

Evaluation of the Japanese Version of the Cancer Survivors' Unmet Needs Scale

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ABSTRACT

Objective: This study aimed to evaluate the psychometric properties of the Japanese version of the Cancer Survivors' Unmet Needs (CaSUN-J) scale among cancer survivors in Japan.

Methods: The CaSUN-J was developed using standardized translation methodology. Content validity was evaluated by a group of experts, and a pilot test was conducted with a convenience sample of 10 cancer patients. A total of 183 Japanese cancer survivors completed the CaSUN-J. The internal consistency of the scale was examined with Cronbach's α . Construct validity was analyzed using correlations with the physical effects, quality of life (QoL), and age. To assess the factorial validity of the CaSUN-J, confirmatory factor analysis (CFA) was performed. **Results:** The CaSUN-J

indicated good readability and high content validity for use as an assessment tool among Japanese cancer survivors. All Cronbach's α coefficients were above the minimum acceptable criterion of ≥ 0.70 . For construct validity, higher physical effect scores, as well as poorer QoL scores and younger patients, were significantly positively associated with higher levels of needs. CFA indicated that the five-factor structure of the CaSUN-J was a good fit to the data. **Conclusions:** The CaSUN-J can serve as a valid and reliable tool to evaluate unmet needs among Japanese cancer survivors.

Key words: Cancer survivors, Japanese, psychometric validation, supportive care, unmet needs

Introduction

Cancer incidence is increasing globally.^[1] Since early detection and treatment have advanced and the aging population continues to grow, the number of cancer survivors is also increasing.^[2] In Japan, the number

of newly-diagnosed cancer patients has increased 2.5 times since 1985,^[3] whereas the 5-year survival rate of cancer patients was 62.1% in 2006–2008, indicating a 7.8% increase from 1997 to 1999.^[4,5]

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The increase in cancer survivors has allowed the issues they face to come to the fore. Cancer survivors experience both short- and long-term physical and psychosocial issues.^[6-8] In fact, they have worse mental and physical health-related quality of life (QoL) than population norms.^[9] The majority of cancer survivors have one or more unmet needs, and unmet needs are significantly related to psychological morbidity and impaired QoL.^[10] In response to these issues, the Institute of Medicine recommended survivorship care plans in 2006.^[11] First, an understanding of supportive care needs from a patient's perspective is essential for the development of patient-centered supportive services.^[12] They have a wide range of supportive care needs, from coping with the physical effects of cancer and its treatment to psychological and psychosocial sequelae, including anxiety, depression, and feelings of isolation.^[13]

The Cancer Survivors' Unmet Needs Measure (CaSUN) is a self-report questionnaire specifically developed to assess the supportive care needs of cancer survivors^[14] that comprises five domains (existential survivorship, comprehensive cancer care, information, QoL, and relations). Insight into these unmet needs may assist in the development of tailored interventions.^[15] The CaSUN has been translated into Dutch, Spanish, and Chinese and has proved to be a valid and reliable assessment tool.^[15-17] Despite being applied to only breast cancer survivors, the validity of the Taiwanese Chinese version was also studied by Fang *et al.*^[18]

In Japan, only a few studies have examined the unmet needs of cancer survivors.^[19,20] All these studies used original scales to measure the unmet needs of cancer survivors; however, the validity and reliability of these scales were not studied. Thus, the growing population of cancer survivors in Japan requires a validated needs assessment tool. This study aimed to evaluate the psychometric properties of the Japanese version of the CaSUN (CaSUN-J) in cancer survivors in Japan.

Methods

This study has two phases. First, the CaSUN was translated from English into Japanese and tested for its content validity. Second, the psychometric properties of CaSUN-J, including internal consistency, construct validity, and criterion-related validity were assessed.

Phase I: Translation and content validity

The translation complied with the World Health Organization guidelines on the process of translation and adaptation of instruments.^[21] One professional translator independently translated the original scale from English into Japanese. The first Japanese version was checked by a bilingual physician. Back translation was carried out by

another professional translator. A panel of seven experts (six nursing researchers and one physician) was convened to identify and resolve discrepancies between the original scale and translated version.

We conducted a pilot test with a convenience sample of 10 cancer patients to evaluate the readability and clarity of CaSUN-J. Each patient was asked if there was anything that was unclear. The scale was then modified in accordance with their recommendations.

Phase II: Psychometric testing of Japanese version of the Cancer Survivors' Unmet Needs

Participants and procedures

The study sample was drawn from a large multinational study of unmet supportive care needs among cancer survivors.^[22] We approached outpatients at oncology departments in three hospitals and the participants of two patient advocacy groups. The outline of the study was briefly explained to the candidates by the attending physician at the outpatient department. The investigator fully explained the study to those who were interested in it. After obtaining written informed consent from the patients, the investigator asked them to complete the questionnaire. For recruitment of candidates in the patient advocacy groups, the investigator explained the outline of the study to patients who attended the patient advocacy meeting and asked those who were eligible and who agreed to participate in the study to complete the questionnaire. We included cancer patients who were 18 years or older; had completed first-line treatment; were not cognitively impaired, and were able to speak and read Japanese. Based on the recommended minimum sample size for confirmatory factor analysis (CFA),^[23] we surveyed 183 patients, 5 for each item.

Measures

We collected demographic and clinical data, including age, gender, primary diagnosis, and completed treatment, using a self-administered questionnaire.

Japanese version of the Cancer Survivors' Unmet Needs

The CaSUN-J contains 35 unmet need items, 6 positive change items, and an open-ended question. Participants were asked to indicate whether the need was met or unmet. The self-perceived strength of the unmet need was marked as weak, moderate, or strong. The total score was the sum of all need items, with higher scores indicating greater unmet needs.

The physical effects subscale of the Cancer Survivors' Survey of Needs and a measure of overall quality of life

The physical effects subscale of the Cancer Survivors' Survey of Needs by the Mayo Clinic Cancer Center

comprises of a total of 50 questions covering five domains, including physical, emotional, social, spiritual, and other domains.^[24,25] The physical subscale has 19 items scored on a 6-point scale from 0 = no concerns to 5 = extreme concerns on which patients rate their concerns with regard to their physical symptoms (e.g., pain, fatigue, and insomnia) on the day of the survey.

The QoL measure is a single-item linear analog scale to rate QoL during the past week, including the day of the survey, ranging from 0 = as bad as it can be to 10 = as good as it can be. Higher scores thus indicate a higher QoL.

Ethical approval

Ethical approval of the study was obtained from the Institutional Review Boards of the Faculty of Nursing and Medical Care, Keio University (No. 239), Keio University School of Medicine (No. 20150219), and Osaka University Hospital (No. 15161). Eligible patients were approached by physicians or nurses at their regular medical appointments or by the study researcher at patient advocacy group meetings. After explaining the overview of the study, we obtained written informed consent from all the participants.

Data collection

We collected data from eligible patients in oncology outpatient departments at one university hospital and two general hospitals, as well as two patient advocacy group meetings from October 2015 to January 2016. The hospital patients completed the questionnaires and returned them to the researcher in the outpatient consulting room. Similarly, the patients at the patient advocacy group meetings returned the questionnaires to the researcher as soon as they were completed. All the returned questionnaires were immediately checked by the researcher.

Statistical analysis

Statistical analyses were performed using the SAS version 9.4 (SAS Institute, Cary, NC, USA) and LISREL 8.8 (Scientific Software International, Inc.). All comparisons were planned, and the tests were two-sided. Statistical significance was defined as $P < 0.05$. Demographic and disease-related characteristics of the participants were analyzed using descriptive statistics.

A panel of seven experts (six nursing researchers and one physician) described the appropriateness and bias of the contents of the translated version. Based on these free descriptions, a debriefing was held with several panel experts to determine by consensus the proper expressions to be used on the questionnaire. Subsequently, we conducted a pilot test with a convenience sample of ten cancer patients to evaluate the readability and clarity of CaSUN-J. The researchers in this study examined the face validity of the

CaSUN-J based on the descriptions concerning unclarity of the words and sentences in questions and response options and reached a consensus.

The reliability of the CaSUN-J was assessed by testing its internal consistency. The internal consistency was measured using Cronbach's α coefficient for the total scale and each subscale, where a value of Cronbach's $\alpha > 0.70$ was deemed acceptable.^[26] Construct validity of the CaSUN-J was assessed by the hypothesis approach. It was anticipated that higher levels of unmet needs would be positively associated with greater physical effects and poorer QoL and would have a weak significant negative correlation with age. To test these approaches, Pearson's correlation coefficients were analyzed to determine the associations of the CaSUN-J with physical effects, QoL, and age.

CFA was performed using LISREL 8.8 software to more precisely test the configuration of the factor structures of the Japanese version of the CaSUN and determine whether the proposed factor structures adequately fit the data. We used multiple fit indices to evaluate model-data fit, including the Chi-squared statistic [relative χ^2 (χ^2/df)] < 3.0 , standardized root mean square residual (SRMR) values < 0.08 , and comparative fit indices (CFI) values > 0.90 .^[27,28]

Results

Phase I: Translation and content validity

Content validity

The CaSUN-J was generally easy to understand and reflected accurately the unmet supportive care needs of cancer survivors in the context of health care in Japan. There was a comment that only one item was a bit difficult to understand: "I need help to explore my spiritual belief..." (Item 34). The panel decided to conduct a pilot test with a sample of Japanese cancer survivors without changing the expression, and subsequently discussed it again in view of the results. We conducted a pilot test with a sample of ten Japanese cancer survivors. The overall acceptability and comprehensibility were found to be good, and no item was excluded. No participants mentioned that the expression in Item 34 was difficult to understand, and therefore retained it unchanged. In the item on fertility (Item 13), however, the term "fertility" was indicated as difficult to understand, and therefore, it was supplemented with an explanation: "fertility (the ability to conceive children)."

The CaSUN-J indicated good readability for use as an assessment instrument among Japanese cancer survivors. On an average, it took approximately 15 min to complete the CaSUN-J. Furthermore, feedback and comments from respondents indicate a perceived need for the CaSUN-J as

a tool to assess the needs of Japanese cancer survivors. The cancer survivors who participated in the pilot test commented that the items in the CaSUN-J are important and valuable: “Cancer survivors are increasing, and they may have diverse problems. I am sure that this study will give them a certain sense of fulfillment.” “This (unmet needs) survey represents my conditions well,” “(The unmet needs are) not only applicable to me. Other people also feel the same way.” In addition, the cancer survivors desperately want healthcare providers to understand these unmet needs: “In my mind, I know how to live from now on, but I cannot keep up mentally and physically. I encourage myself with feelings that other people never understand.”

Phase II: Psychometric testing of Japanese version of the Cancer Survivors’ Unmet Needs

Participant characteristics

In total, 183 patients participated in the study. Of these, 168 submitted completed questionnaires (91.8%). Demographic and disease-related characteristics of the participants are shown in Table 1. The mean age of the participants was 61.4 (standard deviation [SD] = 11.5); the majority were female (66.7%) and almost half of the participants were diagnosed with breast cancer (47.7%). The mean total score of the CaSUN was 0.9 (SD = 0.8). The mean scores for the physical effects and the QoL were 1.2 (SD = 0.8) and 6.8 (SD = 2.0), respectively.

Construct validity

Table 2 shows the correlations between the CaSUN-J total scores and the psychological variables. Higher physical effects scores, as well as poorer QoL scores and lower patient ages, were significantly positively associated with higher levels of need.

Figure 1 shows the results of the CFA. Standardized factor loadings ranged from 0.45-0.93 and error variances from 0.23 to 0.89. On the whole, the model indicated a good fit to the data with $\chi^2/df = 1.62$, CFI = 0.94, SRMR = 0.074 and RMSEA = 0.116 (90% confidence interval 0.107–0.124).

Internal consistency

Cronbach’s α for the total CaSUN was 0.96, and 0.96, 0.84, 0.87, 0.80, and 0.78, respectively, for the subscales of existential survivorship, comprehensive cancer care, information, QoL, and relationship domains. All Cronbach’s α coefficients were above the minimum acceptable criterion of ≥ 0.7 .

Discussion

The CaSUN-J indicated good feasibility for use as an assessment tool among Japanese cancer survivors with high

Table 1: Demographic and disease-related characteristics (n = 168)

Characteristics	n (%)
Age, mean (SD)	61.4 (11.5)
Female	112 (66.7)
Type of primary cancer	
Breast cancer	80 (47.6)
Upper gastroenterological cancer	22 (13.1)
Prostate cancer	17 (10.1)
Colon cancer	15 (8.9)
Malignant lymphoma	10 (6.0)
Gynecology cancer	9 (5.4)
Lung cancer	8 (4.8)
Other types of cancer	6 (3.6)
Unknown	1 (0.6)
CaSUN-J total, mean (SD)	31.6 (26.8)
Physical effects total, mean (SD)	23.1 (15.9)
QoL, mean (SD)	6.8 (2.0)

SD: Standard deviation, QoL: Quality of life, CaSUN-J: Japanese version of the Cancer Survivors’ Unmet Needs

Table 2: Correlations between scores on the Japanese version of the Cancer Survivors’ Unmet Needs and the physical effects scores, the quality of life scores, and selected demographic variables

Variable	Total score of CaSUN-J (n = 143)	P
Age	−0.192*	0.023
QoL	−0.241**	0.004
Physical effects	0.508**	0.000

* $P \leq 0.05$, ** $P \leq 0.01$. Pearson correlation coefficient: Age, QoL, physical effects. QoL: Quality of life, CaSUN-J: Japanese version of the Cancer Survivors’ Unmet Needs

acceptability and comprehensibility. Since the translation of the CaSUN-J complied with the World Health Organization guidelines on the process of translation and adaptation of instruments^[21] to ensure conceptual equivalence to the original CaSUN, it was easy to answer the questions within a short time. The items on the CaSUN-J were important and valuable for Japanese cancer survivors, as shown in the participants’ comments.

Reliability was indicated by the fact that Cronbach’s α coefficients for the total scale and subscales of the CaSUN-J were all > 0.70 , suggesting high internal consistency. These values were equivalent to those of the original CaSUN version by Hodgkinson *et al.* and the Spanish,^[16] Dutch,^[15] and Chinese versions.^[17] The high internal consistency of CaSUN in different language contexts, including this study, constitutes evidence of its strong reliability.

The hypotheses related to construct validity were supported. Unmet needs were significantly correlated with physical effects, QoL, and age. The relationship between higher levels of unmet needs and poorer QoL was reported in previous studies in other language versions of the CaSUN,^[15,16] whereas that between unmet needs and physical effects was not studied. Our qualitative studies

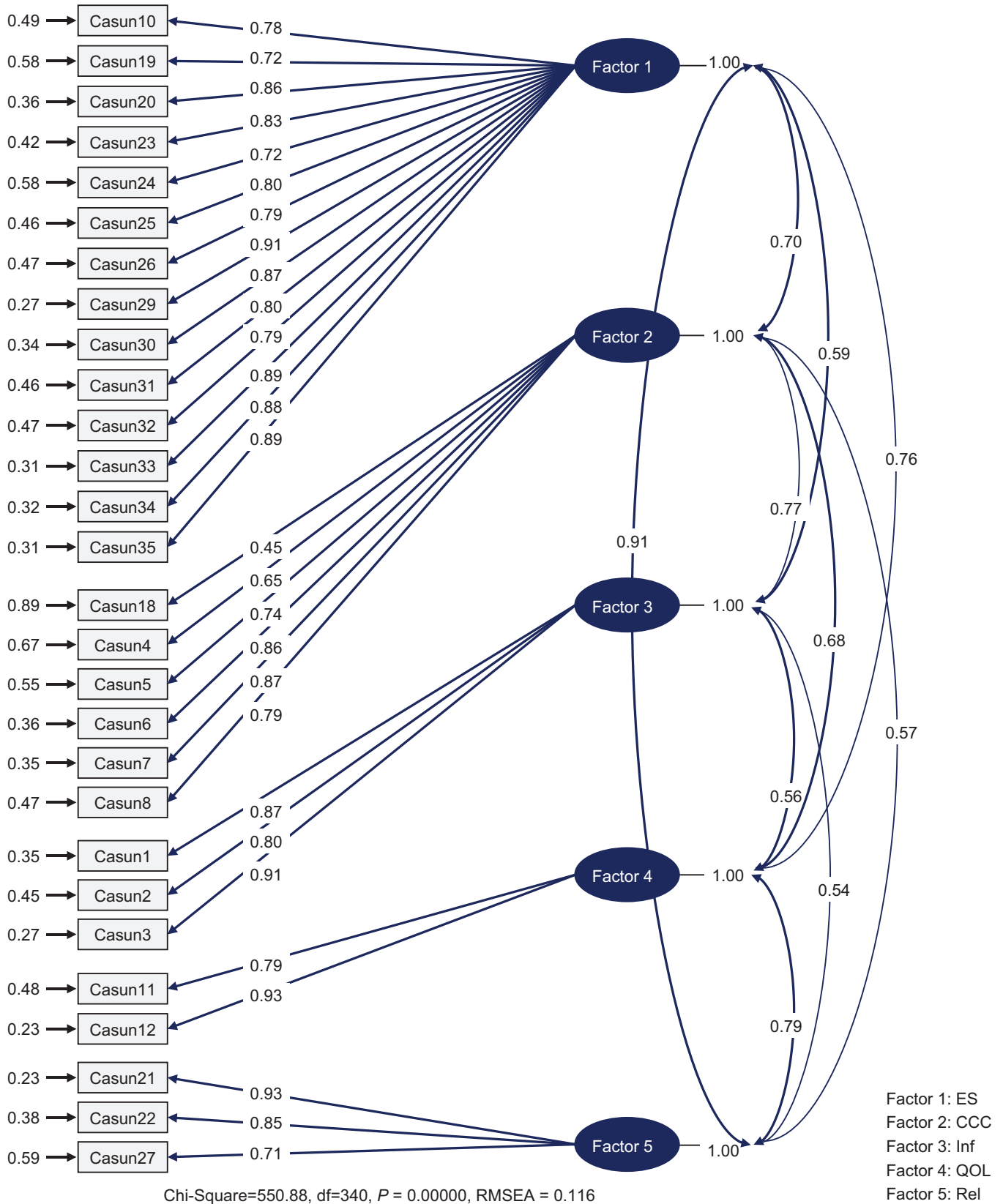


Figure 1: Confirmatory factor analysis of CaSUN-J. ES: Existential survivorship, CCC: Comprehensive cancer care, Inf: Information, QoL: Quality of life, Rel: Relationships, CaSUN-J: Traditional Japanese version of Cancer Survivors' Unmet Need Scale

revealed that cancer survivors suffer from serious physical effects, including hand-foot syndrome and skin toxicities, and have unmet needs related to physical effects.^[29,30] Molassiotis *et al.*^[22] also reported that a high strength of needs was significantly related to higher symptom experience for all physical symptoms in a study of unmet needs among Asian cancer survivors. These studies have provided strong support for the construct validity of the CaSUN-J.

Furthermore, the results of the CFA support the structure of the CaSUN-J as reasonable and congruent with the original English version. Although the five-factor model was confirmed, Item 18 (accessible hospital parking) had the lowest factor loading (0.45) and the largest residual error (0.89). A similar result was obtained for the Chinese version of the CaSUN.^[17] As Xing *et al.*^[17] pointed out, the public transport system is also well developed in Japan, and patients do not always have to drive to the hospital. The item of “accessible hospital parking” may need to be reconsidered in future studies.

Limitations

There are several methodological limitations of this study. First, because this was a cross-sectional designed study, test–retest reliability and criteria validity were not examined. Second, although the CFA supported the original model of the scale, we should be cautious of the fact that their certain items had low factor loadings and large residual errors.

Conclusion

This study confirmed that CaSUN-J can serve as a valid and reliable tool to evaluate unmet needs among Japanese cancer survivors. CaSUN-J has the potential to identify the most beneficial interventions for individual cancer survivors.

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Conflicts of interest

There are no conflicts of interest.

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