

Japan.⁷ Along with wide recognition of the importance of pain management for pediatric cancer patients, development of guidelines for procedural pain management in the Japanese clinical setting is now seen to be necessary. The present study investigated the current situation in Japan regarding pain management in pediatric cancer patients requiring BMAB on the basis of a survey of the Tokyo Children's Cancer Study Group (TCCSG).⁸

Methods

A cross-sectional investigation of pain management in institutions belonging to the TCCSG was conducted. Eligible institutions were defined as those having inpatients with pediatric cancer diagnosed between the age of 6 months and 15 years. BMAB was performed in these patients between 1 January 2010 and 31 December 2010. Pain management included both non-pharmacological intervention and pharmacological management (sedation and/or analgesia).

The questionnaires, which were developed for this purpose, were sent from the TCCSG office to each institution in October 2011 via email with a request to send replies to the TCCSG office. The questionnaire included questions regarding the following: information about the institution, institutional policy on pain management, including non-pharmacological interventions, and pharmacological management for children aged ≥ 3 years, including provision of pharmacological management, sedation and/or analgesia. Details were collected regarding the provider of pharmacological pain management, the setting in which BMAB was usually performed, whether independent doctors monitored patients, the guidelines, manuals, or standards of the institution regarding pain management, local anesthesia, systemic sedatives and/or analgesics, BMAB in outpatients, and differences in pain management in older children compared with children < 3 years.

The efficacy and safety of current pharmacological management practices were examined, and the incidence, handling, and prognosis of adverse events were investigated. Utilization of consulting and coordinating sections in difficult cases at each institution was also investigated. Participants were free to express their opinions in one section of the survey.

Definitions

In the present study, sedation was defined as a drug-induced depression of consciousness during which patients cannot be easily aroused. No intervention is required to maintain a patient airway and spontaneous ventilation. Deep sedation was defined as drug-induced depression of consciousness deeper than the desired level of sedation (e.g. airway is compromised and oxygenation and ventilation are inadequate); some intervention is required to maintain the airway and spontaneous ventilation. Insufficient sedation is defined as drug-induced depression of consciousness less than the desired level (e.g. children are easy to arouse and procedures cannot be accomplished because of pain and/or their motions). Analgesia was defined as pain relief. Pain management was defined as non-pharmacological pain intervention and/or pharmacological pain management. Non-pharmacological pain intervention was defined as pain relief without use of medicine, (e.g. psychological preparation). Pharmacological pain management was defined as pain relief via sedatives and/or analgesics.

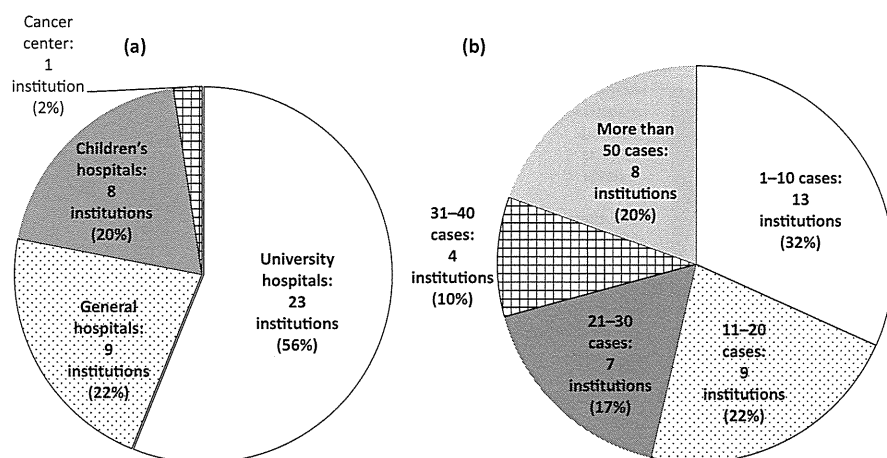
Results

The questionnaire was sent to 57 institutions. Forty-three institutions (75.4%) responded, and no eligible cases were reported in two of the institutions. Thus, eligible responses from 41 institutions (71.9%) were analyzed (Table 1).

Table 1 Responding institutions

<ul style="list-style-type: none"> • Nippon Medical School • Keio University Hospital • Saitama Medical Center • Jichi Medical University • Juntendo University • Showa University • Shinshu University • St. Marianna University School of Medicine • Chiba University • Institute of Clinical Medicine, University of Tsukuba • Teikyo University • Tokai University • The University of Tokyo • The University of Tokyo, The Institute of Medical Science • Tokyo Women's Medical University Medical Center East • Toho University Omori Medical Center • Toho University Ohashi Medical Center • Dokkyo Medical University • Nippon Medical School Chiba Hokusoh Hospital • National Defense Medical College • Yokohama City University • St. Marianna University School of Medicine, Yokohama City Seibu Hospital 	<ul style="list-style-type: none"> • Teikyo University Chiba Medical Center • Kanagawa Children's Medical Center • Gunma Children's Medical Center • National Center for Child Health and Development • Saitama Children's Medical Center • Chiba Children's Hospital • Ibaraki Children's Hospital • Tokyo Metropolitan Children's Medical Center • Nagano Children's Hospital • Kameda Medical Center • Japanese Red Cross Kumamoto Hospital • Japanese Red Cross Narita Hospital • Japanese Red Cross Musashino Hospital • Saiseikai Yokohamashi Tobu Hospital • Saiseikai Yokohamashi Nanbu Hospital • St Luke's International Hospital • Tokyo Metropolitan Cancer and Infectious Diseases Center Komagome Hospital • Tokyo Nishi-Tokushukai • Yokosuka Kyosai Hospital • Shizuoka Cancer Center • Jikei University School of Medicine
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Fig. 1 Basic institution information. (a) Profile: more than half of the eligible institutions were university hospitals, and 20% of them were children's hospitals. (b) The number of eligible cases in each hospital varied from <10 cases to 100 cases.



Basic institution information

More than half of the eligible institutions were university hospitals, and 20% of them were children's hospitals. The number of eligible cases in each hospital varied from <10 to 100 (Fig. 1).

Institutional policy of pain management

Sedation and/or analgesia were provided at all institutions. Non-pharmacological interventions were available at 28 institutions (68%). The combination of disciplines for non-pharmacological interventions was as follows: pediatric oncologists and nurses in eight institutions; pediatric oncologists only in five institutions; pediatric oncologists, nurses, and child or hospital play specialists (CLS/HPS) in four institutions; nurses only, CLS/HPS, nurses and nursery teachers in three institutions each, respectively; CLS/HPS in two institutions. Professionals such as CLS/HPS worked at 9 institutions.

Pharmacological management for children aged ≥ 3 years

In 39 institutions (95%), sedation/analgesia was performed by pediatric oncologists during BMAB in children aged ≥ 3 years. In 36 institutions (87%), BMAB was performed in the treatment room in the hospital ward. Independent doctors monitored patient systemic condition in 27 institutions (66%). No guidelines, manuals, or standards regarding pain management were developed in 37 institutions (90%). Both sedation and analgesia were provided in 39 institutions (95%), and only sedation and analgesia were provided in one institution each. Local anesthesia was provided in 37 institutions (90%) and topical lidocaine was injected prior to BMAB in 30 institutions (73%). Sedatives and/or analgesics were given i.v. in 40 institutions (98%). Topical anesthesia without systemic use was utilized in only one institution. Various combinations of sedatives and/or analgesics were used in different ways depending on the institution. Midazolam was the first drug of choice or was used in

combination with other drugs in 28 institutions. Ketamine was the first drug of choice or was used in combination with other drugs in 20 institutions, and a combination of midazolam and ketamine was used in 15 institutions. Pentazocine was used in nine institutions. BMAB for outpatients was performed in 28 institutions (68%), half of which had strict policies for controlling pain. The institutional policy on pain management for children aged 6 months–<3 years was the same as that for children aged ≥ 3 years in 39 institutions (95%).

Efficacy and safety of pharmacological management

Adequate pain management with or without adverse events was provided at 27 institutions (66%). Insufficient pain management was reported in 12 institutions (29%). Some adverse events were reported in surveys from 33 institutions (80%; Fig. 2). These adverse events included desaturation of oxygen ($n = 25$), insufficient sedation ($n = 18$), and apnea ($n = 11$). Unexpected deep sedation was reported from three institutions. These adverse events were treated by inhalation of oxygen in 25 institutions. Positive airway ventilation was used at one institution. Most adverse events were transient in 78% of institutions. Recovery within 6 h was reported in all cases of medical treatment for adverse events. No serious consequences such as prolongation of adverse events, complications, sequelae, or death were reported (Fig. 3).

Two serious adverse events were reported. One patient was diagnosed with Down syndrome as an underlying condition. This patient had respiratory failure during BMAB and airway management was necessary. Another patient was diagnosed with acute myeloblastic leukemia and upper respiratory tract infection during the procedure. In this case, apnea was the associated complication: therefore, transient biphasic positive airway pressure ventilation was necessary. These two institutions, university hospitals, reported experience of >50 cases of pediatric cancer during the study period.

Consulting and coordinating in difficult cases was possible in 26 institutions (63%). Pediatric anesthetists were available

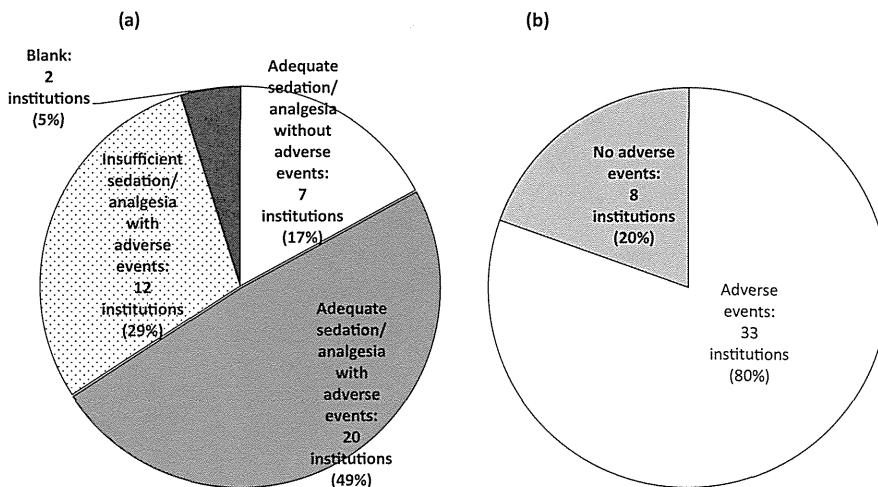


Fig. 2 (a) Efficacy and safety of pharmacological management. Adequate pain management with or without adverse events was provided at 27 institutions (66%). Insufficient pain management was reported in 12 institutions (29%). (b) Adverse events were reported from 33 institutions (80%).

in eight institutions (20%). Consultation and coordination with specialists such as pediatric anesthetists was conducted at 10 institutions (26.3%).

Discussion

Both non-pharmacological intervention and pharmacological pain management were utilized in patients in whom BMAB was performed. The aim of pain management is to achieve maximum safety and efficacy with a minimum of adverse events. Some guidelines or standards have already been developed in Western countries.¹⁻⁵ Adequate and thorough medical assessment, monitoring, and preparation of, adequate sedation and analgesia are provided as a part of regular health care in these countries. In contrast, few reports have been published in Japan on pain management associated with BMAB in pediatric cancer patients from the point of view of safety and efficacy.^{9,10} The present

cross-sectional survey of institutions belonging to the TCCSG was conducted to determine the present status of pain management in the Japanese health-care system. Several issues were identified as a result of this survey.

First, the response rate was 71.9%, which is high. Thus, the present results may provide an adequate representation of the state of pain management in TCCSG institutions. Second, the importance of pain management in pediatric cases has been recognized widely in previous reports in Japan.^{9,10} The present survey reconfirms this fact, because all institutions that participated in the study provided pain management. Differences remain, however, between practices in Western countries and those in Japan. In Western countries, pediatric cancer patients are treated in large facilities such as pediatric oncology centers by specialists. Adequate good-quality pain management is practiced and resources are available in sufficient quantity. Sedation is usually performed in the operating room by pediatric anesthetists or medical professionals such as qualified pediatric advanced life support specialists. Guidelines have been developed and effective sedatives and analgesics, including some opioids and inhalation anesthetics, are recommended for use in the appropriate setting.¹⁻⁵ In contrast, in Japan, pediatric cancer patients are treated in various facilities, as was seen in the present study. In the majority of institutions, sedation was usually performed outside the operating room, in the treatment rooms in the ward, by pediatric oncologists. Furthermore, a survey conducted by the Japanese Society of Pediatric Anesthesiology found that anesthesiologists have provided sedation in 1.8% of all 2 136 771 diagnostic and therapeutic procedures.¹¹ National guidelines for sedation for BMAB have not yet been established.^{10,12} Only four institutions have developed and utilized their own standards. Midazolam and ketamine were used in most institutions, similar to that in Western countries, but in different combinations with other medications. Propofol was used in only three institutions. Moreover, use of pentazocine is unique to Japan.¹³ When Western guidelines are utilized in Japan, these differences in background should be considered and amended as necessary.

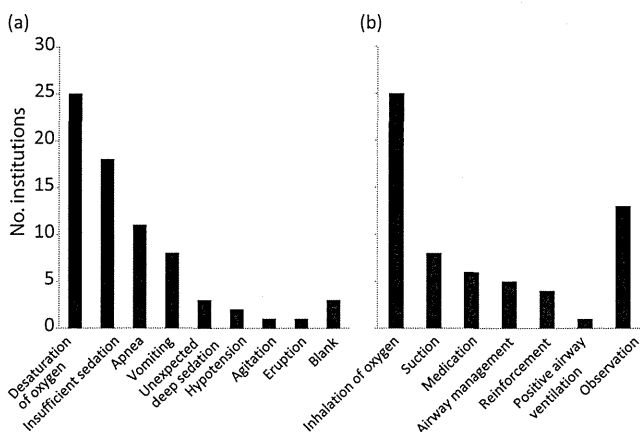


Fig. 3 (a) Adverse events included desaturation of oxygen ($n = 25$), insufficient sedation ($n = 18$), and apnea ($n = 11$). Unexpected deep sedation was reported from three institutions. (b) These adverse events were treated by inhalation of oxygen in 25 institutions. Positive airway ventilation was used at one institution. Most adverse events were transient in 78% of institutions.

Regarding efficacy and safety, the following significant issues were identified. Insufficient sedation/analgesia was reported from 12 institutions. Insufficient pain management may have short- and long-term negative consequences for sick children and their families, both physically and psychologically. In addition, unexpected deep sedation occurred in three institutions, indicating the difficulty of controlling sedation levels in children. Regarding adverse events, approximately half of all responding institutions reported that pain management in their facilities was adequate, but some adverse events occurred nonetheless. In total, 80% of institutions reported some adverse events, which is a significant number. This high prevalence suggests that adverse events can occur in any institution. Fortunately, no serious consequences of adverse events were reported in this survey. This suggests that adverse events were treated appropriately and adequately in the surveyed institutions. Children with underlying and complicated conditions, however, are at high risk for serious adverse events. In addition to two cases in the present survey, children with anterior mediastinal masses have been reported at high risk for life-threatening airway compromise during anesthesia and can present a diagnostic and management challenge.¹⁴ Serious adverse events can occur even in experienced institutions because of the frequency with which BMAB is performed and the fact that high-risk patients are often treated in these institutions. These patients should be identified in advance and adequate preparation made accordingly.

Limitations

This survey focused on institutions rather than individual cases. The limitations of this study are as follows. Institutional variations such as the scale and type of each institution, (number of cases, availability of pediatric oncologists and other specialists, and the number of cooperating departments), may have influenced the results. Case-related factors such as diagnosis, age, and underlying and complicating conditions may also have had an effect. Sedatives and analgesics varied from one institution to another, as did their availability, dosage, and use in combination. Some survey respondents provided unclear details regarding adverse events in individual cases, their total number and incidence, individual patient information and individual adverse event information, and the efficacy of response to these events. The study period was relatively brief, therefore the number of cases was limited. Studies using data from other years, examining patients of other ages, and in other settings, such as outpatients, may be conducted in future. Moreover, although pain is subjective, views from children and their families in this survey were not assessed. Further studies are therefore necessary.

For the first time ever, the Cancer Control Act developed by the Japanese government in 2012 included pediatric cancer.¹⁵ Now consolidation of these institutions of pediatric oncology has been carried out, and 15 core hospitals have been selected and certified by the Government to provide specialized, intensive and comprehensive pediatric cancer treatment. In future, non-pharmacological intervention may ideally be performed by professionals such as the CLS/HPS. Some incentives may be necessary to encourage hospitals to hire such professionals. For

maximum efficacy and safety with a minimum of adverse events, the recognition of risk, preparation for serious adverse events and the sharing of information are paramount.^{1-5,16-18} Some controversy persists.^{18,19} Each institution, however, should be equipped with staff skilled in sedation management, airway management, and cardiopulmonary resuscitation before, during, and after BMAB. Knowledge, skills, and experience related to sedation/analgesia should be enhanced and updated. In particular, in pharmacological management, the cooperation with specialists in pediatrics, pediatric oncology, pediatric anesthesiology, pediatric intensive care/emergency medicine, and pharmacology should be considered.

Conclusions

All institutions that participated in the present survey provided pain management during BMAB. No serious consequences were reported associated with pain management, but significant issues regarding efficacy and safety were identified. Adequate, systematic and thorough assessment, patient monitoring, preparation for adverse events, and cooperation with skilled specialists will aid in achieving maximum safety and efficacy with a minimum of adverse events. Thus quality of life can be improved through adequate pain management for pediatric cancer patients.

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Health-related quality of life in young adults in education, employment, or training: development of the Japanese version of Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales Young Adult Version

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Abstract

Purpose The purpose of the study is to develop a Japanese version of the Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales Young Adult Version (PedsQL-YA-J) and determine the feasibility, reliability, and validity of the scales.

Methods Translation equivalence and content validity were verified using back-translation and cognitive debriefing tests. A total of 428 young adults recruited from one university, two vocational schools, or five companies completed questionnaires. We determined questionnaire feasibility, internal consistency, and test–retest reliability; checked concurrent validity against the Center for Epidemiologic Studies Depression Scale (CES-D); determined convergent and discriminant validity with the Medical Outcome Study 36-item Short Form Health Survey (SF-36); described known-groups validity with regard to subjective symptoms, illness or injury requiring regular medical visits, and depression; and verified factorial validity.

Results All scales were internally consistent (Cronbach's coefficient alpha = 0.77–0.86); test–retest reliability was acceptable (intraclass correlation coefficient = 0.57–0.69); and all scales were concurrently valid with depression

(Pearson's correlation coefficient = 0.43–0.57). The scales convergent and discriminant validity with the SF-36 and CES-D were acceptable. Evaluation of known-groups validity confirmed that the Physical Functioning scale was sensitive for subjective symptoms, the Emotional Functioning scale for depression, and the Work/School Functioning scale for illness or injury requiring regular medical visits. Exploratory factor analysis found a six-factor structure consistent with the assumed structure (cumulative proportion = 57.0 %).

Conclusions The PedsQL-YA-J is suitable for assessing health-related quality of life in young adults in education, employment, or training, and for clinical trials and epidemiological research.

Keywords Adolescent · Feasibility studies · Quality of life · Questionnaires · Young adult

Introduction

Disease and treatment have physical, psychological, and social effects [1, 2], and survivors of chronic childhood disease often experience psychosocial maladaptation in education, employment, or marriage [3–6]. As recent advances in diagnosis and treatment methodology have improved the survival rate for several severe childhood diseases, the long-term support of survivors is an increasing challenge for pediatric and young adult health-care professionals [7, 8]. Indeed, in Japan alone, an estimated 50,000 pediatric cancer patients (approximately 1 in 700 young adults) [9] and 400,000 children with congenital heart disease have survived to adulthood [10].

Under such circumstances, follow-up clinics after treatment are needed to check and screen survivors for

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health and development into adulthood [11], thereby enabling medical and social workers to provide appropriate drug administration, health and psychological education, and social support to survivors and their families. The outcomes of such long-term follow-up can be evaluated based on objective indicators (prevalence of late effects, complications, survival rate, education continuance rate, employment rate) and patient-reported outcomes.

Health-related quality of life (HRQOL) is a patient-reported outcome recognized by clinicians, researchers, and health-care providers as an important multidimensional (physical, psychological, and social) outcome for survivors of chronic childhood disease [9, 12–19]. HRQOL can be measured by several scales. For example, the Medical Outcome Study 36-Item Short Form Health Survey (SF-36) [20–23] measures HRQOL for adults. Other scales, such as the German Quality of Life Questionnaire (KINDL) [24], are used for children but become less useful for longitudinal assessment as survivors mature. However, few scales measure HRQOL with consistency from childhood to adulthood [25].

The Pediatric Quality of Life Inventory 4.0 (PedsQL) Generic Core Scales are a widely used measurement of HRQOL for children aged 2–18 years [26]. This scale has been validated for children with and without several diseases or disabilities and translated into a number of languages, including Japanese [27]. The PedsQL scales are designed in several formats for different age groups, as follows: children aged 2–4 years (toddler), 5–7 years (young child), 8–12 years (child), 13–18 years (adolescent), and 18–25 years (young adult). Further, a version of the PedsQL Generic Core Scales for young adults 18–25 years was recently developed and validated for application in university students [28] and cancer survivors older than 25 years [29]. A modified form was also used for adolescents and young adults (ages 16–25 years) with cancer or blood disorders [30]. Although each format (for toddler, young child, child, adolescent, and young adult) varies to accommodate differences in lifestyle and cognitive development, the measured content and underlying concepts are consistent for all ages. This relatively wide age range and consistency across ranges allow medical practitioners to design longitudinal investigations of HRQOL. Data obtained using such scales can also be compared across international borders.

Here, we report the development of a Japanese version of the PedsQL Generic Core Scales young adult format (PedsQL-YA-J). We investigated the feasibility, reliability, and validity of the scales among young adults in education, employment, or training. Previous tests of the original English version reported the internal consistency, known-groups validity, and convergent and discriminant validity of the scales [28]. We therefore tested these measures and also the retest reliability, concurrent validity, and factorial validity.

Methods

Scale development

Dr. James W. Varni (JWV), the PedsQL developer, permitted translation of the original PedsQL Generic Core Scales Young Adult Version (PedsQL-YA-O) into Japanese using an approved translation procedure [31]. The draft PedsQL-YA-J was developed from the PedsQL-YA-O and the Japanese version of PedsQL Generic Core Scales for younger age groups (PedsQL-J) [27] with the intention of keeping the wording and content consistent with the PedsQL-J and the original (PedsQL Generic Core Scales for younger ages: PedsQL-O) [26] while being sensitive to age-appropriate differences. The consistency of this translation facilitates the evaluation of differences in HRQOL across and between age groups, as well as tracking HRQOL over time.

Identical items on the PedsQL-O and PedsQL-YA-O scales were identically translated in the PedsQL-YA-J and PedsQL-J scales. The only exceptions arose from Japanese language variations or cultural constraints; for example, ‘*the chores around the house*’ was translated into ‘*ie no naka no koto*’ (‘doing things around the house’) for young adults tested on the PedsQL-YA-J and ‘*ie no otetsudai*’ (‘assisting their parents around the house’) for children on the PedsQL-J to ensure that both phrases described age-appropriate chores. The authors discussed this translation and agreed on a single, reconciled version that was conceptually equivalent to the original version and written in easily understood and age-appropriate language.

Following this Japanese translation, a native English translator proficient in Japanese and blinded to the original version then translated the reconciled version back into English. We produced a pilot questionnaire after comparing the back-translated and original versions and making minor amendments to the reconciled version.

Twelve native Japanese-speaking young adults pilot-tested the questionnaire between August and September 2012. The participants differed in age, gender, and education or employment status. A researcher (MK) measured the time taken to complete the questionnaire and interviewed participants using cognitive interviewing methodology [31] after questionnaire completion to deduce the thought processes used in answering the questionnaire. The data obtained from the pilot test were used to produce a final version of the PedsQL-YA-J. As a result, no words or phrases required modification after the pilot test, and we were able to confirm that the participants of the pilot test understood, interpreted, and answered without difficulty. JWV reviewed the conceptual and linguistic equivalence between the final PedsQL-YA-J and the PedsQL-YA-O.

Study population

We recruited young adults aged 18–25 years (age range covered by the PedsQL-YA-J) from three large companies (current or prospective employees), two smaller companies (current employees), one university (students), and two vocational schools (students) between October and December 2012.

Procedure

We recruited participants from the five companies via collaborators who were members of the alumni association of the School of Health Science, The University of Tokyo. Researchers presented the study details to the collaborators, who then distributed the questionnaires and return envelopes to the participants. Participants provided informed consent via the questionnaires and directly returned the questionnaires by mail to the researchers.

We recruited students from the University of Tokyo in collaboration with professors of various faculties, excluding the faculty of medicine (author's affiliation). We recruited vocational school students by direct contact with schoolteachers and principals. A researcher or collaborator presented the study to university or vocational school students orally and in writing following lectures and distributed the questionnaires and return envelopes. Participants provided informed consent by completing the questionnaire and returning it immediately in person or later by mail to the researchers. Information regarding non-participants was not collected.

We tested the retest reliability by providing details of the retest procedure in writing to all participants in the first test and asking for volunteers. We sent retest questionnaires and return envelopes to the participants who had provided their address 1–2 weeks after the initial questionnaire and asked participants to return the retest within a week of receipt.

Ethical considerations

The review board of the Graduate School of Medicine and Faculty of Medicine in the University of Tokyo approved the pilot test and main survey (No. 3841 and 3931). All participants were volunteers and returned the completed questionnaires directly (excluding either the company or school administration) to the researchers.

Measurements

The PedsQL-YA-J has four subscales—Physical Functioning (eight items), Emotional Functioning (five items), Social Functioning (five items), and Work/School Functioning (five items)—and is similar to the PedsQL-O, PedsQL-J, and

PedsQL-YA-O. Respondents were asked to describe the extent to which each item had troubled them over the past 1 month. A 5-point Likert response scale was used (0 = never [a problem]; 1 = almost never; 2 = sometimes; 3 = often; 4 = almost always). Items were reverse-scored and linearly transformed to a 0–100 scale, where higher scores indicate a better HRQOL. To account for missing data, scale scores were computed as the sum of the items divided by the number of items answered. The total from the 23 items was computed in a similar manner. If more than 50 % of the items were missing or incomplete, the scale score was not computed. Previous reports show the original version has acceptable construct validity and internal consistency (Cronbach's coefficient alpha [32] = 0.76–0.86).

The performance of the PedsQL-YA-J was compared with the SF-36 and CES-D scales. Both scales have been validated in Japan and are commonly used in the general population [21, 33]. The SF-36 (version 2) is a 36-item instrument that uses three to six category Likert response scales [20] and produces eight subscales (Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health) and two summary scores (Physical Component Summary and Mental Component Summary). Each scale score and summary score are weighted by norm-based scoring methods [21], where higher scores indicate a better HRQOL. We used the SF-36 scale to test validity as the SF-8 (shortened version of SF-36) scale had been used to verify the validity of the PedsQL-O [28].

The Center for Epidemiologic Studies Depression Scale (CES-D) is a 20-item instrument for assessing symptoms of depression [34]. We used the CES-D to test validity, as this scale has been used to verify the validity of the PedsQL-J [27]. In the CES-D, participants indicate how often they experienced symptoms during the previous week on a four-point scale. A total score is calculated where higher scores represent elevated levels of depressive symptoms. In healthy populations, scores <16 are considered normal, while scores ≥ 16 indicate depression.

Participants were also asked to record their age, gender, first language, educational/employment status (university student, vocational school student, or company employee), working status, living arrangement (living with anyone or alone), subjective symptoms, illness or injury requiring regular medical visits, and subjective opinion of economic status and life. We also added one question to the retest questionnaire: 'Has a significant event affecting you happened since responding to the initial questionnaire?'

Statistical analyses

All analyses were performed using IBM SPSS software, version 19 (SPSS, Inc., Chicago, IL, USA), and the level of

significance was set at 0.05. Score distributions for the PedsQL-YA-J were summarized as mean, standard deviation, minimum and maximum scores, and percentages of floor (0) and ceiling (100) scores, by educational/employment status. We compared mean scores for educational/employment status using Welch's analysis of variance (ANOVA).

Feasibility was determined based on the time taken to complete the pilot questionnaire and the percentage of missing values. Independence of easily missed items was assessed by Cochran's Q test. Reliability was assessed based on internal consistency and retest reliability. Good internal consistency was defined as a Cronbach's coefficient alpha value exceeding 0.70. To determine retest reliability, intraclass correlation coefficients (ICC) between the initial test and retest scores in a one-way random effects model were calculated; an ICC value of 0.40 represented moderate, 0.60 good, and 0.80 high agreement [35]. A paired t test between the initial test and retest scores was used to check whether or not the PedsQL scores had changed.

Validity was assessed based on concurrent validity, convergent and discriminant validity, known-groups validity, and factorial validity. Concurrent validity was checked by calculating Pearson's product-moment correlation coefficients to confirm that the total score and all scale scores were negatively correlated with the CES-D score. Correlation coefficients of 0.10 represent small, 0.30 medium, and 0.50 large correlations [36]. Convergent and discriminant validity were examined by calculating Pearson's product-moment correlation coefficient between the scale scores of the PedsQL-YA-J and the predicted scores from the SF-36 scale. We hypothesized that the correlation of the Physical Functioning scale of PedsQL-YA-J would be highest with that of SF-36, the Emotional Functioning scale of PedsQL-YA-J with the Mental Health scale of SF-36, the Social Functioning scale of PedsQL-YA-J with that of SF-36, and the Work/School Functioning scale of PedsQL-YA-J with the Role Physical scale of SF-36 and Role Emotional scale of SF-36. We hypothesized that the Physical Functioning scale of PedsQL-YA-J would correlate with the Physical Component Summary score of SF-36 rather than the Mental Component Summary score of SF-36 and that the Emotional Functioning scale of PedsQL-YA-J would correlate with the Mental Component Summary score of SF-36 rather than the Physical Component Summary score of SF-36.

We calculated Welch's t test and 95 % confidence intervals between groups to describe known-groups validity and predicted that the Physical Functioning scale score and total score would be low among young adults who had subjective symptoms that the Emotional Functioning scale score and total score would be low among young adults who scored CES-D ≥ 16 and that the Physical Functioning scale, Work/School Functioning scale, and total scores

would be low among young adults who had illness or injury requiring regular medical visits.

We conducted an exploratory factor analysis using the principal factor method and promax rotation. The number of factors was determined so that the discriminant criteria had eigenvalues of 1.0. We hypothesized a five-factor model, being the same as PedsQL-O [26], where two items ('Hurt or ache' and 'Low energy') in the Physical Functioning scale had factor loadings with Emotional Functioning, thus producing one combined factor. The remaining six items of Physical Functioning scale represent one factor. Work/School Functioning items were split into two factors (the first three items of function and the next two items of absence), with Social Functioning considered as one factor.

Table 1 Subject characteristics

	Number of respondents (n)	% Of total
Gender		
Male	190	44.4
Female	238	55.6
Age (years) [mean, SD]	428	[20.1, 1.85]
Educational/employment status		
University student	244	57.0
Vocational school student	151	35.3
Company employee	33	7.7
Working status		
Working full-time	34	7.9
Working part-time	248	57.9
Unemployed	138	31.8
No response	10	2.3
Living arrangement		
Live with others (immediate family, friends, or marriage partner)	281	65.7
Live alone	147	34.3
Subjective symptoms		
Reported	152	36.5
Not-reported	276	64.5
Illness or injury requiring regular medical visits		
Reported	55	12.9
Not-reported	373	87.1
Subjective opinion of current economic status and life		
Very affluent	34	7.9
Reasonably affluent	99	23.1
Normal	190	44.4
Not reasonably affluent	81	18.9
Not very affluent	24	5.6

SD standard deviation, $n = 428$

Table 2 Score distribution of the Japanese version of the PedsQL Generic Core Scales Young Adult Version

	<i>N</i>	Mean	<i>SD</i>	Min.	Floor (%)	Max.	Ceiling (%)
All participants							
Total score	428	86.6	12.6	23.9	0.0	100	5.6
Physical functioning	428	91.7	10.9	0	0.2	100	34.8
Psychosocial summary score	428	83.9	15.4	5	0.0	100	7.0
Emotional functioning	426	80.7	18.8	0	0.2	100	20.2
Social functioning	428	88.6	17.4	0	0.2	100	47.0
Work/school functioning	428	82.5	18.0	0	0.5	100	20.1
University students							
Total score	244	87.2	12.5	30.4	0.0	100	7.0
Physical functioning	244	92.4	10.6	0	0.4	100	37.3
Psychosocial summary score	244	84.5	15.5	25.0	0.0	100	8.2
Emotional functioning	243	82.3	18.5	10.0	0.0	100	24.3
Social functioning	244	87.4	18.2	0	0.4	100	43.0
Work/school functioning	244	83.6	16.8	10.0	0.0	100	20.5
Vocational school students							
Total score	151	86.0	12.6	23.9	0.0	100	4.0
Physical functioning	151	90.9	10.9	37.5	0.0	100	32.5
Psychosocial summary score	151	83.3	15.2	5.0	0.0	100	6.0
Emotional functioning	150	78.0	19.4	0	0.7	100	14.0
Social functioning	151	90.2	16.7	10.0	0.0	100	53.0
Work/school functioning	151	82.0	18.6	0	0.7	100	21.2
Company employees							
Total score	33	85.6	13.6	40.2	0.0	100	3.0
Physical functioning	33	90.6	12.6	34.4	0.0	100	27.3
Psychosocial summary score	33	82.9	15.6	31.7	0.0	100	3.0
Emotional functioning	33	81.2	16.9	40.0	0.0	100	18.2
Social functioning	33	90.2	13.9	45.0	0.0	100	48.5
Work/school functioning	33	77.3	22.9	0	3.0	100	12.1

Missing data were excluded
n = 428

Max. maximum, *Min.*
minimum, *PedsQL* Pediatric
Quality of Life Inventory, *SD*
standard deviation

Results

Sample characteristics

We distributed questionnaires to 842 participants, and 459 (54.5 %) were returned. Thirty-one of these questionnaires were excluded for the following reasons: (1) the questionnaire was incomplete, (2) participant was aged <18 or >25 years, (3) participant's first language was not Japanese, (4) participant's answers to all 20 items in CES-D were either all '0' or '3' (as the CES-D scale allows positive and negative items, questionnaires returning all '0' and all '3' answers were classified as insincere), or (5) participant's answers to all 36 items in SF-36 were identical (similar reason to (4)). A total of 428 (50.8 %) questionnaires were analyzed.

The median age of the participants was 20.0 years (Table 1), and the sample included 244 university students (57.0 %), 151 vocational school students (35.3 %), and 33

company employees (7.7 %). Most company employees were university graduates (*n* = 24 of 33, 73 %), and others had completed graduate school (*n* = 3, 9 %), vocational school (*n* = 3, 9 %), or senior high school (*n* = 3, 9 %).

Scale descriptions

The values for all scales fell in the possible range of 0–100 (Table 2). Nearly half of participants (47.0 %) reported the maximum possible score in the Social Functioning scale, and 34.8 % reported a ceiling effect in the Physical Functioning scale. No floor effect was observed. The mean of the total score and the four scale scores were similar ($\eta^2 = 0.003$, $P = 0.569$ of total score, $\eta^2 = 0.005$, $P = 0.375$ of Physical Functioning, $\eta^2 = 0.012$, $P = 0.096$ of Emotional Functioning, $\eta^2 = 0.006$, $P = 0.251$ of Social Functioning, and $\eta^2 = 0.009$, $P = 0.252$ of Work/School Functioning) across all educational/employment statuses.

Table 3 Reliability of the Japanese version of the PedsQL Generic Core Scales Young Adult Version

	Cronbach's Coefficient Alpha				Retest Reliability ($n = 59$)			
	All	Univ.	Voc.	Comp.	Change ^a	SD	P	ICC
Total Score	0.91	0.91	0.90	0.92	1.8	8.9	0.133	0.68
Physical Functioning	0.77	0.78	0.74	0.85	1.7	9.3	0.153	0.57
Psychosocial Summary Score	0.90	0.91	0.89	0.89	1.8	13.7	0.154	0.73
Emotional Functioning	0.79	0.80	0.78	0.74	1.7	12.6	0.308	0.69
Social Functioning	0.86	0.86	0.87	0.77	1.6	11.7	0.294	0.62
Work/School Functioning	0.80	0.77	0.81	0.84	2.1	13.7	0.239	0.66

Missing data were excluded

$n = 428$

Comp. company employee, *ICC* intraclass correlation coefficient, *PedsQL* Pediatric Quality of Life Inventory, *SD* standard deviation, *Univ.* university students, *Voc.* vocational school student

^a Retest score minus test score

Feasibility

Participants took 1–5 min to complete the PedsQL-YA-J pilot questionnaire. Of all 459 returned questionnaires (including 31 exclusions), an average of 1.2 % of items were incomplete, and missing items were independent of each other ($P = 0.411$).

Reliability

The scales were internally consistent for all participants and in each group by educational/employment status (Table 3). We distributed retest questionnaires to 115 participants, 74 of whom (64.3 %) returned the retest questionnaires. Fifteen questionnaires were excluded because (1) the participant reported a significant event had affected them since the initial questionnaire, or (2) they returned the retest after the prescribed interval.

A total 59 (51.3 %) questionnaires were analyzed for retest reliability. The interval between the initial test and the retest was 8–21 days (median = 16 days). A comparison of respondent characteristics for retest and non-retest participants (Fisher's exact test or Welch's t test) showed that retest participants tended to be older (mean age = 21.4 years, $P = 0.01$) and employed ($n = 12$ [20 %], $P = 0.01$). The initial scores of the retest sample were similar to those of the non-retest sample, and the total as well as each retest scale score were similar to the initial test scale scores (Table 3), indicating moderate to good agreement between the retest and initial scores.

Validity

The PedsQL-YA-J scores were concurrently valid against the CES-D, with Pearson's correlation coefficient for each score as follows: Physical Functioning (−0.43), Emotional

Functioning (−0.57), Social Functioning (−0.46), Work/School Functioning (−0.50), and total (−0.61) (all $P < 0.001$).

Our hypothesis that the correlation would be highest between PedsQL-YA-J Physical Functioning scale and the SF-36 Physical Functioning scale, the Emotional Functioning scale with the Mental Health scale, and the Work/School Functioning scale with the Role Physical scale and Role Emotional scale (Table 4) was confirmed. However, the PedsQL-YA-J Social Functioning scale correlated better with SF-36 Role Emotional scale and Mental Health scale than with the SF-36 Social Functioning scale. The Physical Functioning scale correlated better with the SF-36 Physical Component Summary score than with the Mental Component Summary score, and the Emotional Functioning scale correlated better with the Mental Component Summary score than with the Physical Component Summary score.

Validation for known-groups showed that the Physical Functioning scale was sensitive to subjective symptoms, the Emotional Function scale was sensitive to depression, and the Work/School Functioning scale was sensitive to illness or injury requiring regular medical visits (Table 5). The Physical Functioning scale was insensitive to illness or injury requiring regular medical visits, although the results showed a 1.6-point reduction (95 % confidence interval = −1.3 to 4.6) to illness or injury requiring regular medical visits. The total score was sensitive for subjective symptoms, depression, and illness or injury requiring regular medical visits.

Exploratory factor analysis revealed a structure with six factors, consistent with the assumed structure, supporting factorial validity (Table 6). Two items in the Physical Functioning scale that had factor loadings with Emotional Functioning scale supported the hypothesis. The remaining items of the Physical Functioning scale were divided into

Table 4 Convergent and discriminant validity of the Japanese version of the PedsQL Generic Core Scales Young Adult Version (Pearson's correlation coefficients for each scale)

	MOS 36-Item Short Form Health Survey (SF-36)									
	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS
Physical Functioning	0.60	0.45	0.37	0.38	0.38	0.31	0.44	0.39	0.49	0.32
Emotional Functioning	0.30	0.36	0.25	0.31	0.45	0.34	0.53	0.57	0.30	0.47
Social Functioning	0.26	0.36	0.22	0.25	0.35	0.32	0.44	0.43	0.31	0.35
Work/School Functioning	0.33	0.46	0.28	0.34	0.41	0.35	0.50	0.41	0.42	0.36

Missing data were excluded. All Pearson's correlation coefficients were significant at $P < 0.05$

$n = 428$

BP Bodily Pain, *GH* General Health, *MCS* Mental Component Summary, *MH* Mental Health, *PCS* Physical Component Summary, *PedsQL* Pediatric Quality of Life Inventory, *PF* Physical Functioning, *RE* Role Emotional, *RP* Role Physical, *SF* Social Functioning, *VT* Vitality

two factors, as follows: the first of items 1, 5, and 6, and the second of items 2, 3, and 4. The cumulative proportion was 57.0 %.

Discussion

The results show that the translated PedsQL-YA-J is a feasible, reliable, and valid measure of HRQOL for healthy young adults. None of the four scale scores or the total score differed significantly between the three educational/employment groups (university, vocational school student, and company employee). All four scale scores and the total score were internally consistent regardless of educational/employment status. These results confirm the broad range of application and psychometric properties of the PedsQL-YA for young adults.

Most participants in this study were students in universities or vocational schools, and the mean age (20.1 years) of the participants was in the lower half of the target age range (18–25 years). When our results were compared with those of the Japanese national survey Comprehensive Survey of Living Conditions [37], the proportion of participants reporting subjective symptoms was 15 % higher than that in the previous survey. However, the proportion reporting illnesses and injuries requiring regular medical visits was approximately equal.

Given the socio-economic status of the participants, most are likely to engage in everyday social life. When the scores of university students in the present study were compared with other data [28], the values from the present study were higher in all scales. The greatest difference was found in the Emotional Functioning scale, which was 15.4 points higher than that in previous studies. These findings indicate that the HRQOL of the participants was very good, possibly explaining why the scores for the Physical Functioning and Social Functioning scales showed significant ceiling effects. The observed ceiling effects, particularly of

the Physical and Social Functioning scales are consistent with those of relatively healthy patients exhibiting ceiling effects [30]. The Physical Functioning scale can discriminate physically distressed young adults from healthy ones, although a large sample size is required to discriminate physically fit young adults from those of average fitness. Further, Robert et al. [29] reported the ceiling effect of the Social Functioning scale and discussed its limitation to peer-based relationships and need to be broadened to include romantic relationships for use with adults (aged 25 years or over). Although we concluded that the items on this scale were appropriate for assessment of social functioning continuing longitudinally from childhood, future users should take into account the limited range of relationships for adults.

Our present data showed that the feasibility of the PedsQL-YA-J was high, given that participants were able to complete the questionnaire quickly and the percentage of missing answers was low. The items and format of the PedsQL-YA-J appeared to be easy to understand and answer. The PedsQL-YA-J reliability was also high. Cronbach's alpha coefficients for total and subscales scores were ≥ 0.70 , and an α coefficient ≥ 0.90 for the total score confirmed high internal consistency.

We noted no significant differences in scores between participants completing or not completing the retest, indicating that the data from the retest participants could be used to calculate retest reliability. Although the ICC values showed moderate to good agreement, they did not reach the general standard of reliability (≥ 0.70) [25, 38]. The relatively low ICC of the Social Functioning scale compared with the other scales is consistent with the result of a study using the Persian version of the PedsQL-YA for patients with rheumatoid arthritis in Iran [39]. We consider the markedly low ICCs noted with the Physical and Social Functioning scales to be due to the ceiling effect. The reliability of the PedsQL-YA-J is supported by internal consistency.

Table 5 Known-groups validity of the Japanese version of the PedsQL Generic Core Scales Young Adult Version

	Subjective symptoms				Dif.	95 % CI	P
	Reported (n = 152)		Unreported (n = 276)				
	Mean	SD	Mean	SD			
Total Score	84.4	12.6	87.9	12.4	3.4	0.9–5.9	0.007
Physical functioning	89.2	11.7	93.1	10.1	3.8	1.6–6.0	0.001
Psychosocial summary score	81.9	15.3	85.1	15.3	3.2	0.2–6.3	0.038
Emotional functioning	76.9	20.4	82.7	17.5	5.8	1.9–9.7	0.003
Social functioning	87.8	17.7	89.1	17.3	1.3	–2.2–4.8	0.454
Work/school functioning	80.8	17.6	83.5	18.2	2.8	–0.8–6.3	0.124
	CES-D score				Dif.	95 % CI	P
	16 or over (n = 149)		Under 16 (n = 279)				
	Mean	SD	Mean	SD			
Total Score	78.3	14.0	91.1	9.0	12.8	10.3–15.3	<0.001
Physical Functioning	87.0	13.8	94.2	7.9	7.3	4.9–9.7	<0.001
Psychosocial Summary Score	73.7	17.0	89.4	11.1	15.7	12.7–18.7	<0.001
Emotional Functioning	68.3	19.2	87.3	14.8	19.0	15.5–22.6	<0.001
Social Functioning	80.8	21.0	92.8	13.5	12.0	8.3–15.8	<0.001
Work/School Functioning	72.2	21.4	88.1	13.0	15.9	12.1–19.7	<0.001
	Illness or injury requiring regular medical visits				Dif.	95 % CI	P
	Existence (n = 55)		Non-existence (n = 373)				
	Mean	SD	Mean	SD			
Total Score	83.3	12.8	87.1	12.5	3.8	0.1 to 7.5	0.042
Physical Functioning	90.3	10.3	91.9	10.9	1.6	–1.3 to 4.6	0.275
Psychosocial Summary Score	79.6	16.1	84.6	15.2	5.0	0.4–9.6	0.035
Emotional Functioning	75.7	20.4	81.4	18.4	5.7	–0.2 to 11.5	0.056
Social Functioning	87.4	18.0	88.8	17.4	1.4	–3.7 to 6.6	0.578
Work/School Functioning	76.2	20.6	83.5	17.5	7.3	1.5–13.1	0.015

Missing data were excluded
 n = 428
 CES-D Center for
 Epidemiologic Studies
 Depression Scale, CI confidence
 interval, Dif. difference,
 PedsQL Pediatric Quality of
 Life Inventory, SD standard
 deviation

Content validity was assessed via cognitive interview with participants after questionnaire completion, discussion between the authors with clinical experience in the pediatric area and research experience in scale development, and confirmation by JWV. We confirmed that the Japanese translations of the questions were clear and appropriate for the young adults in the target age range (18–25 years) that the concepts in the scales were understandable and could be answered and concluded that the PedsQL-YA-J and PedsQL-YA-O [28] were equivalent and consistent with PedsQL-J [27].

The total and four subscale scores for the PedsQL were all correlated with the CES-D results indicating concurrent validity. Convergent scales in PedsQL and SF-36 were also correlated, thus verifying convergent and discriminant validity of the PedsQL-YA-J compared with the SF-36 scale, except for the Social Functioning scale. The PedsQL-YA-J Social Functioning scale correlated better with

the SF-36 Role Emotional and Mental Health subscales than with the SF-36 Social Functioning scale. The PedsQL and SF-36 questionnaires might therefore evaluate different aspects of social health and function. In particular, the PedsQL Social Function scale evaluates the difficulty in building a relationship with others by asking questions such as, ‘Do you have difficulty getting on with peers?’ In contrast, the SF-36 Social Functioning subscale evaluates social activity via questions such as, ‘In the past month, how much everyday socializing with your family, friends, and neighbors was disturbed for physical or psychological reasons?’ The PedsQL framework was designed to evaluate a patient’s social development and ability to build relationships with others. In contrast, SF-36 was designed for patients older than 15 years of age [21] and focuses on the nature of adult social activity. These differences may reduce the correlation between the PedsQL and SF-36 Social Functioning scales.

Table 6 Factorial validity of the Japanese version of the PedsQL Generic Core Scales Young Adult Version

	F. 1	F. 2	F. 3	F. 4	F. 5	F. 6
Physical Functioning						
Hard to walk more than one block	−0.09	0.09	0.10	−0.14	0.79	0.04
Hard to run	0.00	−0.01	0.67	−0.04	0.16	0.06
Hard to do sports or exercise	−0.02	0.04	0.98	−0.03	−0.07	−0.02
Hard to lift something heavy	0.06	−0.03	0.63	0.09	0.00	0.04
Hard to take bath or shower	−0.03	0.02	−0.05	−0.01	0.91	−0.03
Hard to do chores around house	0.30	−0.11	0.05	0.20	0.35	−0.08
Hurt or ache	0.43	0.01	−0.05	0.02	0.20	0.08
Low energy	0.57	−0.06	−0.03	0.22	0.16	0.01
Emotional functioning						
Feel afraid or scared	0.56	0.25	0.03	−0.06	−0.10	0.06
Feel sad or blue	0.95	−0.04	0.00	−0.13	−0.08	−0.05
Feel angry	0.57	0.05	0.03	0.02	−0.01	−0.04
Trouble sleeping	0.28	0.07	−0.09	0.18	0.04	0.12
Worry about what will happen	0.64	0.11	0.06	0.05	−0.14	−0.04
Social Functioning						
Trouble getting along with peers	0.10	0.63	0.10	−0.01	0.02	−0.14
Others not wanting to be friend	0.02	0.79	0.04	−0.10	0.02	0.08
Teased	0.13	0.61	−0.13	−0.21	0.00	0.28
Doing things other peers do	−0.04	0.67	−0.05	0.25	0.09	−0.04
Hard to keep up with peers	0.00	0.71	0.01	0.25	0.00	−0.13
Work/School Functioning						
Hard to concentrate	0.02	−0.03	−0.01	0.76	−0.03	0.00
Forget things	0.13	−0.10	0.02	0.58	−0.03	0.11
Trouble keeping up with work/studies	−0.13	0.18	0.02	0.78	−0.09	0.06
Miss work/school-not well	−0.01	0.02	0.04	0.10	−0.01	0.83
Miss work/school-doctor appointment	−0.03	−0.05	0.03	0.05	0.00	0.86

Factor patterns from a principal factor method with promax rotation. The largest factor loadings of each item are bolded
 $n = 423$

F. Factor, *PedsQL* Pediatric Quality of Life Inventory

We confirmed the known-groups validity of the PedsQL Physical Functioning, Emotional Functioning and Work/School Functioning scales were sensitive to subjective symptoms, depression tendencies, and regular medical visits, respectively. Meanwhile, we did not observe any significant differences between the scores for ‘injury or illness requiring regular medical visits’ and the Physical Functioning score. This may be because we did not request details regarding the severity of injuries, illness, or disease requiring medical visits, and participants might have reported minor injuries or illness which did not affect their physical functioning.

Although the factorial analysis identified a six-factor structure (one more than the five factors hypothesized), we do not recommend using the PedsQL-YA-J with different scoring methods from the PedsQL-O, PedsQL-J, and PedsQL-YA-O. Work/School Functioning items split into two different factors hypothesized a priori, being the same

as the PedsQL-O [26] and the modified PedsQL-YA-O [30]. Both factors (work/school functioning and missing) might therefore act together as indicators of Work/School Functioning from different perspectives.

Consistent with our hypothesis, two items split from the Physical Functioning scale, which was similar to the result of a previous study of the PedsQL-O among healthy children [26, 30]. However, of note, the remaining six items of the Physical Functioning scale acted as two factors, where the questions for first, fifth, and sixth items assessed the ability to walk, bathe, or undertake household chores, compared with those in the second, third, and fourth items which assessed the ability to participate in running, jogging, or sports. The former questions identify common tasks that are less strenuous than the latter, and the separation into two groups probably arises because the participants were healthy young adults without difficulty in normal social life. Given that Ewing et al. [30] reported a

different factor structure (six items in one factor) for the modified PedsQL-YA among young adults with cancer or a blood disorder, our present finding may be sample specific. To our knowledge, this is the first report on the structure of factors for the PedsQL-YA in healthy young adults.

Several limitations to the present study warrant mention. First, given that most participants were young and in good health, PedsQL-YA-J data obtained from hospitalized patients with illness or disorders or people without everyday social lives should be interpreted with caution. Participants were also drawn from a limited range of socio-economic groups, and the scale should therefore be tested with other groups before application to other populations. Future studies and analyses are needed to explore the sensitivity and responsibility of the PedsQL-YA-J and its factor structure among young adults with chronic disease. Furthermore, longitudinal studies to monitor children with health problems as they move into young adults are needed.

However, we consider the advantages of this study to include retest reliability, concurrent validity and factorial validity, which were not assessed by the original version [28]. Although the initial PedsQL-YA-O development was restricted to university students [28], our study tested a broader population sample including vocational school students and company employees.

Conclusion

Here, we report that the PedsQL-YA-J is a feasible, reliable, and valid method for assessing HRQOL among young adults in education, employment, or training, or for clinical trials and epidemiological research. This scale measures HRQOL consistently from children to young adults and can thus be used for longitudinal assessments and long-term follow-up studies. Longer-term data for HRQOL will help support the survivors of chronic childhood diseases.

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V. 実施体制名簿

実施体制名簿

区分	名前	所属
業務主任者	真部 淳	聖路加国際大学 聖路加国際病院 小児科
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	渡辺 新	中通総合病院 小児科
	康 勝好	埼玉県立小児医療センター 血液腫瘍科
	富澤 大輔	国立成育医療研究センター 小児がんセンター血液腫瘍科
	後藤 裕明	神奈川県立こども医療センター 血液・再生医療科
	堀 壽成	愛知医科大学 小児科
	出口 隆生	三重大学医学部附属病院 小児科
	高木 正稔	東京医科歯科大学 発生発達病態学分野
	小林 良二	札幌北榆病院 小児思春期科
	中澤 温子	国立成育医療研究センター 病理診断部
	嶋田 博之	慶應義塾大学医学部 小児科
	矢部 普正	東海大学医学部 基盤診療学系再生医療科学
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	前田 尚子	国立病院機構名古屋医療センター 小児科
	森 尚子	新座志木総合病院 緩和ケア科
	山口 悦子	大阪市立大学 医療安全管理部
	力石 健	東北大学医学部 小児科
	佐藤 伊織	東京大学大学院医学系研究科 健康科学・看護学専攻家族看護学分野

