European Journal of Oncology Nursing xxx (2015) 1–7

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Psychometric properties of the Breast Cancer and Lymphedema Symptom Experience Index: The Chinese version

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Keywords:
Breast cancer
Breast neoplasms
Breast cancer survivor
Lymphedema
Symptoms
Symptom distress
Reliability
Validity

A B S T R A C T

Purpose: To translate the Breast Cancer and Lymphedema Symptom Experience Index (BCLE-SEI) into Chinese language and evaluate its psychometric properties among breast cancer survivors with and without lymphedema in China.

Methods: The BCLE-SEI was translated from English to Chinese language using an integrative translation method. The Chinese version was then evaluated for its psychometric properties using a comparison-group and test-retest method. Purposive sampling was used to recruit 219 breast cancer survivors with and without lymphedema in Beijing, China. Cronbach's alpha and test-retest reliability were conducted to assess the reliability; discriminant validity, criterion-related validity and exploratory factor analysis were examined to assess the validity of the instrument.

Results: No semantic modifications to items were needed in terms of comparability of language and similarity of interpretability. Feedback on the pretest of the Chinese version by 15 Chinese breast cancer patients resulted in one item modification. The Chinese version of the instrument demonstrated excellent reliability (Cronbach's alpha = 0.930–0.967) and test-retest reliability (r = 0.572–0.705, $p < 0.001$, $n = 34$). A significant difference was observed between the lymphedema group and non-lymphedema group ($z = -7.127$, $p < 0.001$). The criterion-related validity was supported by negative correlation with the Short-Form Health Survey (physical component summary, $r = -0.612$; mental component summary, $r = -0.540$). Factor analysis for symptom occurrence revealed 5 factors, which explained 66.1% of the total sample variance; 5 factors were also identified in symptom distress, which explained 70.6% of the total sample variance.

Conclusions: The Chinese BCLE-SEI is a reliable and valid instrument to evaluate breast cancer-related lymphedema symptom experience for Chinese breast cancer survivors.

Introduction

Breast cancer is one of the most commonly diagnosed cancers in women in the world as well as in China (Fan et al., 2014; Ferlay et al., 2015). With increased rate and length of survival from breast cancer (Walters et al., 2013), managing late and chronic adverse effects from cancer treatment, such as lymphedema, is imperative to ensure quality of life among women treated for breast cancer. Breast cancer-related lymphedema (hereafter, lymphedema) or accumulation of lymph fluid is one such late and chronic adverse effect from breast cancer treatment (Degnim et al., 2012; Fu et al., 2013a. Lymphedema is a result of obstruction or disruption of the lymphatic system associated with cancer treatment, such as removal of lymph nodes or radiotherapy (Fu, 2014). Patient personal factors also increase the risk of lymphedema, such as obesity or higher body mass index (BMI). Lymphedema negatively impacts breast cancer survivors' quality of life (Fu et al., 2013b; Park et al., 2012), especially physical experience of uncomfortable symptoms related to lymphedema (Degnim et al., 2012; Sierla et al., 2013).

Symptoms related to lymphedema remain the most distressing and debilitating late complications that elicit negative impact on

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http://dx.doi.org/10.1016/j.ejon.2015.05.002
1462-3889/

the breast cancer survivors' quality of life (Degnim et al., 2012; Fu et al., 2013b; Sierla et al., 2013). Such symptoms include swelling, pain, tenderness, soreness, aching, heaviness, tightness, firmness, numbness, fatigue, stiffness, weakness and impaired limb mobility (Armer et al., 2003; Fu et al., 2013a; Fu and Rosedale, 2009).Qualitative research demonstrates that persistent swelling and other symptoms continue to be a daily distress for breast cancer survivors since they are perceived as a constant reminder of cancer as well as creating tremendous limitations on breast cancer survivors' daily living (Fu et al., 2013b; Fu and Rosedale, 2009). Quantitative studies have examined the prevalence or occurrence of symptoms related to lymphedema (Armer et al., 2003; Sierla et al., 2013). No studies have specifically explored lymphedema symptom distress among breast cancer survivors. This may be due to a lack of specific instruments to evaluate breast cancer survivors' distress from lymphedema symptoms.

There are very few reliable and valid instruments that evaluate lymphedema symptoms. *Lymphedema Breast Cancer Questionnaire (LBCQ)* (Armer et al., 2003) is a structured interview or self-report tool to assess lymphedema-related symptoms, including swelling, heaviness, breast swelling, firmness/tightness, numbness, tenderness, aching, stiffness, impaired limb mobility, pocket of fluid formation, and arm weakness. This instrument evaluates patients' symptom occurrence by asking whether a symptom is currently present (today or within the past month) with a response of "yes" or "no". The LBCQ has an acceptable internal consistency using Kuder-Richardson-20 and a high degree of test-retest reliability and validity to discriminate healthy women and women with lymphedema (Armer et al., 2003). However, the LBCQ can only captures categorical data of symptom occurrence and no items cover symptom distress.

With the emerging emphasis on symptom distress as an important patient-centered health outcome, there is an increasing need to assess symptom distress (Fu et al., 2012). Researchers have recently taken efforts to develop the *Breast Cancer and Lymphedema Symptom Experience Index* (*BCLE-SEI*). This involved revising the LBCQ to capture both categorical and ranking data regarding lymphedema symptoms and constructing specific items based on qualitative studies (Fu and Rosedale, 2009). Systematic reviews (Fu et al., 2013b) were also conducted to cover comprehensive aspects of lymphedema symptom distress, such as physical function, occupation, activities of daily living, socialization, leisure activities, mood, self-perception, sleep, and sexuality (Fu et al., 2013b, 2012). The instrument demonstrated high internal consistency reliability with a Cronbach's alpha coefficient of 0.92 (Fu et al., 2013a, 2012). Convergent validity was demonstrated by statistically significant correlations with dimensions of symptom distress ($r = 0.35–0.93$), including functional, emotional & psychological, self-perception, sexual, and sleep (Fu and Rosedale, 2009; Fu et al., 2013a). The BCLE-SEI was able to distinguish breast cancer survivors with and without lymphedema in terms of symptom occurrence and distress ($p < 0.05$) (Fu et al., 2013a, 2012).

As the development of research instruments is both time-consuming and costly, one cost-effective and feasible way is to adapt well-established research-based instruments developed in another country by translating and evaluating the psychometric properties of the translated instrument in the target country (Flaherty et al., 1988). The English BCLE-SEI is an appropriate instrument to be translated into Chinese language for the following reasons: (a) The English version of the BCLE-SEI is a reliable and valid instrument that measures lymphedema symptom occurrence and distress; (b) each item has less than 20 words in English language; (c) it takes about 7–10 min for patients to complete the English BCLE-SEI, and (d) the response frame for reporting symptoms can be customized according to the focus of a study, such as during the past two weeks, last seven days, over the past four weeks, or over the past 3 months.

Purpose of the study

The purpose of this study was to translate the English Breast Cancer and Lymphedema Symptom Experience Index (BCLE-SEI) into Chinese language and test the reliability and validity of the Chinese version of the instrument among breast cancer survivors in China.

Methods

Translation and content validity

We employed a previously successfully-used integrative translation method based on the back translation and cross translation process in which content validity is ensured by the experts' consensus (Fu et al., 2002; Ryu et al., 2013). The method consists of the following steps: (a) 2 bilingual experts translated the original instruments (BCLE-SEI) from English into Chinese language separately, then the Chinese language version was achieved through comparison of the 2 translated versions; (b) 2 bilingual native Chinese-speaking experts translated the Chinese version into English to ensure that the Chinese version had the same implications as the English version; (c) 2 bilingual native Chinese-speaking healthcare experts compared the original English version with the Chinese version to assure that each item had the same implication as the English version and each item was culturally relevant; (d) finally, the 6 experts who were involved in the translation process had to resolve any discrepancies through discussion and revision until an unanimous agreement was achieved on each translated item and a consensus was reached that the Chinese version was consistent semantically with English version.

Research design

A comparison-group and test-retest method was used to evaluate the psychometric properties of the Chinese version of BCLE-SEI.

Ethical consideration and consent process

The study was approved by Peking University Biomedical Ethics Committee. Each participant was informed of their voluntary participation and confidentiality. All the participants in the study signed the informed consent form.

Participants

We used purposive sampling to ensure the recruitment of participants who met the study criteria. The eligibility criteria for participants were: (a) 18 years or older; (b) had a diagnosis of Stage I–III breast cancer; (c) surgery for breast cancer and completed radiation and/or chemotherapy; (d) self-report of no cognitive impairments; (e) able to independently read and make decisions. The exclusion criteria were: (a) the presence of serious mental disorder; (b) the occurrence of tumor metastasis; (c) having non-breast-cancer related lymphedema prior to breast cancer diagnosis. We recruited participants from 2 clinical settings in Beijing: Peking University the First Hospital and Beijing Shijitan Hospital. Thirty-four participants were used to complete test-retest at 1 week interval through convenience sampling.

Please cite this article in press as: Shi, S., et al., Psychometric properties of the Breast Cancer and Lymphedema Symptom Experience Index: The Chinese version, European Journal of Oncology Nursing (2015), http://dx.doi.org/10.1016/j.ejon.2015.05.002