-115)	
CB*				
Continuing	40	78.8 ± 14.5	78.0 (54-115)	.63
Discontinued	16	76.2 ± 6.7	77.0 (65-87)	
Self-care**				
Continuing both MLD and CB	31	79.4 ± 14.2	79.0 (54-111)	.56
Continuing either MLD or CB	17	77.3 ± 12.4	76.0 (62-115)	
Discontinued	8	74.4 ± 5.9	76.0 (65-81)	

Note. MLD: manual lymphatic drainage; CB: compression therapy; SD: standard deviation; * Mann-Whitney U test; ** Kruskal-Wallis test

4.3 Limitations

This study has several limitations that should be considered. First, data were only collected from patients who received treatment at a single hospital, and the sample size was small. Therefore, our findings may not accurately reflect the perceptions of all patients with secondary lymphedema in the lower extremities. Second, given the cross-sectional design, we cannot determine whether the relationship between self-efficacy and self-care were causal. Third, the use of a self-administered questionnaire may have introduced selection bias in the patients that we analyzed, and reporting bias in the patients' responses.

Nevertheless, we believe that our findings will be useful for understanding the self-care status of patients with secondary lymphedema in their lower extremities, as little studies have investigated the self-care status and self-efficacy of these patients. Therefore, to confirm our findings, future longitudinal studies should evaluate self-efficacy expectations regarding the benefits of self-care, and should sample patients from various hospitals in broader areas, in order to provide more generalizable data.

5. CONCLUSIONS

Our findings revealed that 30% of patients with secondary lymphedema in their lower extremities reported discontinuing self-care (MLD or CB). The reported reasons for discontinuing self-care were the time-consuming and cumbersome nature of the procedures, and the absence of perceived benefits. However, the SE scale scores for the groups that continued MLD and/or CB tended to be higher than those for the groups that discontinued the therapy. Thus, we believe that patients with lymphedema should be educated regarding the benefits of self-care. Moreover, the small changes in lymphedema state should be explained to help patients better understand the effects of daily self-care.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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