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Research

Recognition of guidelines and outcome measures for lymphoedema management among healthcare professionals in Japan: A cross-sectional survey

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ABSTRACT

Introduction and Aim : Although domestic and international guidelines and outcome measures have been established for lymphoedema, whether these are being used by healthcare professionals in clinical practice remains unclear. This study aimed to examine the recognition of guidelines and outcome measures for lymphoedema management among healthcare professionals in Japan, following the International Lymphoedema Framework-Chronic Oedema Outcome Measures protocol.

Methods : In this cross-sectional observational study, a self-administered questionnaire, which was distributed through post or email, was used to collect data on the participants' demographics, history of lymphoedema management experience, and recognition of outcome measures. Their variables were described by healthcare professionals with experience managing lymphoedema.

Results : A total of 1,000 healthcare professionals were surveyed, of which 211 (21.1%) responded, and 76 had experience in lymphoedema management. Nursing was the most common occupation. The median experience in lymphoedema management was 7 years. Fifty-one percent of experienced participants and 9% of inexperienced participants measured treatment outcomes. Furthermore, 26% of experienced participants and 7% of inexperienced participants knew the lymphoedema guidelines.

Conclusions : This study clarified the level of recognition of lymphoedema guidelines and the use of outcome measures in lymphoedema management among healthcare professionals in Japan. The recognition of lymphoedema guidelines was limited, with only 26% of those with experience in lymphoedema management reporting familiarity with them. Challenges remain in the dissemination and adoption of guidelines and outcome measures. Moving forward, providing educational opportunities for healthcare professionals and promoting the dissemination of guidelines and outcome measures are essential to improve consistency and enhance care practices.

KEY WORDS : lymphoedema, outcome measures, assessment, education, implementation

Introduction

The lack of uniformity in lymphoedema outcome measures was identified as a problem, and an international survey was conducted in 61 countries to evaluate the perceptions of healthcare professionals regarding lymphoedema outcomes.[1] This study presents the results of this international survey in Japan, compares the lymphoedema outcomes perceived by healthcare professionals with internationally aggregated reports, and proposes recommendations for edema education for healthcare professionals in Japan.

Lymphoedema outcomes have been reported in several studies based on its pathogenesis and symptoms.[2-4] The pathology of lymphoedema is characterized by the accumulation of excessive interstitial fluid in the dermis and subcutaneous tissue due to lymphatic circulation stagnation. Symptoms include chronic edema of various body parts,[5][6] including the extremities, abdomen, pubic region, buttocks, head, and neck. Management includes complex physiotherapy, surgical treatment, and long-term self-care.[4][7][8] Lymphoedema is the greatest risk factor for the development of cellulitis and inflammatory symptoms of pain, which require antimicrobial treatment and hospitalization.[9-12] The physical outcomes reported include the International Society of Lymphology (ISL) stage, size of the affected limb determined by circumference and volume measurements, skin and subcutaneous tissue status, cellulitis, obesity, activity, pain, wounding, and the psychosocial outcomes of quality of life, satisfaction, treatment adherence, and hospitalization due to edema.[9][10][12-15] These outcomes related to lymphoedema assessment are evaluated based on numerous research reports and expert recommendations. These outcomes have been published in several guidelines and best practices.[3][4]

Outcomes are the key indicators of improvement in the quality of medical, health, and nursing care.[12][13] Outcomes include evidence-based and professionally

agreed upon indicators that support decision-making by healthcare professionals, lead to more treatment and care choices, and are directly related to the effects on patients. However, whether healthcare professionals working in various settings are aware of or use lymphoedema outcome measures remains unclear.

This study aimed to examine the recognition of guidelines and outcome measures for lymphoedema management among healthcare professionals in Japan. This study followed the International Lymphoedema Framework-Chronic Oedema Outcome Measures (ILF-COM) protocol.

Materials and Methods

This study was part of the ILF-COM project[1] and was a Japanese study conducted according to the ILF-COM protocol.

1. Research design and participants

A self-administered questionnaire survey was conducted in a cross-sectional observational study. Healthcare professionals were recruited by requesting responses from the members of ILF Japan.

2. Data collection

The survey questionnaire was distributed to potential participants either by post or via email between October 2018 and January 2019. For participants who received the questionnaire by email, a PDF version was attached, and they were requested to either return the completed form as an email attachment or print and send it back by post. For those who received the questionnaire by post, a prepaid return envelope was included to facilitate the postal return of their responses. The questionnaire included basic information about healthcare professionals (i.e., job title, clinical experience, place of work, whether they had experience in managing lymphoedema, and history of lymphoedema management), along with questions on outcomes.

The English version of the questionnaire was developed by the ILF, which was translated into Japanese by Japanese researchers. The validity of the translation was checked by several lymphoedema experts who are fluent in English and Japanese and was verified by experts.

3. Data analysis

Data were analyzed descriptively. Categorical variables are presented as N (%), and continuous variables are presented as medians (interquartile ranges [IQR]). Descriptive statistics were provided separately for two groups: lymphoedema-experienced healthcare professionals and those without lymphoedema experience. In this study, lymphoedema-experienced healthcare professionals were defined as healthcare professionals with experience in lymphoedema management.

4. Ethical considerations

This study was approved by the Ethics Review Committee of Kanazawa University Medical (#54-1). Furthermore, consent was obtained electronically from the participants upon their responses to the questionnaire.

Results

This survey was sent to 1,000 healthcare professionals, and 211 responses (21.1%) were received, including replies via postal mail and email. From the total number of responses, six respondents were excluded because information about their lymphoedema management experience was not provided; thus, 205 clinical professionals (20.5%) were finally included in the analysis.

1. Participant characteristics (Table 1)

Of the 205 healthcare professionals who participated, 76 had experience in lymphoedema management, whereas 129 had no experience in lymphoedema management. The most common occupation in both groups was nursing (67% and 85%, respectively). The median years of lymphoedema management experience among lymphoedema-experienced healthcare professionals was 7 years (IQR: 2.5–11.5 years).

2. Recognition of guidelines and outcome measures in lymphoedema management

Regarding knowledge of lymphoedema guidelines, the proportion of participants who had knowledge of the national guidelines was 26% among lymphoedema-experienced healthcare professionals and 7% among those without lymphoedema management experience. As shown in **Table 2**, regarding the question "In your experience, are the treatment outcomes for chronic oedema/lymphoedema measured?", 51% of lymphoedema-experienced healthcare professionals answered "Yes," whereas only 9% of those without lymphoedema management experience answered "Yes." Regarding

Table 1 Characteristics of the participants.

	Total (N=205)		Lymphoedema-experienced healthcare professionals (N=76)		Healthcare professionals without lymphoedema experience (N=129)	
Professionals						
Nurse	164	(80)	51	(67)	108	(85)
Medical doctor	9	(4)	4	(5)	4	(3)
Physiotherapist	20	(10)	13	(17)	7	(6)
Occupational therapist	8	(4)	5	(7)	3	(2)
Other profession	8	(4)	3	(4)	5	(4)
Years of clinical experienceWorkplace	17	(10–25.5)	18	(14–24)	5	(7–27)
Hospital	123	(60)	57	(74)	66	(51)
Academic institution	42	(20)	6	(8)	36	(28)
Community-based facilities	27	(13)	8	(10)	19	(15)
Lymphoedema specialist center	5	(2)	5	(6)	0	0
Wound specialist center	0	0	0	0	0	0
Other	9	(4)	1	(1)	8	(6)
Years of lymphoedema management			7	(2.5–11.5)		

N indicates the number of participants. Values in parentheses represent percentages (%).
Median (IQR: interquartile range) refers to the median and interquartile range, which are applied to variables measuring years of clinical experience and years of lymphoedema management.

the question "Which of the following do you use in everyday practice to determine outcomes?", the severity classification method revealed that 55% of lymphoedema-experienced healthcare professionals and 11% of those without lymphoedema management experience chose ISL staging. For evaluation methods, 82% of lymphoedema-experienced healthcare professionals and 40% of those without lymphoedema management experience used circumferences without calculating volume. Circumferences for calculating volume were used by 61% of lymphoedema-experienced healthcare professionals and 16% of those without lymphoedema management experience. Photographs were used by 61% of lymphoedema-experienced healthcare professionals and 16% of those without lymphoedema management experience. Furthermore, ultrasonography was used by 32% and 6%, respectively.

For determining deterioration, episodes of cellulitis or erysipelas were reported by 82% of lymphoedema-experienced healthcare professionals and 37% of those without lymphoedema management experience. Overweight was noted by 61% of lymphoedema-experienced healthcare professionals and 21% of those without lymphoedema management experience, and complications of treatment were reported by 33% and 8%, respectively.

For psychosocial effects, quality of life was reported by 82% of lymphoedema-experienced healthcare professionals and 45% of those without lymphoedema management experience. Mobility was noted by 55% of lymphoedema-experienced healthcare professionals and 26% of those without lymphoedema management experience, whereas pain was reported by 51% and 31%, respectively. Patient adherence to treatment was observed by 41% of lymphoedema-experienced healthcare professionals and 9% of those without lymphoedema management experience.

Discussion

This study exhibited healthcare professionals' recognition of the guidelines and outcome measures for lymphoedema management in Japan following by the ILF-COM protocol.

Despite the existence of guidelines and comprehen-

Table 2 Experiences of using outcome measures in lymphoedema management.

	Total (N=205)		Lymphoedema-experienced healthcare professionals (N=76)		Healthcare professionals without ymphoedema experience (N=129)	
	N	(%)	N	(%)	N	(%)
In your experience, are treatment outcomes for chronic edema/lymphoedema measured?						
Yes	50	(24)	39	(51)	11	(9)
Sometimes	19	(9)	8	(11)	11	(9)
No	110	(54)	20	(26)	90	(70)
Don't know	26	(13)	9	(12)	17	(13)
Are there any guidelines for lymphoedema outcome measures in Japan? Please select all that apply						
International	18	(9)	11	(14)	7	(5)
National	29	(14)	20	(26)	9	(7)
No	68	(33)	19	(25)	49	(38)
Don't know	91	(44)	25	(33)	66	(51)
Which of the following do you use in everyday practice to determine outcome? Please select all that apply						
Severity classification method						
ISL staging	56	(27)	42	(55)	14	(11)
CEAP classification	2	(1)	1	(1)	1	(1)
Lymph-ICF	4	(2)	3	(4)	1	(1)
Don't know	131	(64)	26	(34)	105	(81)
Evaluation method						
Circumference only without calculating the volume circumference measurements for volume	114	(56)	62	(82)	52	(40)
Circumferences for calculating the volume	67	(33)	46	(61)	21	(16)
Perometer/infrared imaging	2	(1)	2	(3)	0	0
Water displacement method	2	(1)	2	(3)	0	0
Photographs	66	(32)	46	(61)	20	(16)
Moisture meter	6	(3)	4	(5)	2	(2)
Ultrasound	32	(16)	24	(32)	8	(6)
DEXA scan	1	(0)	1	(1)	0	0
MRI	3	(1)	2	(3)	1	(1)
Bioimpedance	9	(4)	8	(11)	1	(1)
Lymphoscintigraphy	8	(4)	4	(5)	4	(3)
Indocyanine green lymphography	10	(5)	8	(11)	2	(2)
Wound type	11	(5)	7	(9)	4	(3)
Wound size	31	(15)	14	(18)	17	(13)
Don't know	94	(46)	10	(13)	84	(65)
Determining deterioration						
Episodes of cellulitis/erysipelas	110	(54)	62	(82)	48	(37)
Hospital admissions linked to lymphoedema	32	(16)	19	(25)	13	(10)
Complications of the treatment	35	(17)	25	(33)	10	(8)
Weight/BMI (overweight)	73	(36)	46	(61)	27	(21)
Don't know	68	(33)	8	(11)	60	(47)
Psychosocial effect						
Quality of life	120	(59)	62	(82)	58	(45)
Pain	79	(39)	39	(51)	40	(31)
Mobility	75	(37)	42	(55)	33	(26)
Patient adherence to the treatment	43	(21)	31	(41)	12	(9)
Don't know	53	(26)	5	(7)	48	(37)

N indicates the number of participants. Values in parentheses represent percentages (%).
ISL, International Society of Lymphology; CEAP, Clinical (C), Etiological (E), Anatomical (A), and Pathophysiological (P); ICF, International Classification of Functioning; BMI, body mass index.

sive resources for specialized lymphoedema management, only a few healthcare professionals recognized them. In particular, 26% of lymphoedema-experienced healthcare professionals and 7% of those without lymphoedema management experience knew the national guidelines. Furthermore, only 14% of lymphoedema-experienced healthcare professionals and 5% of those without lymphoedema management experience knew the international guidelines. Globally, an ILF study involving 8,014 patients across 15 ILF countries reported that guidelines were used by <50% of the patients. These findings suggest that the use of guidelines is insufficient, both in Japan and internationally. The low recognition of guidelines and related documents suggests the need to explore approaches for improving healthcare professionals' access to these resources. In Japan, ILF Japan translated and published the best practice for the management of lymphoedema.[18] This document is a Japanese translation of the original publication by the ILF in 2006, providing a comprehensive guide to the standard management of lymphoedema, including its pathophysiology, outcome measures, evaluation methods, and treatment approaches.[2] This document is freely accessible for download from ILF Japan's official website. Furthermore, the Japanese clinical practice guidelines for the diagnosis and treatment of lymphoedema have been published,[19] and Japanese healthcare professionals can access them. Globally, resources such as the guidelines for the diagnosis, assessment, and management of lymphoedema,[4) 19] best practice for the management of lymphoedema,[2) 19] the guidelines on the management of cellulitis in lymphoedema[20] and consensus documents are available. These resources are expected to improve practical skills by offering insights into lymphoedema outcomes and management strategies. Currently, these materials are primarily available to healthcare professionals who proactively access the websites hosting them. However, it is necessary for academic organizations, including the ILF and ILF Japan, to consider proactive measures, such as organizing seminars and educational events, to ensure that these materials reach healthcare professionals effectively.

The use of outcome measures in lymphoedema care appears to differ depending on whether healthcare professionals have experience in lymphoedema management. Overall, healthcare professionals with lymphoedema management experience tended to adopt a wider variety of methods, whereas those without such experience appeared to rely on a limited number of basic approaches. Among healthcare professionals with lymphoedema management experience, 82% used limb circumference measurements without volume calculation, and 61% employed methods that incorporated volume calculation. Furthermore, 61% used photographs, 82% monitored cellulitis episodes, and 82% assessed overweight as a determinant of deterioration and quality of life as a psychosocial factor. These methods are straightforward, require minimal specialized equipment, and are relatively easy to integrate into routine clinical workflows. In contrast, ultrasonography was used by 32%, ICG lymphography by 11%, and bioimpedance by 11%. Although these technologies exhibited some level of adoption, their overall use remained limited. The need for specialized equipment and training likely poses significant barriers to their broader implementation. ICG lymphography has been reported in diagnosing, staging, surgical planning, and reverse lymphatic mapping.[21] Ultrasonography can be applied to rule out vinous pathology, surgical planning,[21] and lymphoedema assessment.[22) 23] Bioimpedance is recognized as an effective tool for assessing lymphoedema[24] However, a lack of specialized knowledge and difficulty of costs appeared to restrict their widespread use. Healthcare professionals without lymphoedema management experience demonstrated a different pattern of use. Quality of life assessment was the most frequently reported method, used by 45%, followed by limb circumference measurements without volume calculation, used by 40%. In contrast, the usage rates of ultrasound, ICG lymphography, and bioimpedance were notably low (6%, 2%, and 1%, respectively). These findings suggest that resource-intensive or technically demanding methods are less likely to be adopted in settings with limited resources or training opportunities. These results highlight several challenges in promoting the use of outcome measures in lymphoedema care. Therefore, educational programs tailored to the experience levels of healthcare professionals must be developed, and opportunities for ongoing

training must be provided. Furthermore, research and dissemination of cost-effective and portable equipment for evaluation are essential. Addressing these issues could lead to more comprehensive and effective lymphoedema care across diverse clinical settings, ultimately improving the quality of care provided to patients.

This study has some limitations. Recruitment through members of ILF Japan may have introduced selection bias because a significant portion of participants were affiliated with universities, research institutions, and ILF Japan. Furthermore, the lack of detailed information regarding participants' lymphoedema management credentials, clinical experience, and educational background increases the possibility that the cohort included individuals predisposed to acquiring new knowledge. These factors warrant caution when considering the external validity of the findings.

Taken together, to address the low recognition of guidelines and promote standardized lymphoedema management, implementation strategies should focus on improving lymphoedema education and enhancing recognition of guidelines among multidisciplinary healthcare professionals. Doing so is essential to reduce the risk of worsening lymphoedema, recurrent cellulitis, and the associated decline in patients' quality of life.

Conclusions

This study clarified the level of recognition of lymphoedema guidelines and the use of outcome measures in lymphoedema management among healthcare professionals in Japan. The recognition of lymphoedema guidelines was limited, with only 26% of those with experience in lymphoedema management reporting familiarity with them. The findings suggest that challenges remain in the dissemination and adoption of both guidelines and outcome measures. Moving forward, providing educational opportunities for healthcare professionals, and promoting the dissemination of guidelines and outcome measures are essential to improve consistency and enhance care practices.

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Conflict of Interest

The authors declare no competing financial interests.

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リンパ浮腫に関するガイドラインとアウトカムの日本の医療従事者の認識：横断観察研究

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要　旨

背景・目的：リンパ浮腫の評価指標は国内外で報告があるものの標準化には至っていない。そこで、International Lymphoedema Framework（ILF）が主導した ILF Chronic oedema Outcome Measures（ILF-COM）プロトコルに従い、日本の医療者を対象として、リンパ浮腫ガイドラインの認識とリンパ浮腫アウトカムを調査することとした。

方法：プロジェクトによるプロトコルに準じて実施した。国内の医療従事者を対象とした横断観察研究（自己式質問紙調査）とし、リンパ浮腫のガイドラインやアウトカムに関する認識ついて、リンパ浮腫管理経験の有無で比較した。

結果：医療従事者 1,000 名を対象として質問紙が郵送または配信され、211 名（21.1%）が回答し、そのうち有効回答数が 205 名（20.5%）であった。リンパ浮腫管理経験のある者は 76 名で、看護師が最も多い集団であった。リンパ浮腫ガイドラインを知っている者は経験者 26%、未経験者 7 %であった。リンパ浮腫アウトカムを用いている者は、経験者 51%、未経験者 9 %であった。

結論：本研究は、ILF-COM のプロトコルに準じ、国内の医療従事者を対象としてリンパ浮腫に関するガイドラインとアウトカムの認識を明らかにした。リンパ浮腫ガイドラインの認識はリンパ浮腫管理経験者でも 26%と低かった。今後、リンパ浮腫管理を行う医療従事者への教育の機会の提供、医療従事者へのリンパ浮腫管理のガイドライン等の普及活動の強化が求められる。

キーワード：リンパ浮腫、アウトカム、評価、教育、実装