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Japanese version of the cancer needs questionnaire–young people (CNQ-YP-J): translation and preliminary validation

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Abstract

Background Adolescent and young adult (AYA) patients with cancer experience complex physical and psychosocial development as well as diverse lifestyle changes. Therefore, each patient may have generation-specific needs. This study aimed to develop a Japanese version of the Cancer Needs Questionnaire–Young People (CNQ-YP), namely the CNQ-YP-J, and to verify its reliability and validity among Japanese AYA patients with cancer.

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 with six AYA cancer patients. A total of 87 AYA patients with cancer participated in this study. After exploratory factor analysis, the scale's reliability was examined using Cronbach's α, item-total correlations, and the intraclass correlation coefficient (ICC) of the retest. Criterion-related validity was analysed using correlations between total needs, concerns about physical effects, and quality of life (QOL).

Results The factor analysis revealed 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 negatively correlated with QOL.

Conclusions The CNQ-YP-J developed in this study is a reliable and potentially valid scale that comprehensively assesses the needs of AYA cancer patients in the treatment environment as well as their daily lives. We hope that the use of this scale as a measure of the needs of AYA cancer patients in various settings, including clinical practice, will lead to the provision of optimal medical care and development of support systems, as well as the promotion of information.

Keywords Patient-reported outcomes, Adolescents and young adults, Cancer, Unmet needs, Scale development, Supportive care, Japanese

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Background

Adolescents and young adults (AYAs) can be classified as people aged 15–39 years [1]. In Japan, approximately 20,000 AYAs are diagnosed with cancer annually, accounting for around 2% of all generations [2]. Types of cancer found in AYAs include both childhood and adult cancers and are often diverse and rare [2].

In the last five years, the 'AYA' group has started to gain recognition in Japan, and the 'Third Basic Plan for the Promotion of Cancer Control', formulated in 2018, incorporates 'Enhancement of cancer treatment for AYAs' as a priority issue [3]. However, as the number of AYA cancer patients is smaller than that of other generations, there exist 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 as well as 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 these needs in the treatment environment and throughout daily life over time to provide these patients with age-appropriate care. Additionally, the unmet needs of AYA cancer patients are associated with a worse quality of life (QOL) [7, 8]. Therefore, we hope that by identifying the needs of AYA cancer patients and providing them with individual care, their QOL can be maintained and improved.

Although many studies have qualitatively examined the needs of patients with cancer, we believe that a quantitative scale is a useful tool for measuring the needs of a larger number of patients and examining any changes in their needs over time. While there are existing scales for assessing cancer survivors' needs in Japan [9, 10], they only cover individuals over the age of 18, and may overlook the unique needs of AYA patients. The Cancer Needs Questionnaire–Young People (CNQ-YP) [11] is used overseas to measure the needs of young patients with cancer. However, to date, no similar scale has been developed in Japan. The CNQ-YP was developed and verified by Clinton-McHarg et al. at the University of Newcastle, Australia [11]. It 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, and daily life. The scale has a strong factor structure, excellent internal consistency, and test-retest reliability [11, 12].

This study aimed to develop the Japanese version of the CNQ-YP (titled, the CNQ-YP-J) and verify its reliability and validity. The present work is the first step toward identifying and addressing the current unmet needs of AYA cancer patients in Japan. The development and use of the 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 thus far; these steps will also allow us to assist in the development of optimal medical care and support systems, as well as the provision of information.

Methods

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

Phase I: translation and content validity

The CNQ-YP-J was developed using the Functional Assessment of Chronic Illness Therapy translation methodology [13] after obtaining permission for translation from the original authors. Two Japanese medical professionals (YS and MO) performed forward translation from English to Japanese, and two other medical professionals (MM and AT) prepared an integrated Japanese version. To ensure readability and clarity, it was then reviewed by an AYA bone marrow transplant survivor who had studied in Australia and was fluent in English, following which 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, performed 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 using 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, a review by the original authors, and expert discussions were repeated until content 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 they felt there were any unclear points, and the scale was modified based on their opinions. Through this 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 completed cancer treatment, (2) had been diagnosed with cancer in the last five years, (3) were aged 15 to 39 at the time of diagnosis, (4) were physically and mentally able to complete a survey, and (5) were able to speak and read Japanese. The inclusion criteria were based on the original article [11]. This survey was conducted between April 20 and September 30, 2021, using Survey Monkey (San Mateo, California, USA), an online survey platform. The sample size was determined based on the number of patients that could be recruited within the study period. Participants were recruited through two methods: on-site and online. On-site recruitment leaflets were distributed to eligible patients during outpatient visits at the Department of Hematology, Breast Surgery, and Pediatrics, Kyoto University Hospital. Online recruitment was conducted through the website or social networking services (SNS) of a non-profit organization, and patient groups that AYA cancer patients often visit.

At the beginning of the survey cooperation leaflet, an online questionnaire, an explanation, and an assent document were provided. The respondents were also informed that returning the completed questionnaire would be regarded as providing consent to participate in the study. Participants who were interested in the study registered using the email address registration form provided in the research cooperation flyer, while the researcher later sent them the access URL for the online questionnaire so that only those who met the participation criteria could complete the questionnaire. Participants who consented to the retest were emailed a follow-up survey link one week later. This interval was chosen to minimize recall bias from previous answers and ensure stability of responses over time [14].

Measures

We collected demographic and clinical data, including age, sex, employment status, age at diagnosis, years since diagnosis, cancer type, and treatment type, using a self-administered online questionnaire. In addition to the CNQ-YP-J, concerns about the physical effects and QOL were investigated. In the retest conducted one week later, only the CNQ-YP-J was administered. The CNQ-YP-J before factor analysis consisted of six factors and 70 items, similar to the original CNQ-YP. ‘Factor 2: Education’, ‘Factor 3: Work’, and part of ‘Factor 5: Feelings and Relationships’ were screening items, which limited the number of respondents. Factors 5 and 6 asked about the needs in the previous month. This scale takes approximately 10 min to complete. Each need item was rated on a 5-point scale (1 = no need; 5 = very high need). ‘No need’ means ‘I got all the support I needed for this issue, or this did not apply to me’. Higher total scores indicate greater needs.

The physical effects factor of ‘the Cancer Survivors’ Survey of Needs by the Mayo Clinic Cancer Center’ was used to measure concerns about physical effects. This survey comprises 50 items covering five factors: physical, social, emotional, spiritual, and others [15, 16]. Regarding physical factors, patients rated their concerns about their physical symptoms (e.g. pain, fatigue, and sleep disturbances) on the day of the survey. The aforementioned concerns were rated on a 6-point scale (0 = no worries; 5 = very worrisome), with higher scores indicating more severe physical concerns. Subjective QOL on the day of the survey was assessed using a visual analogue scale. On a scale of 0 (poor) to 10 (good), a higher score indicated a higher QOL.

Following the CNQ-YP-J completion, respondents were asked how important they thought this scale was and responses were given on a 5-point scale (1 = very important, 5 = not at all important).

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 scale, the conditions for deleting items were determined as follows: items that were rated as ‘very high need’ or ‘high need’ by less than 20% of the respondents and those that were significantly correlated with other items in Spearman’s correlation analysis could be deleted [11]. The suitability of the data for factor analysis was examined using the Kaiser–Mayer–Olkin (KMO) indicator of sampling adequacy and Bartlett’s test of sphericity. The KMO indicator was then compared with the adequacy standards (meritorious > 0.80) [17]. The inter-factor correlation matrix was referred to in order to determine the association between the factors.

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 all factors together, as well as each factor individually, and a Cronbach’s α value of > 0.70 was considered acceptable [18]. Additionally, 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 less than 0.11, it is deemed that 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 > 0.7.

In terms of validity verification, criterion-related validity was assessed based on the hypotheses stated below, while factor validity was determined via factor analysis.

Previous studies showed that high levels of unmet needs were significantly associated with poor QOL among AYA cancer patients [8, 9]. Additionally, high unmet needs among cancer survivors were significantly associated with high concerns about physical effects [9, 20]. Therefore, we hypothesised that unmet needs are positively correlated with concerns about physical effects and negatively correlated with QOL. Spearman's correlation analysis was employed to examine the relationships between total needs, concerns about physical effects, and QOL. Data were analysed using IBM SPSS Statistics version 28 (IBM, Armonk, NY, USA). All tests were two-tailed, and statistical significance was set at $p < 0.05$.

Results

Participant characteristics

A total of 87 participants completed the survey, including 26 from Kyoto University Hospital and 61 from SNS and patient groups. Of those who registered using the email address registration form, 92.9% from Kyoto University Hospital and 85.9% from the SNS/patient groups completed the online questionnaire. Table 1 displays the demographic and clinical characteristics as well as the importance of the CNQ-YP-J. There were 23 (26.4%) male and 64 (73.6%) female participants, with a mean age of 33.1 ± 5.7 years. Moreover, 43 (49.4%) patients had breast and gynaecological cancers, and 37 (42.5%) had blood cancer. Concerning the importance of the CNQ-YP-J, 26 (29.9%) participants stated that it was 'very important', 29 (33.3%) declared that it was 'somewhat important', 27 (31.0%) answered 'can't say either', and 5 (5.8%) answered 'not very important'. No participants answered 'not at all important'.

Exploratory factor analysis

Exploratory factor analysis was used to assess 60 items, after excluding 10 screening items. The number of factors was determined using the eigenvalues and scree plots. Factor analysis was repeated using a factor loading of 0.35 > as the criterion, resulting in a five-factor structure, excluding one item with a low factor loading. As a result of the exploratory factor analysis, item 70 (support to manage: going out for social events) was deleted based on the conditions for item deletion. The distribution of responses to item 70 showed that 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, as it could be substituted by item 69.

The cumulative contribution rate of these five factors was 67.7%, while the inter-factor correlations ranged from 0.27 to 0.52, indicating a positive correlation between the factors. The KMO indicator was 0.84,

Table 1 The participants' demographic and clinical characteristics and the importance of the CNQ-YP-J[1]

Characteristics	*N* = 87	*n*	%
Sex			
	Male	23	26.4
	Female	64	73.6
Age	Mean ± SD = 33.1 ± 5.7		
	< 20	1	1.2
	20–24	9	10.3
	25–29	16	18.4
	30–34	16	18.4
	35–39	39	44.8
	40–44	6	6.9
Employment status			
	High school student	1	1.2
	University, Graduate, and Professional School	9	10.3
	Company employee	44	50.6
	Part-time worker	5	5.8
	Unemployed	17	19.5
	Other	11	12.6
Age at diagnosis			
	15–19	5	5.8
	20–24	9	10.3
	25–29	19	21.8
	30–34	31	35.6
	35–39	23	26.4
Time since diagnosis			
	< 6 months	8	9.2
	6 months–1 year	12	13.8
	1–2 years	16	18.4
	2–3 years	15	17.2
	4–5 years	17	19.5
	3–4 years	19	21.8
Type of cancer			
	Breast and gynaecologic cancer	43	49.4
	Blood cancer	37	42.5
	Brain cancer	1	1.2
	Sarcoma	1	1.2
	Respiratory cancer	2	2.3
	Urinary tract cancer	2	2.3
	Other	3	3.5
Type of treatment			
	Surgery	53	60.9
	Anticancer drugs	63	72.4
	Radiotherapy	39	44.8
	Hormone therapy	30	34.5
	Transplant	11	12.6
	Other	6	6.9
Importance of the CNQ-YP-J			
	Very important	26	29.9
	Somewhat important	29	33.3
	Can't say either	27	31.0

Table 1 (continued)

Characteristics	*N* = 87	*n*	%
	Not very important	5	5.8
	Not at all important	0	0

[1] The Japanese version of the Cancer Needs Questionnaire–Young People

confirming the high validity of the scale, and Bartlett's test was $p < 0.0001$, confirming the goodness-of-fit in the factor analysis. Table 2 displays the results of the exploratory factor analysis and inter-factor correlations.

The results of the factor analysis revealed five factors. Factor 1 was named 'Treatment Environment', because it included items pertaining to the effectiveness of the treatment and response of the medical staff. Factor 2 was named 'Feelings and Lifestyle', as it included items related to changes in feelings and independent living during the past month. Factor 3 pertained to managing medication and participating in social activities, and was thus named 'Coping with Symptoms and Activities'. Factor 4 was named 'Interacting with Peers', because it included items related to spending time with and talking to people of the same age. Factor 5 was named 'Coping with Feelings', as 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 had a six-factor structure, but the Japanese version had an eight-factor structure, indicating a shift in structure. Changes to the factor structure and the deletion of items were made with the permission of the original authors.

Internal consistency

Cronbach's α and IT correlation coefficients were calculated to verify the internal consistency of the CNQ-YP-J. The results are summarised in Table 3. Cronbach's α coefficients stood at 0.92 for the entire scale, and ranged from 0.74 to 0.98 for each factor. The IT correlation coefficients ranged from 0.42 to 0.88 for all factors.

Stability

To verify the stability of the CNQ-YP-J, we conducted a retest and calculated the ICC, the results of which are presented in Table 4. The ICC was 0.89 for the entire scale, and ranged from 0.72 to 0.89 for each factor.

Criterion-related validity

Table 5 displays Spearman's correlation coefficients between concerns about physical effects, QOL, and the total of all factors and each factor of the CNQ-YP-J. Concerns about physical effects were positively correlated with needs ($\rho = 0.99$, $p < 0.01$), while QOL was negatively correlated with needs ($\rho = -0.19$, $p = 0.08$).

Participants' responses to the scale

A wide range of opinions was observed, including 'This questionnaire is very pertinent for young cancer patients', 'It has revealed needs that I was not aware of', and 'There are some minor differences among the "no need" responses'. Overall, the feedback was positive.

Discussion

In this study, we developed the CNQ-YP-J to measure the needs of young patients with cancer, and verified its reliability and validity. The scale consisted of 69 items; 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. The scale showed sufficient reliability and validity for tentative use; however, further verification is warranted.

In the factor analysis, the three items in Factor 4 ('Information and Activities') of the original scale were combined into an independent factor in the CNQ-YP-J, which was named 'Interacting with Peers'. The independence of these factors indicates the importance of peer support, that is, support from those who have experienced cancer [2]. This is corroborated by the fact that 47% of the respondents answered 'very high need' and 'high need' for 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. AYA patients with cancer are often treated in and admitted to adult and paediatric wards, with little opportunity to meet their peers in either setting [4]. Additionally, the fact that the importance of AYA cancer has only recently been recognized [3], and support systems such as cancer patient groups are inadequate compared to those in other countries [4], may have contributed to the independence of this factor.

Furthermore, three items included in different factors in the original scale constituted one factor in the CNQ-YP-J. Item 24 (Having cancer treatment staff who let me talk about my feelings) and item 27 (Having cancer treatment staff who talked to me in private, without my family) from the original Factor 1 'Treatment Environment and Care', together with item 44 (Information that described relaxation techniques) from the original Factor 4 'Information and Activities', comprised Factor 5 'Coping with Feelings' in the CNQ-YP-J. The independence of this factor suggests that 'talking' is an important way for AYA cancer patients to cope with their situation. Previous studies have described the importance of AYA cancer patients communicating with others and expressing their feelings [21, 22], and indicated a high need for these patients to undergo counselling [23]. Being diagnosed with cancer at such a young age and being separated from their peers can lead to feelings of isolation and loneliness [24]. Therefore, it is extremely important for them to have an environment in which they feel safe to express themselves.

To verify the criterion-related validity, we examined the correlation between needs and concerns about physical effects, as well as that between needs and QOL, finding that high need was significantly positively correlated with concerns about physical effects and tended to be negatively correlated with QOL. The CNQ-YP-J was found to have high criterion-related validity, with results similar to those in previous studies; for AYA cancer survivors, the higher the need [9, 20], the greater the concerns about physical effects, and the lower the QOL [7, 8].

To assess reliability, Cronbach's α and IT correlation coefficients were calculated, as was the ICC. This scale showed high internal consistency, as the Cronbach's α coefficient exceeded 0.70 [18] for both the overall scale and each factor, while the IT correlation coefficients exceeded 0.11 [19] for all factors. The ICC showed high stability, as it exceeded 0.7 for both the overall scale and each factor.

Overall, the participants' responses were positive, indicating that the CNQ-YP-J is easy to administer and acceptable to patients. In clinical settings, this scale can identify the unmet needs of Japanese AYA patients with cancer, allowing healthcare providers to tailor interventions more effectively. The scale's ability to highlight emotional needs ('Coping with Feelings') underscores the importance of integrating mental health services into cancer care pathways. By utilising this scale, we hope that the diverse needs of AYA cancer patients, which have not been emphasised until now, will be identified, leading to future improvements in the treatment environment and provision of support. Furthermore, the scale can help patients become aware of their own feelings, such as dissatisfaction and requests, and express those feelings to the medical staff. It is further hoped that the environment surrounding AYA cancer patients will improve as a result of enhancing the awareness of not only the medical staff, but also many other people, when it comes to patients' mental state and physical symptoms.

From a research perspective, the CNQ-YP-J provides a foundation for further studies aimed at understanding the evolving needs of AYA cancer patients over time. Longitudinal studies using this scale could explore differences in needs across treatment phases and into survivorship. Furthermore, cross-cultural comparisons using the CNQ-YP and its Japanese version could provide valuable insights into cultural influences on cancer care. To address the limitations of the current study, researchers should aim to recruit larger and more diverse samples, ensuring adequate representation of younger age groups, male patients, and individuals with a broader range of cancer types.

This study has several limitations that should be noted. First, the sample size was small. Previous studies have stated that, for factor analysis, the number of participants included should be at least five times that of the number of items on the scale [25]. As the original scale comprised 70 items, only a 1:1 item–participant ratio was achieved. Factor analysis with a larger sample size may provide a factor structure different from that revealed in the present study. However, given that only one item was deleted, and the reason for this was clear, we believe that the small sample size did not have a significant impact on the CNQ-YP-J. Second, the demographic and clinical characteristics of the participants were highly biased. The number of participants aged 15–24 was small (11.5% of the total), as was the proportion of men and diagnosis of cancers other than breast, gynaecological, and blood cancers. Owing to the clinical characteristics of AYA cancer patients, recruitment through SNS and patient groups is a limitation. Future studies should include patients with a wider range of characteristics. In future research, it is critical to addressing the current study's limitations, such as sample size and demographic biases. Moreover, inclusion of diverse types of patients and further evaluation of convergent validity will strengthen the generalizability of the findings and refine the scale's applicability in various clinical settings. In addition, we plan to conduct confirmatory factor analysis and differential item functions analysis in future studies, using larger and more diverse samples, to further validate the factor structure of the CNQ-YP-J and ensure that it is free from measurement bias across demographic subgroups.

Table 2 Exploratory factor analysis

Content of the questionnaire			**Factor loadings[b]**				
			Factor 1	**Factor 2**	**Factor 3**	**Factor 4**	**Factor 5**
Factor 1 - Treatment Environment (32 items)							
My cancer treatment staff telling me:	I1[a]	about my diagnosis	0.92	-0.02	0.12	0.06	-0.30
	I2	what might happen during my treatment	0.95	-0.03	0.12	-0.07	-0.22
	I3	whether I had an option to refuse treatment	0.72	-0.02	-0.02	0.00	-0.07
	I4	about the short-term side-effects of treatment	0.91	-0.03	0.15	-0.04	-0.23
	I5	about the long-term side-effects of treatment	0.86	-0.12	0.10	-0.07	0.12
	I6	about the possibility of recovery	0.78	-0.27	0.19	-0.01	0.10
	I7	what might happen when treatment finished	0.83	-0.18	0.22	-0.03	0.03
	I8	whether I would be able to have children in the future	0.67	-0.04	0.25	0.01	-0.08
	I9	whether my treatment was working	0.75	0.12	0.03	-0.02	-0.11
	I10	my test results as soon as possible	0.80	0.25	-0.04	0.03	-0.18
	I11	the way I feel physically and mentally was normal	0.63	0.10	-0.07	0.04	0.23
Being able to have:	I12	time for myself	0.64	-0.03	0.02	0.00	0.16
My cancer treatment staff telling me:	I13	how to manage my medication	0.44	-0.01	0.19	0.12	-0.01
	I14	what I could do to stay healthy	0.67	-0.19	0.18	-0.01	0.18
	I15	what to do if I noticed a particular side-effect	0.58	0.04	0.14	-0.08	0.24
Having cancer treatment staff who:	I16	listened to my concerns	0.64	-0.06	-0.01	0.07	0.35
	I17	treated me as an individual	0.70	0.17	-0.16	-0.11	0.34
	I18	respected me and treated me thoughtfully	0.83	0.04	-0.12	-0.15	0.29
	I19	were approachable and felt comfortable with	0.70	-0.08	-0.08	-0.02	0.52
	I20	had a warm heart and were friendly	0.73	-0.12	-0.05	-0.06	0.49
	I21	could have a laugh with me	0.65	0.09	-0.16	0.09	0.36
	I22	explained what they were going to do or what I could expect before the procedure	0.76	0.19	0.00	0.05	-0.11
	I23	spoke to me in a way that I could understand	0.78	0.13	-0.05	0.02	0.01
	I25	let me ask questions easily	0.56	0.10	0.05	-0.05	0.43
	I26	support me to let me make decisions about my treatment	0.51	0.22	-0.16	-0.05	0.45
Being able to have:	I28	keep my privacy	0.42	0.21	-0.20	0.12	0.21
	I29	spend time in a comfortable environment	0.57	0.11	-0.06	0.18	0.21
	I30	eat delicious foods	0.49	0.03	-0.09	0.18	0.06
	I31	a choice of the cancer specialist who treated me	0.57	0.14	-0.04	-0.02	0.16
	I32	same staff throughout the treatment period	0.38	0.12	-0.01	0.04	0.38
	I33	a choice of times for appointments (e.g. medical tests or outpatient care)	0.44	0.09	-0.01	0.09	0.16
Finding information that:	IV43	was specifically designed for me	0.39	0.04	0.08	0.22	0.22
Factor 2 - Feelings and Lifestyle (15 items)							
Support to face:	V45	frustration and disappointment I felt when things didn't go my way	-0.20	0.45	0.28	0.04	0.31
	V46	anxious or nervous	-0.16	0.50	0.29	-0.04	0.29
Support to face worries about:	V47	my cancer spreading	0.07	0.84	-0.01	0.00	-0.12
	V48	my cancer returning	0.05	0.80	-0.01	-0.10	0.02
	V49	whether my treatment has worked	0.11	0.91	-0.02	-0.04	-0.15
	V50	having a cancer treatment	0.14	0.94	-0.13	-0.05	-0.17
	V51	how my family is coping	0.00	0.61	0.21	0.10	0.05
Support to be able to:	V52	find my strength to accept treatments and reality	0.00	0.78	0.10	-0.09	0.15
	V53	accept my diagnosis	0.01	1.01	-0.24	0.02	-0.03
	V54	be independent	-0.09	0.79	-0.03	0.01	0.16
Support to be able to:	VI59	make plans or think about the future	-0.07	0.54	0.13	-0.02	0.25
Support to cope with:	VI60	changes in my physical ability	0.05	0.55	0.28	0.03	0.01
	VI61	changes in my appearance	0.13	0.49	0.20	0.07	-0.10

Table 2 (continued)

Content of the questionnaire			**Factor loadings**[b]				
			Factor 1	**Factor 2**	**Factor 3**	**Factor 4**	**Factor 5**
	VI62	not being able to do the same thing as other people the same age	-0.24	0.71	0.27	0.04	0.09
	VI63	being too worried for my parents to let me do anything	0.10	0.62	-0.21	-0.11	-0.03
Factor 3 - Coping with Symptoms and Activities (6 items)							
Support to cope with:	VI64	pain	0.18	-0.10	0.80	-0.02	-0.01
	VI65	take medicine or control medication	0.16	-0.01	0.59	0.00	-0.09
	VI66	physical side-effects of treatment	0.16	0.06	0.70	-0.09	0.05
	VI67	fatigue	-0.01	0.19	0.76	-0.03	0.13
	VI68	the difficulty of moving around easily where I wanted	-0.03	0.42	0.53	-0.12	0.11
Support to manage:	VI69	taking part in social activities	-0.06	0.19	0.43	0.23	0.09
Factor 4 - Interacting with Peers (3 items)							
Being able to:	IV40	spend my time with people my age	-0.12	0.02	0.00	0.91	0.10
	IV41	talk to people my age who have been through a similar experience	0.16	0.03	-0.05	0.78	-0.14
Being able to have:	IV42	leisure spaces, recreation, and events	0.05	-0.21	-0.05	0.56	0.10
Factor 5 - Coping with My Feelings (3 items)							
Having cancer treatment staff who:	I24	let me talk about my feelings	0.50	-0.09	0.07	0.04	0.58
	I27	talked to me in private without my family	0.38	-0.03	0.02	0.03	0.67
Finding information that:	IV44	described relaxation techniques	0.27	0.11	0.08	0.09	0.39
		Inter-factor correlations	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
		Factor 1	——	0.48	0.41	0.33	0.42
		Factor 2		——	0.50	0.46	0.52
		Factor 3			——	0.27	0.31
		Factor 4				——	0.49
		Factor 5					——
		Contribution rate (%)	45.98	10.21	4.80	3.80	2.95
		Cumulative contribution rate (%)	45.98	56.19	60.98	64.78	67.73

[a] Item numbers are from the original scale. Roman numerals denote factors of the original version.

[b] The criterion for the factor loadings is 0.35.

Table 3 Cronbach's α and item–total correlations

Factor	**Number of items**	**Cronbach's α**	**Item–total correlation**
1	32	0.98	0.55–0.88
2	15	0.95	0.46–0.84
3	6	0.89	0.59–0.86
4	3	0.78	0.49–0.52
5	3	0.88	0.64–0.84
6	3	0.74	0.42–0.69
7	3	0.87	0.68–0.85
8	4	0.86	0.48–0.87
Total	69	0.92	——

Table 4 The ICC[1] of the retest

Factor	*n*	First Average ± SD[2]	Second Average ± SD	ICC
1	71	80.48 ± 39.55	72.96 ± 35.35	0.89
2	71	29.32 ± 15.75	29.01 ± 14.45	0.88
3	71	10.65 ± 5.92	9.28 ± 4.44	0.76
4	71	8.30 ± 3.79	7.66 ± 3.44	0.78
5	71	8.20 ± 4.33	7.31 ± 3.89	0.84
6	12	6.60 ± 2.88	6.58 ± 2.97	0.72
7	55	8.48 ± 4.29	7.40 ± 4.03	0.80
8	68	3.67 ± 2.49	3.40 ± 1.78	0.73
Total	71	148.27 ± 63.88	136.32 ± 57.00	0.89

[1] Intraclass correlation coefficient

[2] Standard deviation

Table 5 Correlation between needs, concerns about physical effects, and quality of life

Needs	Concerns about physical effects		Quality of life	
Factor	ρ	*p*	ρ	*p*
1	0.93	< 0.01*	-0.15	0.17
2	0.73	< 0.01*	-0.21	0.05*
3	0.62	< 0.01*	-0.34	< 0.01*
4	0.53	< 0.01*	-0.02	0.88
5	0.89	< 0.01*	-0.20	0.06
6	0.30	0.35	-0.05	0.89
7	0.82	< 0.01*	-0.20	0.09
8	0.63	< 0.01*	-0.17	0.14
Total	0.99	< 0.01*	-0.19	0.08

*$p < 0.05$

Conclusions

The CNQ-YP-J developed in this study is a reliable and potentially valid scale that comprehensively assesses the needs of AYA cancer patients in the treatment environment as well as their daily lives. We hope that the use of this scale as a measure of the needs of AYA cancer patients in various settings, including clinical practice, will lead to the provision of optimal medical care and development of support systems, as well as the promotion of information.

Abbreviations

AYA	Adolescent and young adult
QOL	Quality of life
CNQ-YP	Cancer Needs Questionnaire–Young People
CNQ-YP-J	Japanese version of the Cancer Needs Questionnaire–Young People
SNS	Social networking service
KMO	Kaiser–Mayer–Olkin
IT	Item–total
ICC	Intraclass correlation coefficient

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Author contributions

Y.S. designed the study; collected data, analysed, and interpreted the data; and drafted the manuscript. M.M. arranged the pilot test participants, developed the CNQ-YP-J, and reviewed the manuscript. M.O. and A.T. developed the CNQ-YP-J and reviewed the manuscript. A.H. advised on factor analysis methods and reviewed the manuscript. Dr T.CM. developed the CNQ-YP and advised on and reviewed the CNQ-YP-J. Y.M. performed the back-translation and supported the review by the original authors during the development of the CNQ-YP-J. M.K. and Y.S. named each factor after the factor analysis. Additionally, M.NT. and T.T. interpreted the data and reviewed the manuscript, while T.A. and A.T. reviewed the manuscript and supervised the entire research process. All authors read and approved the final version of the manuscript.

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Data availability

The data that support the findings of this study are not openly available because they have not been approved by the ethics committee, so as to protect participant privacy. However, the anonymous datasets generated and/or analysed in the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of Kyoto University Graduate School and Faculty of Medicine (No. R2794-2). All participants were provided, through an online document, information regarding the purpose and content of the study, study methods, voluntary participation, sending back the questionnaire (which constituted consenting to the study), right to withdraw, protection of personal information, guarantee of anonymity, data storage and deletion methods, and publication of research results. Consent to participation was obtained via the signing of an informed consent sheet. The physical effects factor of 'The Cancer Survivors' Survey of Needs', which was used to measure concern about physical effects, was an adaptation of an existing factor—an adaptation that was performed after obtaining permission from the developing organization.

Informed consent

Informed consent was obtained from all participants via an online questionnaire. Returning the completed questionnaire implied consent to participate, and all necessary explanations were provided in the online document. Participants aged < 20 years were asked to provide parental consent, and informed consent was obtained from all the parents of minor participants.

Consent for publication

Not Applicable.

Competing interests

The authors have no relevant financial or non-financial interests to disclose.

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