

Development, validity, and reliability of the Japanese version of the Cancer Needs Questionnaire - Young People (CNQ-YP-J)

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Abstract

Background: Adolescent and young adult (AYA) cancer patients experience complex physical and psychosocial development and diverse lifestyle changes. Therefore, each may have generation-specific needs. This study aimed to develop the Japanese version of the Cancer Needs Questionnaire – Young People (CNQ-YP-J) and verify its reliability and validity among AYA cancer patients in Japan. Methods: The CNQ-YP-J was developed using a standardized translation methodology. Content validity was assessed by a group of experts, and a pilot test was conducted on six AYA cancer patients. About 87 Japanese patients with AYA cancer participated in this study. After exploratory factor analysis was conducted, the scale's reliability was examined using Cronbach's α , item-total correlations, and intraclass correlation coefficient (ICC) of the retest. Criterion-related validity was analyzed using correlations between total needs and concerns about physical effects and quality of life (QOL). Results: Factor analysis showed an eight-factor structure, different from the original scale, with one item excluded, resulting in a 69-item scale. Cronbach's α coefficient and ICC were above the minimum acceptable criterion of 0.70, demonstrating high reliability. Concerning criterion-related validity, high needs were positively correlated with high concerns about physical effects and tended to be negatively correlated with QOL. Conclusion: The CNQ-YP-J is a reliable and valid scale to comprehensively assess the needs of AYA cancer patients in Japan.

Introduction

Adolescent and young adults (AYA) refer to people aged 15 to 39 years.¹ In Japan, approximately 20,000 AYAs are diagnosed with cancer each year, which is approximately 2% of all generations.² Cancer types in AYAs include both childhood and adult cancers, and are often diverse and rare.²

Since the last five years, “AYA” has begun to be recognized in Japan, and the “Third Basic Plan for the Promotion of Cancer Control” formulated in 2018 incorporates “Enhancement of cancer treatment for AYA” as a priority issue.³ However, since the number of AYA cancer patients is smaller than that of other generations, there are difficulties such as lack of experience in medical care and consultation support, and few experienced specialists.⁴

AYA cancer patients may also face several generation-specific challenges. They experience complex physical and psychosocial development and diverse lifestyle changes, including further education, employment, marriage, and childbirth.² As a result, each of them has specific needs,⁵ which are reported to change over time with age and lifestyle.⁶ Therefore, it is essential to understand their needs in the treatment environment and daily lives over time to provide them with age-appropriate care. Additionally, unmet needs of AYA cancer

patients are associated with a worse quality of life (QOL).^{7,8} Therefore, we hope that by identifying AYA cancer patients' needs and leading them to individual care, their QOL would be maintained and improved.

Although many studies have qualitatively examined the needs of people with cancer, we believe that a quantitative scale is a useful tool for measuring the needs of a larger number of cancer patients and for examining any changes in needs over time. There are scales assessing cancer survivors' needs in Japanese;^{9,10} however, these scales cover ages over 18 years and may overlook the AYA cancer patients' unique needs. "The Cancer Needs Questionnaire – Young People (CNQ-YP)"¹¹ is used overseas to measure the needs of young cancer patients. However, to date, there is no similar scale in Japan. The CNQ-YP was developed and verified by Tara et al. at the University of Newcastle, Australia.¹¹ This is a multidimensional, patient-reported scale designed to measure the perceived unmet needs of AYA cancer patients and survivors. The CNQ-YP consists of six factors and 70 items: treatment environment and care, education, work, information and activities, feelings and relationships, daily life. The scale showed a strong factor structure, excellent internal consistency, and test-retest reliability.^{11,12}

The development and use of the Japanese version of the CNQ-YP (CNQ-YP-J) are expected to enable us to understand the diverse needs of AYA cancer patients in Japan, which have not been measured quantitatively so far, and assist in the development of optimal medical care and support systems and the provision of information. This study aims to develop the CNQ-YP-J and verify its reliability and validity.

Materials and Methods

This study consisted of two phases. First, we developed the CNQ-YP-J and verified its face and content validity. Second, we assessed the reliability and validity, including criterion-related validity, internal consistency, and stability.

Phase I: Translation and content validity

The development of the CNQ-YP-J was performed according to the Functional Assessment of Chronic Illness Therapy translation methodology¹³ after obtaining translation permission from the original authors. Two Japanese medical professional researchers (YS and MO) performed the forward translation from English to Japanese, and two other medical professional researchers (MM and AT) prepared the integrated Japanese version. It was then reviewed by an AYA bone marrow transplant survivor who had studied in Australia and was fluent in English to ensure readability and clarity, and a draft of the Japanese version was prepared. Two researchers (PT: a native English speaker fluent in Japanese and YM: a bilingual medical professional researcher with experience in translating scales), who had not seen the original scale, each performed a back-translation from Japanese to English and then worked with other authors to produce a back-translated integrated version. Based on this, the original authors reviewed the discrepancies with the original scale, and 11 medical experts (three doctors, one nurse, two physical therapists, and five occupational therapists) identified and corrected the discrepancies between the original and Japanese versions. Back-translation, review by the original authors, and expert discussions were repeated until the content's consistency with the original scale was ensured. The completion of the translation process led to the creation of the CNQ-YP-J.

We conducted a pilot test with a convenience sample of six AYA cancer patients to evaluate the readability and clarity of the CNQ-YP-J. We asked each participant if there were any unclear points, and the measure was modified based on their opinions. Through the above process, we verified the face and content validity of the CNQ-YP-J.

Phase II: Survey of the CNQ-YP-J in AYA cancer patients

Participants and procedures

AYAs were eligible to participate in this survey if they: 1) had received treatment for cancer, 2) had been diagnosed with cancer in the last five years, 3) were aged 15 to 39 inclusive at the time of diagnosis, 4) were physically and mentally able to complete a survey, 5) were able to speak and read Japanese. There were two reasons for setting the participant criteria within five years of diagnosis. One because the participants

were considered to still be affected by diagnosis and treatment, and the other to minimize recall bias. The participant criteria were based on the original article.¹¹ The target age of the CNQ-YP-J is between 15 and 45 years (diagnosed between 15 to 39 years and within 5 years of diagnosis), the same as the participant criteria of this study.

This survey was conducted using Survey Monkey (San Mateo, California, USA). Survey Monkey is an online survey platform and is widely used as a patient-reported outcome in academic research (Pubmed search has over 400 articles from 2006 to 2022). We recruited participants between April 20 and September 30, 2021, through the outpatient clinics of the Department of Hematology, Breast Surgery, and Pediatrics at Kyoto University Hospital and social networking service (SNS) via patient groups to which AYA cancer patients belonged or a non-profit organization.

The flyer for recruiting survey participants was distributed through the above-mentioned organizations and those who were interested in this survey registered in the e-mail address registration form. The email address registration form included a PDF of the study description and the question, “Are you between 15 to 39 years old, diagnosed with cancer, and within five years of diagnosis (have you been treated)?”. Only those who answered ‘yes’ to the above were allowed to proceed to the next page and were asked to provide their email address. In this way, by following the double steps from the leaflet to the email address registration form, only patients who met the criteria were able to answer the questionnaire.

After that, the researcher sent the URL to access the online questionnaire, so that only participants who met the participation requirements could complete the questionnaire. At the beginning of the questionnaire, in addition to the study description (PDF), the researcher stated that the submission of the questionnaire constituted consent to the study. Participants who were given permission were retested a week later. The time frame of a week was set to minimize the possibility of significant changes in the patients’ needs or recall of previous answers.¹⁴ This study was approved by the Ethics Committee of Kyoto University Graduate School and Faculty of Medicine (No. R2794-2).

Measures

We collected demographic and clinical data, including age, sex, employment status, age at diagnosis, years since diagnosis, type of cancer, and type of treatment, using a self-administered online questionnaire. In addition to the CNQ-YP-J, their concerns about physical effects and QOL were inquired. In the retest conducted a week later, only the CNQ-YP-J was administered. The CNQ-YP-J before the factor analysis consisted of six factors and 70 items as the original CNQ-YP. “Factor 2: Education,” “factor 3: Work,” and part of “factor 5: Feelings and Relationships” are screening items, which limits the number of respondents. Factor 5 and 6 ask about the needs in the past month. This scale takes approximately 10 minutes to complete. Each need item is rated on a 5-point scale (1 = no need; 5 = very high need), with higher scores indicating greater needs.

To assess concerns about physical effects, we used the physical effects factor of “The Cancer Survivors’ Survey of Needs by the Mayo Clinic Cancer Center.”^{15,16} On this factor, the patients rate their concerns about their physical symptoms (e.g., pain, fatigue, and sleep disturbance) on the day of the survey. This is rated on a 6-point scale (0 = no worries; 5 = very worrisome), with higher scores indicating more severe physical concerns. Concerning the QOL, the subjective QOL on the day of the survey was assessed using a single-item linear analog scale. Survey Monkey prepared a line with 0(poor) at the left end and 10(good) at the right end, and the participants were asked to mark the appropriate position on the straight line. Higher scores indicated a higher QOL.

Statistical analysis

Exploratory factor analysis was conducted using the maximum likelihood method and Promax rotation, and the factor structure was determined by deleting an item. Following the original article, the conditions for deleting items were determined as follows: items that were answered “very high need” or “high need” by less than 20% of the respondents and that had significant correlations with other items in the Spearman’s

correlation analysis could be deleted.¹¹ The suitability of the data for factor analysis was examined using the Kaiser–Mayer–Olkin (KMO) (adequacy standards > 0.80)¹⁷ and Bartlett’s test. The inter-factor correlation matrix was referred to for the association between each factor.

The reliability of the CNQ-YP-J was assessed using the following method: based on the factor structure established by factor analysis, internal consistency was measured using Cronbach’s α coefficients for the overall and each factor, and a value of Cronbach’s $\alpha > 0.70$ was considered acceptable.¹⁸ Additionally, the item-total (IT) correlation analysis was conducted to examine the correlation between each item and the total scale score. In general, if the correlation coefficient is lower than 0.11, the item must be retranslated or modified.¹⁹ Stability was verified using the retest method by examining the intraclass correlation coefficient (ICC); reliability was assured if the ICC was above 0.7.

For validity verification, criterion-related validity was assessed based on hypotheses, in addition to factor validity by factor analysis. Previous studies have shown that among AYA cancer patients, higher unmet needs are significantly associated with higher concerns about physical effects^{9,20} and with lower QOL^{8,9}. Therefore, we hypothesized that unmet needs would be positively correlated with concerns about physical effects and negatively correlated with QOL, and we used Spearman’s correlation analysis to examine the associations.

For validity verification, it is common practice to use a scale that is considered the gold standard. However, no similar Japanese scale has been to measure the needs of AYA cancer patients. Therefore, validation was conducted by measuring concerns about physical effects^{9,20} and QOL^{8,9}, which have been shown to correlate with the needs of cancer patients in previous studies. A similar approach was used in a previous article¹⁰ that developed a Japanese version of a needs scale for cancer patients of all ages. Data were analyzed using IBM SPSS Statistics version 28 (IBM, Armonk, NY, USA). All tests were two-tailed with $p < 0.05$.

Results

Participant characteristics

Eighty-seven participants completed this survey (completion rate 87.3%). Twenty-three (26.4%) participants were male and 64 (73.6%) were female, with a mean age of 33.1 ± 5.7 years (Table 1). Forty-three (49.4%) patients had breast and gynecologic cancer, followed by 37 (42.5%) with blood cancer.

Exploratory factor analysis

Exploratory factor analysis was conducted on 60 items, excluding 10 screening items. The number of factors was determined by eigenvalues and scree plots. Factor analysis was repeated using a factor loading of $0.35 <$ as the criterion, finally ending with a five-factor structure, excluding one item with a low factor loading. As a result of the exploratory factor analysis, item 70 (Support for managing: going out for social events) was deleted. This was based on the conditions for deleting the items.¹¹ The distribution of responses on item 70 showed that a total of 6% of the respondents answered “very high need” and “high need.” Additionally, items 70 and 69 (Support to manage: taking part in social activities) showed a significant correlation ($\rho = 0.72$, $p < 0.01$), which led to the deletion of item 70 since it could be substituted by item 69.

The cumulative contribution rates of the five factors were 67.7% and the inter-factor correlations ranged from 0.27 to 0.52 (Table2). The KMO indicator was 0.84, and Bartlett’s test was $p < 0.0001$, indicating high appropriateness and goodness of fit in the factor analysis, and justification of sample size.

The results of the factor analysis established five factors. Factor 1 was named “Treatment Environment” because it included items about the effectiveness of the treatment and the response of the medical staff. Factor 2 was named “Feelings and Lifestyle” because it included items about changes in feelings and independent living. Factor 3 was about managing medication and taking part in social activities, and thus was named “Coping with Symptoms and Activities.” Factor 4 was named “Interacting with Peers” because it included items about spending time with and talking to people of the same age. Factor 5 was named “Coping with Feelings” because it included talking about personal things and ways to relax. Eventually, the CNQ-YP-J

consisted of 69 items and eight factors, including the three screening factors (“Education,” “Work,” and “Relationships with Close People”) that had been left out during the factor analysis. The original scale showed a six-factor structure, but the Japanese version showed an eight-factor structure, indicating a shift in structure. Changes to the factor structure and deletion of items were made with the permission of the original authors.

Reliability

Cronbach’s α , indicating the internal consistency, was 0.92 for the whole scale and ranged 0.74-0.98 for each factor (Table 3). The IT correlation coefficients ranged 0.42-0.88 for all factors. The ICC, indicating the stability, was 0.89 for the whole scale and ranged 0.72-0.89 for each factor (Table 4).

Criterion-related validity

Concerns about physical effects were positively correlated with needs ($\rho = 0.99, p < 0.01$) and QOL tended to be negatively correlated with needs ($\rho = -0.19, p = 0.08$) (Table 5).

Discussion

In this study, we developed the CNQ-YP-J as a scale to measure the needs of young patients with cancer and verify its reliability and validity. The scale consisted of 69 items and eight factors, including “Treatment Environment,” “Feelings and Lifestyle,” “Coping with Symptoms and Activities,” “Interacting with Peers,” “Coping with Feelings,” “Education,” “Work,” and “Relationships with Close People,” were established and showed sufficient reliability and validity.

In the factor analysis, the three items in factor 4 “Information and Activities” of the original scale became an independent factor “Interaction with peers” in the CNQ-YP-J. The independence of the factors may indicate the high importance of peer support, i.e., support amongst those who have experienced cancer.² This is supported by the fact that 47% of the respondents answered “very high need” and “high need” to item 41 (Being able to talk to people my age who had been through a similar experience), indicating the highest need out of all 69 items. We think that the reason for the independence of factor was that AYA cancer patients are often treated and hospitalized across adult and pediatric wards and therefore have fewer opportunities to meet their peers in the treatment environment, and that support system such as cancer patients’ groups are inadequate compared to other countries.⁴

Furthermore, the two items in factor 1 “Treatment Environment and Care” and one item in factor 1 “Treatment Environment and Care” of the original scale became an independent factor “Coping with Feelings” in the CNQ-YP-J. The independence of this factor may indicate that “talking” is an important way for AYA cancer patients to cope with their situation. Previous studies have shown that communication with others, expressing their feelings,^{21,22} and counseling²³ are very important for them. Diagnosing cancer at such a young age and being separated from their peers can lead to feelings of isolation and loneliness.²⁴ Therefore, it is very important for them to have an environment in which they feel safe to express themselves.

Regarding the Cronbach’s α and the IT correlation coefficient, which indicates the internal consistency, the Cronbach’s α exceeded 0.70¹⁸ for both the overall scale and each factor, and the IT correlation coefficient exceeded 0.11¹⁹ for all factors. In addition, the ICC, which indicates stability, exceeded 0.7 for both the overall scale and each factor, indicating high reliability of the CNQ-YP-J.

Furthermore, we examined the relationship between needs and concerns about physical effects and QOL, and found that high need was significantly positively correlated with concerns about physical effects and tended to be negatively correlated with QOL. These results were similar to previous studies: among AYA cancer survivors, the higher the need, the higher the concern for physical consequences,^{9,20} and the lower the quality of life,^{7,8} indicating criterion-related validity of CNQ-YP-J.

By utilizing this scale, we hope that the diverse needs of AYA cancer patients will be identified and lead to future improvements in providing support and a treatment environment. we also hope that not only

the medical staff but also many people will understand the mental and physical condition of AYA cancer patients, and the environment surrounding them will improve.

This study has several limitations. First, the sample size was small. Previous studies have stated that factor analysis should have at least five times as many participants as items in the scale,²⁵ but in this study, only a 1:1 item-participants ratio was achieved. Second, the demographic and clinical characteristics of the participants were highly biased. The number of participants aged 15–24 years was small (11.5% of the total), as was the proportion of males and cancers out of the breast, gynecologic cancer, and blood cancer. Further studies should include patients with a wider range of characteristics.

Conclusion

The CNQ-YP-J, developed in this study, is a reliable and valid scale that comprehensively assesses the needs of AYA cancer patients, from their treatment environment to daily lives. By utilizing this scale in various settings, including clinical practice, we hope that the development of optimal medical care and support systems and the provision of information in the future.

Conflict of Interest Statement

The authors declare no conflicts of interest associated with this manuscript.

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