

The benefit of self-management skills in gynaecological cancer patients in preventing clinically manifest lymphoedema

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Key words

Subclinical lymphoedema, self-management skills, gynaecological cancer, education

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Abstract

Aim: This study investigated the performance of self-management skills and associated factors for subclinical lymphoedema in gynaecological cancer patients who had been educated on lymphoedema prevention. **Methods:** This cross-sectional study included 69 patients in the period 12–18 months postoperatively. We assessed self-management skills on an 11-item scale comprising ‘Observe swelling’, ‘Maintain physical condition’, and ‘Prevent deterioration’ subscales. The patients’ demographic and clinical backgrounds and understanding of the lymphoedema prevention education were analysed as potential associated factors. **Results:** Although 87% of patients understood the education, only 19% performed the skill ‘Observe swelling’. The skill ‘Maintain physical condition’ was performed by 39% of patients, which was the highest among all the subscales. A history of undergoing radiotherapy was significantly associated with rarely seeking help from others in the skill of ‘Maintain physical condition’. **Conclusion:** The performance of SM skills was not equivalent to the understanding of education. It is necessary to re-evaluate the timing and contents of the education for early detection of lymphoedema. Ongoing nursing support would also be needed.

Severe lower-limb lymphoedema (LLL) affects the quality of life (QOL) of patients with gynaecological cancer. In 2018, the worldwide incidence of gynaecological cancer was approximately 560,000 (International Agency for Research on Cancer, 2020). In 2020, the incidence in Japan was 41,200 (Center for Cancer Control and Information Services, 2020).

Gynaecological cancer is primarily treated with lymph node dissection (Kim et al, 2015). However, lymphatic drainage impairment may occur after lymph node dissection, causing LLL, a troublesome sequelae in gynaecological cancer cases (Ryan et al, 2003; Kim et al, 2015). The incidence of LLL in patients with gynaecological cancer is 11.4%–40% (Beesley et al, 2007; Achouri et al, 2013), and the risk factors include the number of dissected lymph nodes, postoperative radiotherapy and infection (Beesley et al, 2007; Achouri et al, 2013). When

LLL becomes severe, patients experience lifelong QOL issues, including physical problems (e.g. limited range of motion) and psychosocial problems (e.g. appearance and financial burden) (Ryan et al, 2003; Kim et al, 2015).

Because the early appearance of lymphoedema must be addressed to prevent severe LLL, patients are expected to understand the risk and incorporate self-management (SM) skills into their daily lives (Sharman and Koelmeyer, 2011; 2013). Early lymphoedema detection is crucial (International Society of Lymphology, 2020).

Lymphoedema is classified from stage 0 to III according to progression. Stage 0 refers to subclinical lymphoedema with no apparent symptoms; only subtle changes, such as discomfort, caused by impaired lymphatic transport are observed (Mullen, 2015). LLL from subclinical lymphoedema is usually detected around 12–24 months postoperatively (Akita et al, 2013). The

diagnostic criteria for LLL are still vague, and patients with gynaecological cancer exhibiting subclinical lymphoedema tend to miss the early appearance of lymphoedema. Therefore, recognising the early appearances of lymphoedema around the 12-month postoperative period is necessary. Thus, it is important for patients to incorporate SM skills into their daily lives. Skills such as skin care and moisturising, infection prevention behaviours, weight control and self-referral to medical check-up for any changes observed are required for patients with subclinical lymphoedema (Mullen, 2015).

Although patient education on severe lymphoedema prevention is necessary, the performance of SM skills is reportedly insufficient (Vural et al, 2020). According to best practice guidelines, high-risk patients should be identified and educated promptly (International Lymphoedema Framework, 2006).

In Japan, postoperative education

Table 1. Patient characteristics (n=69).

		Median	IQR
Age (years)		53.0	45.5–66.0
BMI		22.9	20.8–25.0
Time since lymph node dissection (months)		14.0	13–17
		n	%
Disease	Endometrial cancer	30	43.5
	Cervical cancer	25	36.2
	Ovarian cancer	9	13.0
	Other	5	7.2
Disease stage	I	48	69.6
	II	7	10.1
	III	9	13.0
	IV	5	7.2
Lymph node dissection	Pelvic lymph node	35	50.7
	Para-aortic lymph node	7	10.1
	Pelvic and para-aortic lymph node	27	39.1
Chemotherapy	Yes	42	60.9
	No	27	39.1
Radiotherapy	Yes	7	10.1
	No	62	89.9
Marital status (3 did not respond)	Yes	45	65.2
	No	21	30.4
Working status (3 did not respond)	Yes	33	47.8
	No	33	47.8
Educational background	High school	24	34.8
	Junior college	19	27.5
	University/college	19	27.5
	No answer	7	10.1

BMI = body mass index; IQR = interquartile range

on severe lymphoedema prevention for patients with cancer who have undergone lymph node dissection has been covered by a national insurance service since 2008 (Wagner et al, 2017). Medical professionals provide education for patients during hospitalisation and 1 month after discharge. However, asymptomatic patients are less likely to perform SM skills for the prevention of severe lymphoedema (Bosompra et al, 2002). It was reported that patients were inadequately participating specific risk-reduction behaviours 3 months after surgery (Sharman and Koelmeyer, 2011). According to several studies, patient education has been insufficiently provided (Vural et al, 2020).

There are few studies to date examining SM skills in patients with gynaecological cancer who have subclinical lymphoedema.

Most previous studies have focused on patients with breast cancer (Bosompra et al, 2002; Sharman and Koelmeyer, 2011, 2013). Meanwhile, it was reported that education was associated with SM skills concerning infection-preventing behaviours in the patients with gynaecological cancer in the 10-year postoperative period (Mizuma et al, 2017). However, the SM skills of patients with gynaecological cancer during the early detection of LLL have not been investigated. Factors related to SM skills are also unknown.

Aim

This study aimed to investigate SM skills during the early detection of LLL in patients with gynaecological cancer manifesting with subclinical lymphoedema who had

received education on the prevention of severe lymphoedema, and to explore the factors associated with SM skills.

Methods

Study design and sampling

This quantitative, cross-sectional, descriptive study recruited patients with gynaecological cancer who had subclinical lymphoedema and attended the outpatient clinic. The inclusion criteria were: history of lymphadenectomy in the last 12–18 months, age >20 years and experience of postoperative education.

This education was provided for 30 minutes using a brochure individually after the surgery. Educational content included lymphoedema pathogenesis, risk factors, complex decongestive therapy content, infection prevention and weight control and daily living precautions; all of these are standardised in Japan (Wagner et al, 2017).

The exclusion criteria were: diagnosis of lymphoedema and/or oedema caused by other illnesses; or physical or mental issues that would have restricted their participation, as determined by their physicians.

Data collection

Data were collected from April 2019 to April 2020. Eligible patients provided informed consent before participating in the study during their visits to the outpatient clinic. Then, they individually answered the questionnaire. Finally, the authors collected the epidemiological data from the electronic medical records. Our institution’s medical ethics committee approved the study (Approval No. R1931).

Measurement

Questionnaire related to patients’ characteristics and education

Using the questionnaires, details were collected on patient characteristics. Body mass index (BMI) was calculated during the survey. Yes/no questions were asked about education, such as ‘Did you understand the education provided by the nurses?’ Additionally, the frequency of opportunities for taking education, either once or twice, was examined.

Lymphoedema Self-Management Skill scale

The Lymphoedema Self-Management Skill scale measures patient’s SM skills for

Table 2. Distribution of responses on three subscale scores (n=69).

	n	Sum of 5-7	7 (always done)	6 (almost always done)	5 (somewhat done)	4 (neither)	3 (not done well)	2 (hardly done)	1 (not at all)
Observe swelling									
Pressing the skin with your fingers to check the degree of swelling	69	30 (43.4)	4 (5.8)	11 (15.9)	15 (21.7)	5 (7.2)	5 (7.2)	9 (13.2)	20 (29.0)
Pinching the skin to see the extent of the swelling	69	14 (20.3)	3 (4.3)	4 (5.8)	7 (10.2)	6 (8.7)	13 (18.8)	12 (17.4)	24 (34.8)
Touching your skin every day and not missing the spread of even the smallest swelling	69	23 (33.3)	3 (4.3)	7 (10.2)	13 (18.8)	9 (13.2)	7 (10.2)	13 (18.8)	17 (24.5)
Maintain physical condition									
Consulting a lymphoedema specialist if you feel body differently	69	27 (39.1)	4 (5.8)	11 (15.9)	12 (17.4)	11 (15.9)	11 (15.9)	7 (10.2)	13 (18.8)
Seeing a doctor if a swollen area hurts	69	22 (31.9)	10 (14.5)	8 (11.6)	4 (5.8)	13 (18.8)	10 (14.5)	6 (8.7)	18 (26.1)
Getting advice from someone you trust if you are troubled	69	31 (45.0)	10 (14.5)	14 (20.3)	7 (10.2)	11 (15.9)	6 (8.7)	7 (10.2)	14 (20.3)
Hydrating in a way that is appropriate for your condition	69	46 (66.7)	12 (17.4)	20 (29.0)	14 (20.3)	8 (11.6)	8 (11.6)	2 (2.9)	5 (7.2)
Prevent deterioration									
Avoiding increased skin temperature by bathing	69	34(49.2)	6 (8.7)	15 (21.7)	13 (18.8)	15 (21.7)	7 (10.2)	3 (4.3)	10 (14.5)
Choosing hypoallergenic detergents and cosmetics	68	45(66.1)	9 (13.2)	26 (38.2)	10 (14.7)	8 (11.7)	8 (11.7)	1 (1.5)	6 (9.0)
Lying down and resting if the skin in the swollen area is reddish and high temperature	66	16(24.3)	4 (6.1)	6 (9.1)	6 (9.1)	20 (30.4)	9 (13.7)	4 (6.1)	17 (25.7)
Moisturising swollen areas with creams every day	66	28(42.4)	12 (18.1)	9(13.7)	7 (10.6)	8 (12.2)	11 (16.7)	7 (10.6)	12 (18.1)

lymphoedema (Arai and Toume, 2016). It has 16 items, divided into four subscales: 'Observe swelling' (3 items), 'Maintain physical condition' (4 items), 'Prevent deterioration' (4 items) and 'Self-massage' (5 items). Each item is answered on a 7-point Likert scale (1 = never done to 7 = always done). A sum of 5-7 indicated that patients diligently performed such these skills.

'Self-massage' has not been proven to have preventive effects on subclinical lymphoedema, so was excluded from this study (Japan Lymphedema Study Droup, 2018). Therefore, only 11 SM skills were included. To assess the study's reliability,

the authors checked its internal consistency. Cronbach's α coefficients for the 'Observe swelling', 'Maintain physical condition' and 'Prevent deterioration' scales were 0.831, 0.811 and 0.710, respectively.

Hospital Anxiety and Depression Scale

The authors used the Hospital Anxiety and Depression Scale (HADS), a 14-item scale that measures anxiety and depression in outpatients. In HADS, the intensity of each symptom is measured by a 4-point Likert scale. The total score range (0-21) for each symptom is interpreted as normal (0-7), mild (8-10) or moderate (11-21). A

score of ≥ 8 indicates anxiety or depression. HADS is also reliable and valid, with a Cronbach's α coefficient of 0.77 (Zigmond and Snaith, 1983).

Data analysis

Descriptive statistics were obtained for each variable. The SM skills were determined from the descriptive statistics of the questions for the three subscales and then converted into a median (interquartile range [IQR]) score of 1-7. Then, the authors totalled the scores of all 11 items and identified those who achieved an overall median sum of 5-7. Next, the authors analysed the three subscales.

Table 3. Relationship between factors of education and the three subscales (n=69).

			Observe swelling		Maintain physical condition		Prevent deterioration	
		n	Median (IQR)	P-value	Median (IQR)	P-value	Median (IQR)	P-value
Opportunities for education	Once	33	3.0 (1.8–4.5)	0.612	4.0 (2.6–5.5)	0.773	4.3 (3.1–5.1)	0.909
	Twice	36	3.3 (1.7–4.7)		4.5 (3.0–5.5)		4.3 (3.3–5.0)	
Understanding the education	Yes	60	3.2 (2.0–4.7)	0.221	4.4 (2.8–5.5)	0.600	4.3 (3.3–5.0)	0.849
	No	9	2.0 (1.1–3.6)		4.8 (3.2–5.4)		3.9 (3.0–5.4)	

Note: Mann–Whitney U test; P<0.05. IQR = interquartile range

Factors related to SM skills, such as education, postoperative treatment and patient characteristics, were assessed. The SM skills of the three subscales were the dependent variables, whereas the factors were the independent variables in the Mann-Whitney U test or Kruskal-Wallis test. If a significant difference was found in the Kruskal-Wallis test, the groups were compared by multiple comparisons and Bonferroni’s correction; p<0.05 was considered significant. All statistical data were analysed by IBM SPSS Statistics for Windows, version 26.0 (IBM Corp, Armonk, NY, US).

Results

After examining the medical records, we selected 110 patients initially, of whom 21 withdrew. Furthermore, we excluded 6 patients with oedema caused by other illnesses, 5 with an existing diagnosis of LLL diagnosis and 9 with intense physical and/or emotional distress. Ultimately, 69 patients participated in the study.

Patients’ characteristics

Table 1 lists the characteristics of the participants. The median values for age, BMI and time since lymph node dissection were 53.0 years (IQR 45.5–66.0), 22.9 (20.8–25.0) and 14.0 months (13–17), respectively. Of the 69 participants, 48 (69.6%) had stage I disease and 7 (10.1%) had radiotherapy histories for cervical cancer. Regarding the HADS score, 27 (39.1%) had anxiety and 19 (27.5%) had depression.

Patients’ SM skills

The median scores for the three subscales were ‘Observe swelling’ 3.0 (1.8–4.7), ‘Maintain physical condition’ 4.5 (2.9–5.5) and ‘Prevent deterioration’ 4.3 (3.3–5.0), while a sum of 5–7 was found in 13 (18.8%), 27 (39.1%) and 20 (29.0%) of the participants, respectively. Table 2 shows the distribution of the score range for the 11 items.

Factors related to the SM skills

Table 3 presents the relationship between education and SM skills. Among the 69 participants, 60 (87%) understood the education and 9 (13%) did not. There was no association between understanding or frequency of education and SM skills.

Table 4 shows the relationship between postoperative treatment, patient characteristics and the SM skills. In the ‘Maintain physical condition’ subscale, the group with no radiotherapy history had significantly higher SM skills than the group with such history. For no radiotherapy, the median was 4.5 (IQR 3.1–5.5) versus radiotherapy 2.8 (1.7–4.6); P=0.046.

The degree of lymph node dissection had a significant difference in the ‘Maintain physical condition’ (P=0.026) and ‘Prevention of deterioration’ (P=0.043) in terms of performing the SM skills. Furthermore, post hoc multiple comparisons showed significant differences between the pelvic and para-aortic lymph node and para-aortic lymph node dissection in the ‘Maintain physical condition’ (pelvic and para-aortic lymph node: median 4.8 [IQR 3.5–5.5] versus para-aortic lymph node: 1.8 [1.5–4.3]; P=0.007) and ‘Prevention of deterioration’ (pelvic and para-aortic lymph node: median 4.5 [IQR 3.8–5.5] versus para-aortic lymph node: 3.0 [2.5–4.3]; P=0.025).

Discussion

This study investigated the performance of the SM skills and the associated factors in patients with gynaecological cancer manifesting subclinical lymphoedema who had received education on severe lymphoedema prevention. The findings revealed that although 87% of the patients understood the education, the majority executed inadequate SM skills. The ‘Observe swelling’ skill was particularly low, at 18.8%. Patients who had a history of radiotherapy had poorer SM skills.

The low rate of the skill ‘Observe swelling’ indicates the need for assistance in increasing patient awareness. This skill involves the detection of early signs of swelling by touching the skin and examining the patient physically (Arai and Toume, 2016). Mizuma et al (2017) reported that 10-year postoperative patients with swelling were more likely to observe their lower limbs. Early warning signs felt by patients with subclinical lymphoedema include groin pain, tingling sensation and lethargy (Ryan et al, 2003). Considering these signs as early warning signs of lymphoedema is important. Therefore, medical professionals should educate patients again to enhance the implementation of the ‘Observe swelling’ skill. Education should emphasise performing a physical check-up by pinching and touching the affected lower limbs, not simply observing the limbs.

It has been mentioned that less-performed SM skills are caused by patient’s situation rather than knowledge (Armer et al, 2011). A study reported that patients at risk of lymphoedema did not perform SM skills because of the lack of reality regarding symptom onset, similar to the patients in this study (Sharman and Koelmeyer, 2011). Although the patients understood the postoperative education, they might not practise the SM skills because lymphoedema was not a reality for them and had never happened to them.

Regarding the factor of postoperative treatment, unexpectedly, patients with radiotherapy history were less likely to perform this, including seeking assistance from others. In gynaecological cancer, the indication for postoperative radiotherapy depends on the disease status. Postoperative radiotherapy is a standard treatment for patients at risk for recurring cervical cancer at stage I–II (Chemoradiotherapy for Cervical Cancer Meta-analysis Collaboration, 2008). In this study, patients with radiotherapy

Table 4. Relationship between the factors of postoperative treatment, patient characteristics and the three subscales (n=69).

			Observe swelling		Maintain physical condition		Prevent deterioration	
		n	Median (IQR)	P-value	Median (IQR)	P-value	Median (IQR)	P-value
Age (years)	<40	11	3.7 (3.0–4.7)	0.547	3.0 (2.5–4.3)	0.394	4.5 (3.3–5.8)	0.455
	41–69	49	3.0 (1.7–4.7)		4.5 (3.0–5.5)		4.0 (3.0–5.0)	
	>70	9	2.0 (1.5–5.2)		5.0 (2.4–5.4)		4.3 (3.3–4.9)	
BMI	<24.9	51	3.0 (1.7–4.7)	0.631	4.5 (3.0–5.5)	0.143	4.3 (3.3–5.0)	0.359
	≥25	18	2.3 (1.9–3.9)		3.8 (1.9–4.8)		3.8 (2.8–5.1)	
Lymph node dissection	Pelvic	35	2.3 (1.7–3.7)	0.088	4.0 (2.5–5.5)	0.026*	3.5 (3.3–4.8)	0.043*
	Para-aortic	7	4.3 (2.0–5.3)		1.8 (1.5–4.3)		3.0 (2.5–4.3)	
	Pelvic and para-aortic	27	3.3 (2.0–5.0)		4.8 (3.5–5.5)		4.5 (3.8–5.5)	
Chemotherapy	Yes	42	3.3 (2.0–4.6)	0.288	4.5 (3.1–5.5)	0.479	4.3 (3.3–5.2)	0.206
	No	27	2.3 (1.7–4.7)		4.0 (2.8–5.6)		3.8 (2.9–4.8)	
Radiotherapy	Yes	7	3.7 (1.0–4.6)	0.556	2.8 (1.7–4.6)	0.046*	2.9 (1.9–3.7)	0.070
	No	62	3.0 (1.0–4.7)		4.5 (3.1–5.5)		4.3 (3.3–5.2)	
Marital status	Yes	45	3.0 (1.8–4.7)	0.724	4.5 (3.0–5.5)	0.294	4.0 (3.3–5.3)	0.761
	No	21	3.0 (1.8–4.3)		4.0 (2.8–5.3)		4.3 (3.1–4.5)	
Working status	Yes	33	3.3 (2.3–4.5)	0.337	4.5 (3.1–5.6)	0.277	4.3 (3.2–5.1)	0.096
	No	33	2.3 (1.5–4.7)		4.0 (2.9–5.1)		3.8 (2.6–4.9)	
Educational background	High school	24	3.0 (1.8–4.7)	0.241	5.0 (3.1–5.5)	0.385	3.4 (3.0–4.4)	0.210
	Junior college	19	3.3 (2.3–5.3)		4.5 (3.0–5.5)		4.8 (3.4–5.3)	
	University	19	2.3 (1.3–4.0)		4.0 (2.8–5.0)		4.3 (3.5–4.5)	
Anxiety	≥8	27	3.7 (2.0–4.7)	0.134	4.5 (3.8–5.5)	0.530	4.5 (3.0–5.5)	0.758
	<8	42	3.0 (1.7–3.8)		4.1 (2.9–5.3)		4.1 (3.3–4.6)	
Depression	≥8	19	2.3 (1.0–3.7)	0.249	4.0 (2.5–5.0)	0.112	3.0 (2.3–4.5)	0.050
	<8	50	3.0 (2.0–4.7)		4.5 (3.0–5.5)		4.3 (3.4–5.1)	

Note: Mann–Whitney U test; Kruskal–Wallis test; $p < 0.05^*$. BMI = body mass index; IQR = interquartile range

history also had cervical cancer, and they were less likely to perform the ‘Maintain physical condition’ skill, which includes seeking help from others. Thus, the impact of radiotherapy may be the reason why such patients did not perform the skill of seeking help for lymphoedema.

Along with postoperative education, patients with radiotherapy history should receive nursing support for the symptoms that arise later. A study examining the QOL of patients with gynaecological cancer in the 12 months from their last radiotherapy reported worsening menopausal symptoms and sexuality problems (Arrunda et al, 2019). Hence, patients with radiotherapy history might have post-treatment functional disability and insufficient recognition of radiotherapy as a risk factor for lymphoedema.

To enhance self-care for preventing severe lymphoedema, patients need not only education, but also comprehensive

support (Armer et al, 2011). Patients with a history of radiotherapy should be given nursing support during the post-treatment period to assess for any treatment-related late symptoms and to encourage them to seek medical attention at the first sign of lymphoedema.

Regarding the factor of patient characteristics, depression was a possible factor associated with the SM skills. Sharman and Koelmeyer (2013) examined factors associated with SM skills in patients at risk of lymphoedema and reported that mental distress negatively correlated with SM skills. The present study showed that patients with depression tended to perform each skill less, although this was not statistically significant.

SM skills must be considered for patients’ cognitive factors as well as postoperative education, as these can influence the SM skills (Armer et al, 2011). Cognitive factors, such as sense of

control over lymphoedema, self-efficacy and perceived self-regulatory ability, are influential factors associated with SM skills in patients with breast cancer (Sharman and Koelmeyer, 2013). The cognitive factors of patients with gynaecological cancer who have subclinical lymphoedema should be examined in a future study.

This study has some limitations. First, we investigated our cohort between 12–18 months postoperatively and did not observe how SM skills changed from the baseline. Future longitudinal studies are needed to determine the progression of the SM skills. Second, this study was conducted at a single facility, which may have biased the results. Third, this study has a small sample size.

Conclusion

Although postoperative education was well understood, SM skills were poor in patients with gynaecological cancer who

had subclinical lymphoedema during the early detection of postoperative LLL. Patients were less likely to perform the 'Observe swelling' skill, which would aid in the early detection of lymphoedema. Support is needed to encourage patients to be fully aware of the early warning signs of lymphoedema by providing the education not only after surgery but also after early detecting LLL. Despite the fact that radiotherapy history is a risk factor for lymphoedema, patients who had been treated with radiotherapy were less likely to perform the SM skill of seeking assistance from others. Therefore, patients with a history of radiotherapy must be assessed for late symptoms and provided with ongoing nursing support.

Acknowledgements

The authors are grateful to the patients who participated in this study.

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