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Young carers in Japan: Reliability and validity testing of the BBC/University of Nottingham young carers survey questionnaire and prevalence estimation in 5000 adolescents

Akiko Kanehara PhD, MPH[1] | Ryo Morishima PhD[1,2] | Yusuke Takahashi MD[1,3] | Haruna Koike PhD[1] | Kaori Usui MA[4] | Shun-ichi Sato MD[1] | Akito Uno MD[1] | Yutaka Sawai MD[1] | Yousuke Kumakura MD, MPH[1,5] | Sho Yagishita MD, PhD[6] | Satoshi Usami PhD[7] | Masaya Morita MD, PhD[1] | Kentaro Morita MD, PhD[8] | Sho Kanata MD, PhD[9] | Naohiro Okada MD, PhD[1,10] | Syudo Yamasaki PhD[11] | Atsushi Nishida PhD[11] | Shuntaro Ando MD, PhD[1,4] | Shinsuke Koike MD, PhD[1,10,12,13,14] | Tomoko Shibuya PhD[15] | Stephen Joseph PhD[16] | Kiyoto Kasai MD, PhD[1,4,12,13]

[1]Department of Neuropsychiatry, The University of Tokyo Hospital, Tokyo, Japan

[2]The Health Care Science Institute, Tokyo, Japan

[3]St. Luke's International Hospital, Tokyo, Japan

[4]Department of Neuropsychiatry, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

[5]Department of Mental Health, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

[6]Department of Structural Physiology, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

[7]Graduate School of Education, The University of Tokyo, Tokyo, Japan

[8]Department of Rehabilitation, The University of Tokyo Hospital, Tokyo, Japan

[9]Department of Psychiatry, Teikyo University Hospital, Tokyo, Japan

[10]The International Research Center for Neurointelligence at The University of Tokyo Institutes for Advanced Study, The University of Tokyo, Tokyo, Japan

[11]Research Center for Social Science & Medicine, Tokyo Metropolitan Institute of Medical Science, Tokyo, Japan

[12]University of Tokyo Institute for Diversity & Adaptation of Human Mind, Tokyo, Japan

[13]University of Tokyo Center for Integrative Science of Human Behavior, Graduate School of Art and Sciences, The University of Tokyo, Tokyo, Japan

[14]Center for Evolutionary Cognitive Sciences, Graduate School of Arts and Sciences, The University of Tokyo, Tokyo, Japan

[15]Faculty of Humanities, Seikei University, Tokyo, Japan

[16]School of Education, University of Nottingham, Nottingham, UK

Correspondence
Kiyoto Kasai, MD, PhD, Department of Neuropsychiatry, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-8655, Japan.
Email: kasaimd@gmail.com

Abstract

Aim: Young carers (YCs) refer to children under the age of 18 who assume responsibilities that would normally be assumed by adults, such as caring for family members in need of care. In recent years, the concept of YCs has been expanding in Japan, and the government has been rapidly implementing strategies to support them. There is a need for a survey scale for YCs that uses standardized methods that can be compared internationally.

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Method: The BBC/University of Nottingham Survey for estimating the prevalence of YCs and caring activities of United Kingdom adolescents was translated into Japanese, and its reliability and validity were tested with 313 adolescents. Moreover, the prevalence of YCs was estimated in a school-based survey among 5000 adolescents.

Results: The Young Carers Scale Japanese version (YCS-J) was acceptably reliable and valid. The original six-factor model for caring activity in the Multidimensional Assessment of Caring Activities Checklist for Young Carers (MACA-YC18) was supported by confirmatory factor analysis. The prevalence of YCs among 5000 adolescents in the Tokyo metropolitan area was estimated to be 7.4%, comparable to that reported in Western countries and in recent surveys in Japan using nonstandardized methods. YCs exhibited significantly higher scores for prosocial behavior and emotional symptoms than non-YCs.

Conclusions: The YCS-J, as an internationally comparable instrument, will be useful for understanding the actual situation of YCs in Japan, and to disseminate and implement support through cooperation among education, welfare, and healthcare sectors.

KEYWORDS

Japan, prevalence, reliability, validity, young carers

INTRODUCTION

Young carers (YCs) refer to children and adolescents under the age of 18 who assume responsibilities that would normally be assumed by adults, such as caring for family members in need of care and performing household chores.[1,2] The United Kingdom (UK) is a leader in promoting support for YCs. The term "carer" was born when attention was drawn to the burden experienced by family members while caring for a person with a disease or disability. From the perspective of protecting the rights of children to study and do what they want to do as children, teenagers who take care of their families are called YCs because they assume the burden of care that should normally be borne by society and adults. In the UK, laws concerning YCs and related support in schools have been developed.[2,3]

Following the lead of the UK, surveys and research on YCs have been conducted in Western countries such as Sweden, Switzerland, Canada, and the United States.[4–9] In Japan, the introduction of the concept of YCs and the effort to establish support has been slow, but the activities of the Japan Carers Federation and the introduction of the UK's approach in a book by Shibuya[10] have spread awareness of the concept. In addition, Saitama Prefecture, which is adjacent to Tokyo, took the lead over other prefectures in establishing an ordinance and surveying the actual situation surrounding YCs.[11] Furthermore, the Ministry of Health, Labor and Welfare (MHLW) and the Ministry of Education, Culture, Sports, Science, and Technology (MEXT) have jointly deliberated on the establishment of a support system.[12]

To disseminate and implement support for YCs in Japan in the future, a survey of the actual situation is indispensable. In the UK, a survey conducted jointly by the British Broadcasting Corporation (BBC) and the University of Nottingham in 2018 revealed that about 22% of participants met the definition of YCs, and about 7% of the participants were responsible for high amounts of care.[13] Other European countries have recently conducted studies on the prevalence of YCs, and reported rates of 4.5%–7.9%.[7,14] In Japan, Hamashima and Miyakawa[15] found that 5.2% of respondents (high school students, $N = 5246$) were YCs, while the Saitama Prefecture website[11] found 4.1% of 11th-grade high school students ($N = 48{,}261$) were carers, and the MHLW/MEXT survey (2021) found that 5.7% of respondents (8th-grade junior high school students, $N = 5558$) and 4.1% of respondents (11th-grade full-time high school students, $N = 7407$) were YCs. The definitions of YCs in these Japanese surveys were similar to those in the UK, but they did not use a standardized scale. Okuyama[16] developed the Young Carer Psychological Scale Japanese version based on the Young Carer of Parents Inventory (YCOPI),[17] which was not intended for prevalence estimation of YCs. It is necessary to conduct epidemiological surveys using internationally comparable scales to promote the support of YCs in Japan by learning from the advanced efforts in the UK and other countries. In this study, we developed a Japanese version of the questionnaire in collaboration with the original authors of the BBC and University of Nottingham survey, and verified its reliability and validity. In addition, two questions, which are part of the full scale and are used to determine the prevalence of YCs, were asked to 5000 junior and senior high school students to estimate the prevalence in Japan. Moreover, some previous literature discussed potential positive outcomes in young carers,[18,19] and we sought to investigate whether YCs may be associated with not only emotional symptoms but also positive outcome such as prosocial behavior.

METHODS

Overall study design

This study includes two aims (Aim 1 and 2). Aim 1 is the development of the Young Carers Scale Japanese version, and the reliability and

validity were tested. Aim 2 is the survey of prevalence of young carers in Japan.

Participants

Participants for Aim 1 were 313 junior and senior high school students residing in the Tokyo metropolitan area, including 145 private junior high school students (8th grade, 13–14 years old, all males), 86 private high school students (11th grade, 16–17 years old, all males), and 82 participants from the Tokyo Teen Cohort (11th and 12th grade high school students, 16–18 years old, male 43, female 39).[20,21]

Aim 2 was conducted through cooperation with the Association for Saitama Private Junior and Senior High Schools, and the heads and administrators of Saitama Prefecture. This study employed a cross-sectional survey design using an anonymous questionnaire with 21 schools (n = 9 junior and n = 12 senior high schools) from October 1 to November 7, 2020. Willingness to participate was verified by obtaining written informed consent. Of the 5538 recruited students, 5000 agreed to participate (response rate = 90.3%).

Development of the Young Carers Scale Japanese version (Aim 1)

First, the questionnaire used in the 2018 BBC/University of Nottingham Survey, available in Appendix A of the original paper,[13] was translated into Japanese with permission from the original author, Dr. Stephen Joseph. The survey questionnaire includes eight questions. Q1 and Q2 are used to operationally determine whether the respondent is a YC. Q1 asks if there is someone in the respondent's home who suffers from an illness or disability. If he/she answers yes to Q1, Q2 then asks whether he/she helps to look after the person and does things to help them around the home. YCs were operationally defined as those who answered yes to both Q1 and Q2. Q3 and Q4 ask about the relationship between the family member being cared for and the respondent (mother, father, sibling, grandparent, other) and what type of disability or disease the family member needs care for (physical disability, learning disability, mental health problems, etc.). Q5 corresponds to a modified version of the Multidimensional Assessment of Caring Activities Checklist for Young Carers (MACA-YC18[22]; see Table 1 for the 18 items from this

TABLE 1 Item questions for the Japanese version of the MACA-YC18

Item no.	Domain	Question	Cronbach's α	Factor loadings of CFA
1	Domestic chore	Clean your own bedroom	0.577	0.544
2		Clean other rooms		0.682
3		Wash up dishes or put dishes in a dishwasher		0.511
4[a]	Household management	Change wardrobes seasonally, or replace light bulbs or batteries in the house	0.573	0.604
5		Take responsibility for shopping for food		0.599
6		Help with lifting or carrying heavy things		0.491
7	Financial/practical	Help with financial matters such as dealing with bills, banking money, or collecting benefits	0.372	0.344
8		Work part time to bring money in		0.287
9		Interpret, sign, or use another communication system to help someone in the house		0.593
10	Personal care	Help someone in the house to dress or undress	0.662	0.635
11		Help someone in the house to have a wash		0.68
12		Help someone in the house to have a bath or shower		0.585
13	Emotional care	Keep someone in the house company, for example sitting with them, reading to them, and talking to them	0.664	0.631
14		Keep an eye on someone in the house to make sure they are alright		0.761
15		Take someone in the house out, for example for a walk or to see friends or relatives		0.525
16	Sibling care	Take brothers or sisters to school	0.837	0.633
17		Look after brothers or sisters whilst another adult is nearby		0.939
18		Look after brothers or sisters on your own		0.841

Abbreviation: CFA, confirmatory factor analysis.

[a]In the original version, the question was “decorate rooms.”

checklist), originally intended to query YCs as to the domains and the amounts of caring activities. The modified version is an 18-item questionnaire that asks what type and amount of caring activities are provided by adolescents in general, not necessarily specific to YCs. The 18 items are divided into six domains (each consisting of three items; see Table 1): domestic chores, household management, financial/practical, personal, emotional, and sibling care. Each item of the MACA-YC18 was examined for its suitability for Japanese culture. Items considered incompatible with Japanese culture were replaced after consultation with Dr. Joseph. Next, to investigate whether the questionnaire sentences were understandable to teenagers, semistructured interviews were conducted with three junior high school students and five junior high school teachers to ask them to assess the understandability of the questionnaire. The results were compiled, and the Japanese translation was finalized by a team of researchers consisting of psychiatrists, psychologists, and psychiatric social workers with many years of clinical experience. The back-translation was commissioned by an outside translation company, and the translators had not seen the original version of the scale before or during the translation back to English. The original author confirmed it to be consistent with the original version.

Reliability and validity testing (Aim 1)

Internal consistency

Cronbach's α was calculated using the data on 313 MACA-YC18 and those on six domains to examine reliability.

Test-retest reliability

The test–retest intraclass correlation coefficient (ICC) of the MACA-YC18 total score was calculated for 28 high school students who were administered the Young Carers Scale Japanese version (YCS-J) for the second time within 1 month after the first administration.

Convergent validity

A question asking about time spent engaging in caring activities on weekdays and weekends was included, following the method used in the development of the MACA-YC18.[22] The correlation between MACA-YC18 total score and time spent on caring activities was tested.

Predictive validity

Prosocial behavior score on the Strength and Difficulty Questionnaire (SDQ)[23] was used to test the predictive validity of the MACA-YC18 in the YCS-J.

Discriminant validity

We compared scores on each of the six domains of the MACA-YC18 between two groups: YC, those who met the definition of a YC (those who answered yes to both Questions 1 and 2), and non-YC, those who answered no to Q1 (those who answered "not sure" to Q1 were excluded).

Structural validity

Finally, a confirmatory factor analysis (CFA) was conducted on the MACA-YC18 data to test the goodness of fit of the original model (six factors each consisting of three items[22]).

Survey of prevalence of young carers in Japan

Because the survey on the prevalence of YCs was conducted as part of a questionnaire survey for educational purposes, only two items, Questions #1 and #2, were requested to be answered to reduce the psychological burden on the participants. SDQ data were also collected from most of the participants.

Statistical analysis

All statistical analyses were conducted using IBM SPSS version 27 and AMOS version 28.

For testing convergent validity (Aim 1), we used Spearman's rank correlation and judged the Japanese version of the MACA-YC18 to be valid when a positive and significant correlation was found between the total score on the MACA-YC18 and the total time spent on caring activities per week ($P < 0.05$, two-tailed).

For testing predictive validity, Spearman's ρ was calculated between the total score on the MACA-YC18 and each score on the five factors of the SDQ (prosocial behavior, difficulties in emotional symptoms, conduct problems, hyperactivity/inattention, and peer relationship problems). We judged the MACA-YC18 Japanese version to be valid if the MACA-YC18 total score showed a positive and significant correlation (Spearman's rank correlation, $P < 0.05$, two-tailed) with the SDQ prosocial behavior score but no positive correlation with the other four factors. We did not correct for multiple statistical comparisons because we had a specific prediction in advance.

For testing discriminant validity, we used the Mann-Whitney U test and considered it to be further evidence of validity if we found that YCs performed significantly more caring activities in at least some MACA-YC18 domains ($P < 0.05$, two-tailed). We did not correct for multiple statistical comparisons because we had a specific prediction in advance.

For CFA, the acceptability of the model fit was judged by the following standards: a comparative fit index (CFI) >0.90 and root mean square error of approximation (RMSEA) values of <0.10.[24,25]

For Aim 2, we compared scores on five factor scores and total difficulties (sum of the four difficulty factor scores) on the SDQ between YC and non-YC groups using *t*-tests. In advance, we predicted that scores on prosocial behavior, emotional symptoms, and total difficulties would be higher for YCs than for non-YCs ($P < 0.05$). We did not correct for multiple statistical comparisons because we had a specific prediction in advance.

Ethical procedure

The ethical committee of the Faculty of Medicine, The University of Tokyo approved the study (2019271NI-(3); 10069-(25); 2019326NI-(4)). Written informed consent was obtained for the interviews with three junior high school (7th–9th grade) students from themselves and from their parents. Written informed consent was also obtained for the interviews with five junior high school teachers. Each interviewee received a prepaid card worth JPY 5000 (approximately 45 USD).

To obtain reliability and validity data, senior high school students (11th grade) provided informed consent for their participation (approval number: 2019271NI-(3)). The participants expressed their consent to participate in the study by responding to the questionnaires. For junior high school students (8th grade), data were obtained from questionnaire responses administered as part of a study to develop materials to enhance psychological resilience in this age group (Approval Number: 2019326NI-(4)). Senior high school students (11th–12th grades) from the Tokyo Teen Cohort Study gave written informed consent for their participation (Approval Number: 10069-(25)). The participants in the study testing reliability and validity did not receive compensation.

To obtain data on the prevalence of YCs, willingness to participate was verified by obtaining written informed consent (Approval Number: 2019271NI-(3)). Participants in the survey were not compensated.

RESULTS

Development of YCS-J (Aim 1)

As a result of the interviews with junior high school students and teachers, regarding Q1, there were comments that the words "illness" and "disability" might be difficult for respondents to understand, so the following note was added: "Examples of illnesses and disabilities include cancer, epilepsy, heart problems, physical disability, intellectual disability, and mental health problems." It was also found that asking them to choose "I do not provide help" in Q3 or "I do not look after anybody" in Q4, even if they did not answer "Yes" to Q1 or Q2, could be confusing. For this reason, we created a questionnaire that instructed respondents to skip Q3 and Q4 and proceed to Q5 if they answered "No" or "Nobody has an illness or disability" for Q2. Furthermore, as a result of administering the completed questionnaire to 313 students to verify its reliability and validity, it was found that asking students to answer "Nobody has an illness or disability" again in Q2, even if they answered "Not sure" or "No" to Q1, could also cause confusion. In the final Japanese version to be published in this paper (Supplementary Material), if the answer is "Not sure" or "No" in Q1, the instruction is to skip Q2, Q3, and Q4 and proceed to Q5. In addition, the final YCS-J also modified Q8 for the respondents to choose from grades 7 through 12.

As a result of the examination of the suitability of the items for Japanese culture, three modifications were made. The first concerns physical disability as mentioned in Q4. In the original version, the example description of physical disability includes difficulties in getting around and lifting things, but when we checked with the original author, it also included sensory disabilities. Therefore, in the Japanese version, we added "problems with seeing and hearing" as examples.

The second modification concerns the term "learning disability" in Q4. When we checked with the original authors, they intended the meaning of intellectual disability, so in the Japanese version this is described as intellectual disability.

The third modification regards Item 4, "Decorate rooms" in Q5 (MACA-YC18). Japanese people do not decorate their rooms as people do in the UK, and adolescents might not be able to imagine what the item means. Alternatively, Japanese people change out the clothes in closets or wardrobes every season. In the original MACA YC-18 (2009), the preliminary list of 42 items was subjected to factor analysis, and "decorate rooms" was the third-ranked item comprising the household management factor. The fourth-ranked item, which was dropped in the final 18-item version was "do repairs to the home," which is relatively popular for Japanese people as household management, and YCs are likely have to carry out such repairs on behalf of other family members, for example, replacing light bulbs or batteries of the electronic devices. Therefore, we revised the Item 4 to "change the wardrobes seasonally, or replace light bulbs or batteries in the house."

Reliability and validity testing (Aim 1)

A total of 28/313 (8.9%) respondents answered "Yes" to both Questions 1 and 2, meaning they met the operational definition of YCs.

Internal consistency

The Cronbach's α coefficient was 0.761, indicating acceptable internal consistency. The Cronbach's α coefficients for six domains of MACA-YC18 are reported in Table 1.

Test–retest reliability

The test–retest ICC was 0.719, indicating moderate test–retest reliability.

Convergent validity

The MACA-YC18 total score showed a significant positive correlation with the time spent on caring activities per week ($n = 86$, Spearman's $\rho = 0.381$, $P < 0.001$).

Predictive validity

The MACA-YC18 total score showed a significant positive correlation with the score on the prosocial behavior domain of the SDQ ($N = 231$, Spearman's $\rho = 0.174$, $P = 0.008$) but not for scores on the other four domains ($\rho < 0.059$).

Discriminant validity

The Mann–Whitney U test for group comparison of scores on domains of MACA-YC18 found that YCs ($N = 28$) were significantly associated with higher levels of caring activities than those with no caring responsibilities ($N = 256$) for the financial/practical ($P = 0.016$), personal ($P = 0.014$), and sibling care ($P = 0.033$) domains (Table 2).

Structural validity

The goodness-of-fit indices in the CFA were CFI 0.906 and RMSEA 0.059, indicating an acceptable fit. Factor loadings for each item on the MACA-YC18 are reported in Table 1.

Prevalence estimation of young carers in Japan (Aim 2)

Demographic variables are shown in Table 3. Using the operational criteria, 6.7% (52/780) of junior high school students and 7.5% (318/4220) of high school students (7.4% for a total of 370/5000) were judged to be YCs. The comparison of SDQ factors between YC ($N = 370$) and non-YC ($N = 4147$) showed that scores for prosocial behavior ($t = 4.36$, $p < 0.001$), emotional symptoms ($t = 5.15$, $p < 0.001$), and total difficulties ($t = 3.96$, $p < 0.001$) were significantly higher in the YC group than in the non-YC group (Table 4). Additionally, although not predicted in advance, we found a small but significant difference in scores for the attention/hyperactivity factor ($t = 2.05$, $P = 0.041$).

DISCUSSION

This study was conducted in collaboration with the University of Nottingham with the aim of developing a Japanese version of the questionnaire used in the Young Carers Survey conducted jointly by the BBC and University of Nottingham, and verifying its reliability and validity. As a result, YCS-J was found to be reliable and valid. In addition, when the prevalence of YCs in Japan was estimated for the first time using this standardized method, the two-item estimated prevalence among 5000 junior and senior high school students in the Tokyo metropolitan area was 7.4%.

In terms of reliability testing, the Cronbach's α and test–retest ICC of this study were both acceptable. Regarding validity testing, the correlations between the MACA-YC18 total score and the time spent on caring activities and the prosocial behavior domain score on the SDQ were also significant as hypothesized. In addition, those who met the criteria for YCs were engaged in significantly more care activities than those with no caring responsibilities in three of the MACA-YC18 domains. Furthermore, the model fit indices in the CFA

TABLE 2 Comparison of MACA-YC18 domain scores and well-being between YC and non-YC

		YC $N = 28$		Non-YC $N = 256$		Group comparison Mann–Whitney U test	
MACA domain scores	**Range**	**Mean**	**SD**	**Mean**	**SD**	**Mann–Whitney U**	**P-value**
Domestic chore	0–6	2.07	1.44	2.46	1.44	4126.5	0.179
Household management	0–6	2.29	1.88	2.18	1.44	3574.5	0.981
Financial/practical	0–6	0.68	0.91	0.36	0.78	2834.0	**0.016***
Personal care	0–6	0.32	0.77	0.11	0.48	3143.0	**0.014***
Emotional care	0–6	1.64	1.57	1.14	1.37	2933.5	0.094
Sibling care	0–6	1.32	2.02	0.50	1.09	2934.5	**0.033***
MACA total score	0–30	8.32	5.62	6.74	3.94	3115.5	0.254
Well-being total score	0–24	11.46	5.34	12.38	3.95	3829.0	0.551

Abbreviations: MACA-YC, Multidimensional Assessment of Caring Activities Checklist for Young Carers; YC, young carers.

*$P < 0.05$.

TABLE 3 Descriptive statistics of study participants (total *N* = 5000)

Grade, *N* (%)		
7th	5	(0.1)
8th	764	(15.3)
9th	11	(0.2)
10th	326	(6.5)
11th	3605	(72.1)
12th	289	(5.8)
Gender, *N* (%)		
Male	2739	(54.8)
Female	2214	(44.3)
Other	24	(0.5)
Country of origin, *N* (%)		
Japanese	4886	(97.7)
Other	55	(1.1)
Living with parent, *N* (%)		
Both	4196	(83.9)
Single	659	(13.2)
No	145	(2.9)
Number of siblings, mean (SD)	1.13	(0.9)
Young carer, *N* (%)	370	(7.4)
Prosocial behavior, mean (SD)	6.12	(2.2)
Emotional symptoms, mean (SD)	3.99	(2.7)
Conduct problems, mean (SD)	1.92	(1.5)
Attention/hyperactivity, mean (SD)	3.72	(2.2)
Peer relationship problems, mean (SD)	2.48	(1.7)
Total difficulties score, mean (SD)	12.1	(5.4)

were acceptable for the original six-factor structure of the MACA-YC18.

The prevalence rate was 8.9% among the 313 adolescents participating in the reliability and validation tests, and 7.4% among the 5000 junior and senior high school students. These rates were lower than the UK rate of 22% using the same operational criteria[13] but are consistent with the results reported in other countries and in surveys conducted in Japan using nonstandardized methods. The reason for the lower rate in Japan in comparison to the UK is not clear, but it may be due to the high degree to which mothers are responsible for domestic work in Japanese households and the lower rate of people receiving psychiatric care as well as the lower prevalence rate of psychiatric disorders in Japan compared to Western countries (Kawakami et al., 2005). It is possible that even if a child has a substantial role in the care of a family member, the child may not be aware or informed that the family member has a mental illness. Alternatively, the concept of YCs is less prevalent in society, and it is also possible that the YCs are not aware that they themselves are providing care. Some youth live with an ill relative without self-identification as carers by youth. In fact, the literature on young carers indicates that to some extent most youths perform caregiving tasks and assume some responsibility for contributing to family functioning even in families without ill members. Therefore, youth caregiving is considered to occur on a continuum and applicable to diverse youth caregiving contexts, although it is likely to be intensified by illness in a family member, especially if the ill family member is a parent.[26,27]

Among the 5000 students, as expected, the YCs had higher scores on the SDQ for prosocial behavior, emotional symptoms, and total difficulties. The high scores for emotional symptoms may justify the need to identify and support YCs in school settings. Although this was not expected, the fact that attention/hyperactivity scores were higher in YCs is difficult to interpret. However, one possibility is that YCs may be distracted by the dual tasks of schoolwork and care, and a longitudinal study to test this hypothesis is warranted.

This study has several limitations. First, when recruiting participants for reliability and validity testing, the original plan was to collect data primarily from public junior and senior high schools in the Tokyo metropolitan area, taking into account the socioeconomic

TABLE 4 SDQ differences between YC and non-YC

	YC (*N* = 370)				Non-YC (*N* = 4147)				Group comparison	
SDQ factors	*N*	Attrition (%)	Mean	(SD)	*N*	Attrition (%)	Mean	(SD)	*t*	P-value
Prosocial behavior	361	2.4	6.7	(2.1)	4017	3.1	6.1	(2.2)	4.36	0.000*
Emotional symptoms	361	2.4	4.6	(2.7)	4017	3.1	3.9	(2.6)	5.15	0.000*
Conduct problems	361	2.4	1.9	(1.5)	4013	3.2	1.9	(1.4)	0.95	0.343
Attention/hyperactivity	361	2.4	3.9	(2.3)	4017	3.1	3.7	(2.2)	2.05	0.041*
Peer relationship problems	361	2.4	2.6	(1.8)	4011	3.3	2.4	(1.6)	1.89	0.060
Total difficulties score	361	2.4	13.1	(5.9)	4010	3.3	11.8	(5.3)	3.96	0.000*

Abbreviations: SDQ, Strength and Difficulties Questionnaire; YC, young carer.

*$P < 0.05$.

background of the region; however, COVID-19 limited the number of collaborating schools, resulting in a bias toward males over females. In addition, most of the data were from private schools, which may have led to selection bias in terms of socioeconomic background. However, the socioeconomic bias may not be substantial as the prevalence of YCs in the sample ($N = 313$) was 8.9%, which is higher than that reported in previous large-scale surveys in Japan. Second, it is possible that financial/practical, personal, and sibling care may not be experienced by regular Japanese children and is more likely to be experienced by young caregivers than the other items, but it is also possible that there was a selection bias in the sample for scale development and this may have been due to the small number of participants and lack of power. Third, although CFA indicated structural validity of the MACA-YC18, Cronbach's α for the financial/practical domain was relatively low. Therefore, care should be taken in the use of the scores for the six domains. Fourth, the 5000-person survey carried out to estimate prevalence was conducted as part of another survey, therefore considering the burden on the participants, the decision was made to use only two items, which was a limitation. However, even in this case, the prevalence was almost the same as that of large-scale surveys in Japan using nonstandardized methods, and it seems safe to estimate that the prevalence of YCs in Japan is around 4%–7% at present. Fifth, this study was conducted during the COVID-19 pandemic, which may have impacted on the findings.[28] It is possible that the results were influenced by changes in the individual's own and family relationships due to school, club activities, etc., of the individual and siblings, circumstances related to parental employment, and changes in the socioeconomic status of the family. Finally, YCS-J assesses only caregiving tasks but there are other important psychological components of youth caregiving that might be worth assessing (i.e. caregiving responsibilities and experiences[26] in future studies.

CONCLUSION

Our study developed a Japanese version of the questionnaire used in the Young Carers Survey conducted jointly by the BBC and the University of Nottingham and verified its reliability and validity. The prevalence of YCs in Japan was estimated to be 7.4% among 5000 adolescents. In the future, we would like to use the full scale of the YCS-J to clarify in detail what type of care children engage in and what type of stress they experience, depending on to whom and for what reason they provide care, in order to amass evidence for a specific support strategy in cooperation among the sectors of education, welfare, and healthcare.

PATIENT CONSENT STATEMENT

Written informed consent was obtained for the interviews with three junior high school (7th–9th grade) students from themselves and from their parents. Written informed consent was also obtained for the interviews with five junior high school teachers. Each interviewee received a prepaid card worth JPY 5000 (approximately 45 USD).

To obtain reliability and validity data, senior high school students (11th grade) provided informed consent for their participation (approval number: 2019271NI-(3)). The participants expressed their consent to participate in the study by responding to the questionnaires. For junior high school students (8th grade), data were obtained from questionnaire responses administered as part of a study to develop materials to enhance psychological resilience in this age group (Approval Number: 2019326NI-(4)). Senior high school students (11th–12th grades) from the Tokyo Teen Cohort Study gave written informed consent for their participation (Approval Number: 10069-(25)). The participants in the study testing reliability and validity did not receive compensation.

To obtain data on the prevalence of YCs, willingness to participate was verified by obtaining written informed consent (Approval Number: 2019271NI-(3)). Participants in the survey were not compensated.

AUTHOR CONTRIBUTIONS

Akiko Kanehara, Ryo Morishima, Yusuke Takahashi, Haruna Koike, Kaori Usui, Akito Uno, Yutaka Sawai, Yousuke Kumakura, Sho Yagishita, Masaya Morita, Kentaro Morita, Naohiro Okada, Tomoko Shibuya, Stephen Joseph, and Kiyoto Kasai conceptualized and designed the study. Akiko Kanehara, Ryo Morishima, Haruna Koike, Kaori Usui, Shun-ichi Sato, Naohiro Okada, Syudo Yamasaki, Atsushi Nishida, Shuntaro Ando, Sho Kanata, and Kiyoto Kasai acquired the data. Akiko Kanehara, Ryo Morishima, Satoshi Usami, Naohiro Okada, and Kiyoto Kasai analyzed the data and drafted the manuscript. All authors participated in result interpretation; moreover, they reviewed and approved the final version of the manuscript.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The availability of the data in this study is not open access due to the provisions of the ethics committee and the extent of the participants' consent. If readers wish to apply for the use of data, they must contact the corresponding author and consult the Ethics Committee, Faculty of Medicine, The University of Tokyo.

ETHICS APPROVAL STATEMENT

The ethical committee of the Faculty of Medicine, The University of Tokyo approved the study (2019271NI-(3), 10069-(25), and 2019326NI-(4)).

ORCID

Kentaro Morita http://orcid.org/0000-0002-0490-5013
Naohiro Okada http://orcid.org/0000-0002-8338-2758
Kiyoto Kasai http://orcid.org/0000-0002-4443-4535

REFERENCES

1. Aldridge J, Becker S Children who care: inside the world of young carers. Loughborough: Department of Social Sciences, Loughborough University; 1993.
2. Aldridge J. Where are we now? Twenty-five years of research, policy, and practice on young carers. Crit. Soc. Policy. 2018;38:155–65.
3. Sempik J, Becker S. Young adult carers at school: experiences and perceptions of caring and education. London: Carers Trust; 2013.
4. Jarkestig-Berggren U, Bergman AS, Eriksson M, Priebe G. Young carers in Sweden – a pilot study of care activities, view of caring, and psychological well-being. Child Fam. Soc. Work. 2019;24:292–300.
5. Kavanaugh MS, Stamatopoulos V, Cohen D, Zhang L. Unacknowledged caregivers: a scoping review of research on caregiving youth in the United States. Adolesc. Res. Rev. 2016;1:29–49.
6. Leu A, Jung C, Frech M, Sempik J, Moser U, Verner M, et al. Study protocol: young carers and young adult carers in Switzerland. BMC Health Serv Res. 2018;18:183.
7. Leu A, Frech M, Wepf H, Sempik J, Joseph S, Helbling L, et al. Counting young carers in Switzerland: a study of prevalence. Child. Soc. 2019;33:53–67.
8. Leu A, Wepf H, Sempik J, Nagl-Cupal M, Becker S, Jung C, et al. Caring in mind? Professionals' awareness of young carers and young adult carers in Switzerland. Health Soc Care Commun. 2020;28:2390–8.
9. Stamatopoulos V. Supporting young carers: a qualitative review of young carer services in Canada. Int J Adolesc Youth. 2016;21:178–94.
10. Shibuya T Young carers. Tokyo: Chuo-Koron-Shinsha Inc.; 2018. (in Japanese).
11. Saitama Prefecture. Saitama Prefecture website. 2020 [cited Aug 12, 2021]. Available from: https://www.pref.saitama.lg.jp/documents/187028/youngcarer.pdf
12. The Ministry of Health, Labour, and Welfare. The Ministry of Health, Labour, and Welfare website. 2021 [cited Aug 12, 2021]. Available from: https://www.mhlw.go.jp/content/11907000/000767890.pdf
13. Joseph S, Kendall C, Toher D, Sempik J, Holland J, Becker S. Young carers in England: findings from the 2018 BBC survey on the prevalence and nature of caring among young people. Child Care Health Dev. 2019;45:606–12.
14. Nagl-Cupal M, Daniel M, Koller MM, Mayer H. Prevalence and effects of caregiving on children. J Adv Nurs. 2014;70:2314–25.
15. Hamashima T, Miyakawa M. The prevalence of young carers in high schools and the status of their care: results from a questionnaire survey of students in public high schools in Osaka Prefecture. J. Health Welf. Stat. (Kosei-no-Shihyo). 2018;65:22–9. (in Japanese).
16. Okuyama S. Development of young carer psychological scale Japanese version. Int. J. Brief Ther. Fam. Sci. 2018;8:1–22.
17. Cox K, Pakenham K. Confirmatory factor analysis and invariance testing of the young carer of parents inventory (YCOPI). Rehabil Psychol. 2014;59:439–52.
18. Joseph S, Sempik J, Leu A, Becker S. Young carers research, practice and policy: an overview and critical perspective on possible future directions. Adolesc. Res. Rev. 2020;5:77–89.
19. Robison OMEF, Inglis G, Egan J. The health, well-being and future opportunities of young carers: a population approach. Public Health. 2020;185:139–43.
20. Ando S, Nishida A, Yamasaki S, Koike S, Morimoto Y, Hoshino A, et al. TTC scientific and data collection team. Cohort profile: the Tokyo Teen Cohort study (TTC). Int J Epidemiol. 2019;48:1414–g.
21. Okada N, Ando S, Sanada M, Hirata-Mogi S, Iijima Y, Sugiyama H, et al. Population-neuroscience study of the Tokyo TEEN Cohort (pn-TTC): Cohort longitudinal study to explore the neurobiological substrates of adolescent psychological and behavioral development. Psychiatry Clin Neurosci. 2019;73:231–42.
22. Joseph S, Becker S, Becker F, Regel S. Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. Child Care Health Dev. 2009;35:510–20.
23. Goodman R. The strength and difficulties questionnaire: a research note. J Child Psychol Psychiatry. 1997;38:581–586.
24. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. Struct Equ Model. 1999;6:1–55.
25. MacCallum RC, Browne MW, Sugawara HM. Power analysis and determination of sample size for covariance structure modeling. Psychol Methods. 1996;1:130–49.
26. Landi G, Pakenham KI, Crocetti E, Grandi S, Tossani E. Examination of the tripartite model of youth caregiving in the context of parental illness. Psychol Health. 2022a;37:397–418.
27. Pakenham KI, Bursnall S, Chiu J, Cannon T, Okochi M. The psychosocial impact of caregiving on young people who have a parent with an illness or disability: comparisons between young caregivers and noncaregivers. Rehabil Psychol. 2006;51:113–26.
28. Landi G, Pakenham KI, Grandi S, Tossani E. Young adult carers during the pandemic: the effects of parental illness and other ill family members on COVID-19-related and general mental health outcomes. Int J Environ Res Public Health. 2022b;19:3391.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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