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Culturally adapted translation of LYMPH-Q upper extremity module from English to Mandarin Chinese

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ABSTRACT

Background: Breast cancer-related lymphedema (BCRL) is one of the debilitating complications after breast cancer treatment. Several forms of patient-reported outcome measures (PROMs) were developed to evaluate the severity of BCRL based on the patients' perspective. LYMPH-Q Upper Extremity Module is a newly developed questionnaire for BCRL. This study aimed to demonstrate the process of translation and cultural adaption from English to Mandarin Chinese.

Methods and results: The translation process followed the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) best-practice guidelines for the translation and cultural adaption of PROM. The process included four steps: forward translation, back translation, back translation review, and patient interviews. In total, five patients with BCRL were recruited for patient interviews.

The forward translation step involved two professional translators whose native language was Mandarin Chinese. A reconciled translated version was produced. In the back translation step, the reconciled translated version in Mandarin Chinese was sent to another professional translator whose native language was English. The back-translated version in English was sent back to the developer of LYMPH-Q for review. In this step, 22 items were revised. In the final step of patient interviews, 15 items were revised based on the patients' feedback.

Conclusion: The development of Mandarin Chinese version of LYMPH-Q Upper Extremity Module and its utilization in conjunction with the existing objective measures could provide a more well-rounded picture of the status of patients with BCRL worldwide.

1. Introduction

Breast cancer is the most common cancer diagnosed among women worldwide, contributing to 25 % of the total number of new cancer cases diagnosed in 2018 [1]. The overall breast cancer death rate increased by 0.4 % per year from 1975 to 1989, but it decreased rapidly thereafter, with a total decline of 40 % until 2017 [2]. This was attributed to improvements in treatment and earlier detection [3]; however, breast cancer-related lymphedema (BCRL), a debilitating sequela of breast cancer treatment occurring in one in five patients [4], has been drawing more attention among breast cancer survivors and healthcare providers. In the past 20 years, a total of 240 studies related to the treatment of BCRL were published. Recently the lack of attention on BCRL treatment has been corrected, as the majority were published in the past five years [5]. Traditionally, the evaluation of the severity of arm lymphedema

was based on several objective measures, such as circumference measurement, water displacement [6], bioimpedance [7], lymphoscintigraphy, indocyanine green (ICG) lymphography [8], or magnetic resonance lymphangiography (MRL) [9]. However, the dissociations between the objective assessments of healthcare providers and subjective symptoms experienced by patients were sometimes encountered in clinical setting [10]. Therefore, various patient-reported outcome measures (PROMs), which are questionnaires developed to provide subjective assessments from the patients' own perspective, were developed [11]. The LYMPH-Q Upper Extremity Module, a recently developed questionnaire designed to rectify the limitations observed in current Patient-Reported Outcome Measures (PROMs) for upper extremity lymphedema, was first published in the English language in 2021 [12]. Recognizing the global significance of Mandarin Chinese as one of the most widely spoken languages, efforts were promptly

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undertaken to ensure this questionnaire's accessibility to a broader audience. Thus, a pivotal aspect of this initiative involved the translation and cultural adaptation of the LYMPH-Q Upper Extremity Module into Mandarin Chinese, aiming to enhance its relevance and utility within Mandarin-speaking populations. This study, consequently, aims to elucidate the intricacies of the translation and cultural adaptation process.

2. Patients and methods

All translation and cultural adaptation steps followed the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) best-practice guidelines for the translation and cultural adaptation of PROMs [13]. The first step was to select the members of the translation team, consisting of a project manager, two forward translators, and one back translator. The project manager's role was to oversee the translation process and serve as the main contact with the Q-Portfolio team who developed the LYMPH-Q Upper Extremity Module. The two forward translators must have Mandarin Chinese as their native language and be fluent in English. The back translator must have English as the native language and be fluent in Mandarin Chinese. These translators must be qualified professional translators. We cooperated with the President Translation Service Group International (PTSGI) (Taipei, Taiwan). The two forward translators produced a reconciled version in Mandarin Chinese and sent it to the back translator, who was responsible in translating the version back to English. The back translation was sent back to the project manager, who sent the back translation to the Q-Portfolio team for review. The Q-Portfolio team would review the back translation and then either approve it or request a revision. If changes were required, the forward translations should be revised according to the comments from the Q-Portfolio team. If no changes were required or the revised version was accepted by the Q-Portfolio team, the project manager could proceed in conducting cognitive debriefing interviews with patients. Patients with BCRL were recruited from the authors' clinics. The patients were interviewed either in person or via telephone to obtain their feedback on questionnaire items. This process was approved by the institutional review board of National Taiwan University Hospital (202112145RINB). The translation would be revised to improve its comprehension according to the patients' feedback. The Q-Portfolio team would approve the final version and format the translation for distribution.

3. Results

A total of 22 items were revised after the Q-Portfolio team reviewed the back translation by PTSGI, Inc. (Table 1). In total, five patients with BCRL were recruited for interview. The patient characteristics are shown in Table 2. All of them were female, with an average age of 57.2 ± 7 years old. The average duration of arm lymphedema was 6.5 ± 4.5 years. One patient was interviewed in person, while the other four patients were interviewed via telephone. The duration of each interview was about 20 min. Fifteen items were revised based on the patients' response and suggestions (Table 3). The final edition was approved by the Q-Portfolio team.

4. Discussion

In clinical settings, objective findings sometimes could not truly reflect the patients' own perceptions about their swollen extremities. For example, most patients could feel lightness and softness over their swollen arms after lymphovenous anastomosis [14], which is a microsurgical treatment for lymphedema [15]; however, sometimes, the circumference measurement could not detect a significant reduction in arm volume. Conversely, a clinically and statistically significant reduction in the volume of the swollen limb could be noted, but the patients would still complain about the limitations in their daily functionalities.

Table 1
Revised items in the back-translated step.

Original version	Back-translated version	LYMPH-Q Team comment	Revised Chinese version
Pain when your arm is touched?	Do you feel pain when touching your arm?	Each of these items should not be a question with a "Yes or No" answer. Patients need to be able to answer with Severe, Moderate, etc. Is this clear in the translation? In the English, they are purposely incomplete sentences, more like statements. Perhaps you could phrase it like: "How is the pain when"	當您的手臂被觸碰到時, 疼痛程度如何?
Pain when your arm is at rest?	Do you feel pain if not moving your arm?	The same	當您的手臂未活動時, 疼痛程度如何?
Arm feeling hotter or colder than normal?	Do you feel warmer or cooler in your arm than your body temperature?	The same	如果手臂有感覺比平時溫熱或較冷的話, 程度如何?
Arm feeling stiff?	Do you feel rigid in your arm?	The same	如果手臂有感覺僵硬的話, 程度如何?
Arm symptoms disturbing your sleep (eg, pain, swelling)?	Is there any symptom (e.g., pain, swelling) disturbing your sleep?	The same	如果手臂症狀有干擾到您的睡眠的話(例如, 疼痛、腫脹), 程度如何?
Aching feeling in your arm?	Do you feel persistent pain in your arm?	The same	如果手臂有感到酸痛的話, 程度如何?
Arm feeling numb?	Do you feel numbness in your arm?	The same	如果手臂感到麻木的話, 程度如何?
Pressure in your arm?	Do you feel compression in your arm?	The same	如果手臂感到壓迫感的話, 程度如何?
Pain when you move your arm?	Do you feel pain when moving your arm?	The same	活動手臂時, 疼痛程度如何?
Clumsiness (eg, dropping or spilling things)?	Do you feel less active in your arm (e.g., easy to drop or spill over)?	The same	手臂是否較不靈活(例如, 容易掉東西或打翻東西)? 程度如何?
Tingling in your arm (ie, pins and needles feeling)?	Do you feel tingling in your arm (nail or needle stick)?	The same	如果手臂有刺痛感(釘子或針刺的感覺)的話, 程度如何?
Arm feeling tired?	Do you feel tired in your arm?	The same	如果手臂有疲勞感的話, 程度如何?
Arm feeling weak (ie, lack of strength)?	Do you feel weakness in your arm (without any strength)?	The same	如果手臂有無力感(沒有力氣)的話, 程度如何?
Arm feeling heavy?	Do you feel heavy in your arm?	The same	如果手臂有感覺沉重的話, 程度如何?
Arm swelling?	Do you feel swelling in your arm?	The same	如果手臂有腫脹感的話, 程度如何?

(continued on next page)

Table 1 (continued)

Original version	Back-translated version	LYMPH-Q Team comment	Revised Chinese version
How difficult is it for you to use your arm with lymphedema?	Does lymphedema caused by breast cancer surgery affect the functions of your arm?	"caused by breast cancer surgery" is not in original. Also, should ask "how difficult"	使用有淋巴水腫的手臂有多困難?
... people seeing your arm?	How people think of your arms	"seeing" vs "think"	別人看著您的手臂時?
... how your arm looks when you wear a long-sleeved shirt?	How does it look the arm with compression sleeve	this is about "long-sleeved shirt" not "compression sleeve", as they are supposed to be thinking of their arm without it	當您穿長袖襯衫時, 您的手臂看起來如何?
... how your arm looks in photos?	The look of the arm in the mirror	"in photos" vs "in the mirror"	手臂在照片中呈現的樣子。
... the overall size of your arm?	Larger arm due to arm swelling	should just be general - size	您手臂的整體大小?
Frustrated?	Depressed?	We just want to make sure that this is different than Item 4. Frustrated is like being upset about something one can't change	沮喪?
How easy the arm sleeve was to put on?	The mobility after putting on the compression sleeves	this should just be about "putting on", not mobility	穿脫袖套容易嗎?

Table 2

Characteristics of patients for interview.

No.	Age	Gender	Education	Duration of lymphedema (yr)	Stage of lymphedema ^a
1	57	F	High school	7	2
2	70	F	College	3	3
3	57	F	Unavailable	3.5	2
4	50	F	High school	4	3
5	72	F	High school	15	3
	57.2 ± 7 ^b			6.5 ± 4.5 ^b	

^a Based on International Society of Lymphology (ISL) Staging.

^b Average ± s.d.

Therefore, PROMs have been gaining popularity among lymphedema healthcare providers [11].

In the development process of an ideal PROM, patient involvement is an essential step because PROM should be tailored to the measure outcomes that matter most to patients, and are easily understood by the general public. However, a systematic review by Beelen et al. identified that 13 of the current 14 extremity lymphedema-related PROMs were developed with limited input from patients, and only one study conducted qualitative interviews with patients (ULL-27) [16,17]. In addition, only 6 of them were developed specifically for upper extremity lymphedema [17]. Another systematic review also mentioned that the quality of PROM was low to moderate based on the criteria for reliability and validity in the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) [18]. Therefore, the LYMPH-Q Upper Extremity Module was developed by the Q-Portfolio team to address the existing issues in the current PROMs for upper extremity lymphedema [12]. The LYMPH-Q Upper Extremity Module was developed through a collaboration between several universities and hospitals in Canada, USA, and Denmark. The process was multi-phased, including a qualitative interview and field-test study [12]. The components of LYMPH-Q upper extremity module included symptoms, function, appearance, psychological, information, and arm sleeve. The number of items in LYMPH-Q upper extremity module was 110, compared to 35,

Table 3

Revised items based on patients' feedback.

Original version	Before patients' interview	Difficulties during interview	Final version
None	毫無	too simplified to be understood quickly	一點也不會
Pain when your arm is at rest?	當您的手臂未活動時, 疼痛程度如何?	too simplified to be understood quickly	當您的手臂沒有活動時, 疼痛程度如何?
Arm swelling?	如果手臂有腫脹感的話, 程度如何?	too simplified to be understood quickly	如果手臂有腫脹的感覺的話, 程度如何?
Putting on or taking off clothes?	穿脫衣物	The new version is more colloquial, more easily understood.	穿脫衣服
Holding a phone to your ear?	手持電話靠近耳邊	too simplified to be understood quickly	手持電話靠近耳朵旁邊。
Using your hand and fingers (eg, type, write)?	使用雙手和手指 (例如, 打字、寫字)。	only the swlloen side, the previous version indicated both hands	使用手和手指 (例如, 打字、寫字)
... how your arm looks when you wear a long-sleeved shirt?	當您穿長袖襯衫時, 您的手臂看起來如何?	The new version is more colloquial, more easily understood.	當您穿長袖衣服時, 您的手臂看起來如何?
... having to dress in a way to hide your arm?	必須穿著遮蓋手臂的服飾。	The new version is more colloquial, more easily understood.	必須穿著遮蓋手臂的衣服。
... not being able to wear certain clothes because of your arm?	因為手臂的狀況, 而無法穿著某些款式的服飾。	The new version is more colloquial, more easily understood.	因為手臂的狀況, 而無法穿著某些款式的衣服。
... how your arm looks in a sleeveless shirt?	穿著無袖服飾時, 手臂看起來的樣子。	The new version is more colloquial, more easily understood.	穿著無袖衣服時, 手臂看起來的樣子。
Sometimes	有時	too short to be understandable	有時候
Never	從不	too short to be understandable	從來不會
How well the arm sleeve fit (ie, not too tight or too loose)?	壓力袖套的合身度 (鬆緊度是否剛好)?	The new version is more colloquial, more easily understood.	壓力袖套的合身程度 (鬆緊度是否剛好)?
How helpful the arm sleeve was in reducing swelling?	壓力袖套減緩腫脹的效果?	The new version is more colloquial, more easily understood.	壓力袖套減少腫脹的效果?
How clothes fit your arm with the arm sleeve on?	穿著壓力袖套時, 外衣的合身度。	The new version is more colloquial, more easily understood.	穿著壓力袖套時, 外面衣服的合身程度。

the average number of items of the current 14 extremity lymphedema-related PROMs. This provided healthcare professionals and researchers a BCRL-specific PROM with a strong content and construct validity [12].

Mandarin Chinese is commonly considered as the Standard Chinese, and it is often simply called "Chinese." Mandarin Chinese is one of the six official languages of the United Nations, widely spoken in some Asian areas. According to Ethnologue, Chinese (along with some minor varieties) is the most spoken language across the world, and there are approximately 1.3 billion speakers, comprising 16 % of the world's population [19]. To provide the Chinese-speaking population an easier access to LYMPH-Q, a culturally adapted translation in Chinese is necessary. During the patient interview step, based on the patients' responses, some minor revisions were done to improve the understandability of each sentence. The final version should be as plain and understandable for patients with varying degrees of literacy and educational backgrounds. In addition, the translation in this study was written in Traditional Chinese, but some Chinese-speaking countries use Simplified Chinese. The difference between Traditional and Simplified Chinese is mainly the reduced stroke count per character, which could be converted easily by a variety of softwares. Their grammars and pronunciations are similar and understandable between different users.

The limitations of this study may be the number of forward and backward translators, the number of patients enrolled, and the non-evenly distributed educational background of the enrolled patients. Despite those numbers had met the requirement of ISPOR best-practice guidelines, to increase the number of translators and patients enrolled, and to recruit a group of patients with more evenly distributed educational background, are likely to generate a more widely applicable version of translation.

5. Conclusion

The incorporation of LYMPH-Q into the existing array of objective measures represents a significant stride towards obtaining a comprehensive understanding of the condition of patients with BCRL. The introduction of a culturally adapted translation in Mandarin Chinese serves as a pivotal step towards global inclusivity and accessibility. This adaptation ensures that a broader spectrum of patients and clinicians worldwide can avail themselves of the invaluable insights provided by LYMPH-Q, transcending linguistic barriers and fostering a more universally applicable approach to the management of BCRL.

Declaration of competing interest

None

References

- [1] Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA A Cancer J Clin* 2018;68:394–424.
- [2] American Cancer Society I. Breast cancer facts & figures 2019–2020. 2019.
- [3] Berry DA, Cronin KA, Plevritis SK, et al. Effect of screening and adjuvant therapy on mortality from breast cancer. *N Engl J Med* 2005;353:1784–92.
- [4] DiSipio T, Rye S, Newman B, Hayes S. Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis. *Lancet Oncol* 2013;14: 500–15.
- [5] Al-Sakkaf AM, Masia J, Auladell-Rispau A, et al. Evidence mapping of the treatments for breast cancer–related lymphedema. *Plastic and Reconstructive Surgery Global Open* 2022;10.
- [6] Hidding JT, Viehoff PB, Beurskens CH, van Laarhoven HW, Nijhuis-van der Sanden MW, van der Wees PJ. Measurement properties of instruments for measuring of lymphedema: systematic review. *Phys Ther* 2016;96:1965–81.
- [7] Shah C, Vicini FA, Arthur D. Bioimpedance spectroscopy for breast cancer related lymphedema assessment: clinical practice guidelines. *Breast J* 2016;22:645–50.
- [8] Yoon JA, Shin MJ, Shin YB, et al. Correlation of ICG lymphography and lymphoscintigraphy severity stage in secondary upper limb lymphedema. *J Plast Reconstr Aesthetic Surg* 2020;73:1982–8.
- [9] Miseré RM, Wolfs JA, Lobbes MB, van der Hulst RR, Qiu SS. A systematic review of magnetic resonance lymphography for the evaluation of peripheral lymphedema. *J Vasc Surg: Venous and Lymphatic Disorders* 2020;8: 882–892. e882.
- [10] Sackey H, Johansson H, Sandelin K, et al. Self-perceived, but not objective lymphoedema is associated with decreased long-term health-related quality of life after breast cancer surgery. *Eur J Surg Oncol* 2015;41:577–84.
- [11] Cornelissen AJ, Kool M, Keuter XH, et al. Quality of life questionnaires in breast cancer-related lymphedema patients: review of the literature. *Lymphatic Res Biol* 2018;16:134–9.
- [12] Klassen AF, Tsangaris E, Kaur MN, et al. Development and psychometric validation of a patient-reported outcome measure for arm lymphedema: the LYMPH-Q upper extremity module. *Ann Surg Oncol* 2021;28:5166–82.
- [13] Wild D, Grove A, Martin M, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. *Value Health* 2005; 8:94–104.
- [14] Scaglioni MF, Fontein DB, Arvanitakis M, Giovanoli P. Systematic review of lymphovenous anastomosis (LVA) for the treatment of lymphedema. *Microsurgery* 2017;37:947–53.
- [15] Beederman M, Garza RM, Agarwal S, Chang DW. Outcomes for physiologic microsurgical treatment of secondary lymphedema involving the extremity. *Ann Surg* 2020;276:e255–63.
- [16] Launois R, Alliot F. Quality of life scale in upper limb lymphoedema—a validation study. *Lymphology* 2000;33:266–74.
- [17] Beelen LM, van Dishoeck A-M, Tsangaris E, et al. Patient-reported outcome measures in lymphedema: a systematic review and COSMIN analysis. *Ann Surg Oncol* 2021;28:1656–68.
- [18] Prinsen CA, Makkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res* 2018;27:1147–57.
- [19] Eberhard DM, Simons Gary F, Fennig Charles D. *Ethnologue: languages of the world*. twenty-fifth ed. Dallas, Texas: SIL International; 2022.