

## Original Article

## Development and psychometric properties of the social adjustment scale for youth cancer survivors in South Korea

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## ABSTRACT

**Objective:** We developed a new scale—the Social Adjustment Scale for Youth Cancer Survivors—and examined its psychometric properties.**Methods:** In the scale's development stage, preliminary items were constructed based on the results of a concept analysis of the hybrid model, literature review, and interviews. These items were then reviewed through content validity and cognitive interviews. In the validation stage, 136 survivors were recruited from two children's cancer centers in Seoul, South Korea. An exploratory factor analysis was performed to identify a set of constructs, and validity and reliability were tested.**Results:** Starting with 70 items constructed through literature review and interviews with youth survivors, the final scale comprised 32 items. The exploratory factor analysis identified four domains—namely, role achievement in one's present position, harmony in relationships, disclosure and acceptance of cancer history, and preparation and expectation for future roles. Correlations with quality of life indicated good convergent validity ( $r = 0.82$ ,  $P < 0.001$ ). The Cronbach's  $\alpha$  of the overall scale was 0.95, indicating excellent internal consistency; and the intraclass correlation coefficient was 0.94 ( $P < 0.001$ ), suggesting high test-retest reliability.**Conclusions:** The Social Adjustment Scale for Youth Cancer Survivors exhibited acceptable psychometric properties in measuring the social adjustment of youth cancer survivors. It can be used to identify youths facing difficulty in adjusting to society after treatment and to investigate the effect of interventions implemented to promote social adjustment among youth cancer survivors. Future research is needed to examine the applicability of the scale in patients across diverse cultural backgrounds and healthcare systems.

## Introduction

The overall survival rates of childhood cancer exceed 85% although a wide range of rates are reported by cancer type.<sup>1</sup> Most children and adolescents diagnosed with cancer undergo the treatment successfully, and the completion is an event for celebration.<sup>2</sup> However, some survivors struggle with social adjustment, including difficulty in educational achievement, employment, independence, friendships, and romantic relationships.<sup>3</sup> These social issues may negatively affect survivors' overall quality of life (QoL).<sup>4</sup>

In Cavell's tricomponent model,<sup>5</sup> social competence comprises three components—namely, social skills, social performance, and social adjustment. Social adjustment exists at the top of the hierarchy and is defined as an individual achieving socially desirable and developmentally appropriate goals. Youths, defined in this study as those aged 15–24 years (<https://www.un.org/en/global-issues/youth>), include adolescents and young adults. Adolescence and early adulthood must be considered together, considering the fluid boundary and interconnections between these periods.<sup>6</sup> Youths are expected to prepare for the developmental tasks of adulthood, form mature social

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relationships, and maintain the role of a student.<sup>7</sup> These developmentally required tasks are key in the assessment of youths' social adjustment.<sup>8</sup> A youth who has completed the scheduled treatment for childhood cancer may experience the dual difficulty of achieving regular developmental tasks and returning smoothly to where they were before cancer treatment<sup>7,9</sup>; therefore, a tool that reflects both youths' developmental tasks and the unique aspects that they experience after cancer treatment is required.

Childhood cancer survivors are reported to be at a higher risk for anxiety and depression than their counterparts and have lower socioeconomic achievements regarding college graduation, employment, and marriage.<sup>10,11</sup> Among cancer survivors, factors affecting these negative social outcomes include brain tumors, treatment of the central nervous system, and physical sequelae.<sup>10,12,13</sup> However, when cancer survivors

were compared with other adolescents and adults of the same age, no significant difference was found in the quality of relationships and educational and occupational status.<sup>14,15</sup> Thus, the level of social adjustment in youth cancer survivors varies among studies.

Social adjustment is a highly complex and multidimensional concept because related characteristics change across the developmental trajectory.<sup>8</sup> Nevertheless, a single question on demographic information (ie, marriage or employment) has been used in numerous studies to measure childhood cancer survivors' social adjustment.<sup>10,16</sup> Another study used the social well-being domain of the Pediatric QoL Inventory 4.0 Generic Core Scales<sup>17</sup>—a highly reliable and valid measure of QoL in childhood cancer survivors.<sup>18</sup> This tool includes aspects of interactions with friends and school functioning; as such, it has certain limitations to comprehensively measure youths' social adjustment. The Korean version of the

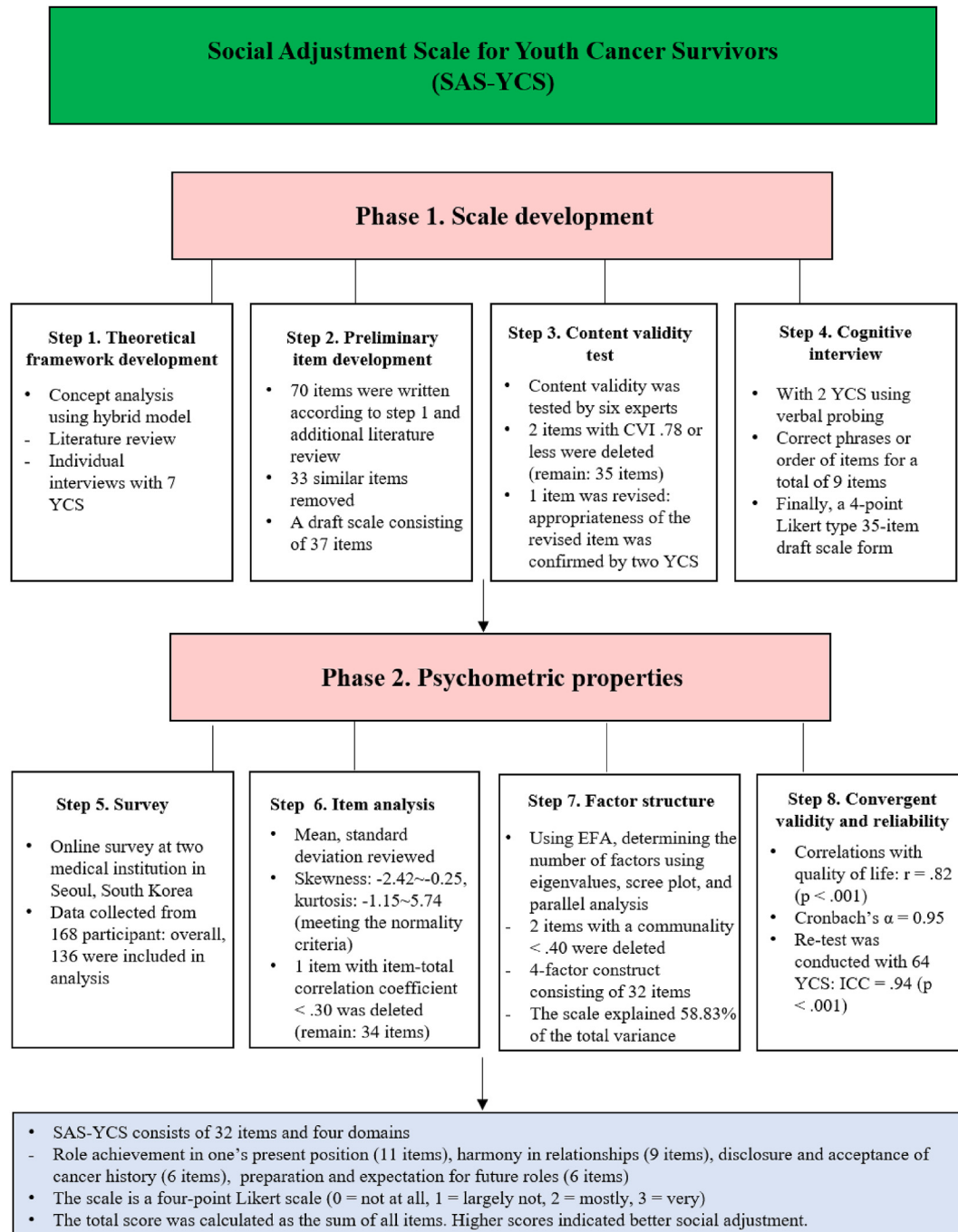


Fig. 1. Summary of the two phases. YCS, youth cancer survivors; CVI, content validity index; EFA, exploratory factor analysis; ICC, intraclass correlation coefficient.

Minneapolis–Manchester QoL Instrument-Adolescent Form (KMMQL-AF) has been adapted and validated specifically for adolescent cancer survivors.<sup>19</sup> This scale was developed to measure QoL; however, only the peer-relationships and intimacy domains assess social functioning; thus, we concluded that this scale does not appropriately measure the concept of social adjustment in cancer survivors. The Social Adjustment Inventory for Children and Adolescents is a 77-item interview scale for children and adolescents aged 6–18 years with and without depression and assesses four attributes of social adjustment—namely, school functions, spare-time activities, peer relations, and home behaviors.<sup>20</sup> However, youth cancer survivors' characteristics may differ from those of youths with other chronic diseases or youths without diseases. Youth cancer survivors may face various clinical symptoms, and the treatment sequelae may impact their social adjustment. Therefore, developing a tool to measure the multidimensional aspects of social adjustment in childhood cancer survivors is necessary.

A standardized and validated tool would help to objectively assess the level of social adjustment and, accordingly, implement appropriate management.<sup>8</sup> Thus, we developed the Social Adjustment Scale for Youth Cancer Survivors (SAS-YCS) and examined its psychometric properties such as convergent validity, internal consistency, and test-retest reliability. This instrument will be useful in short- and long-term follow-ups of this population who are potentially at risk for negative social adjustment.

## Methods

This study has two phases: (1) scale development and (2) evaluation of the psychometric properties of the SAS-YCS. The two phases are summarized in Fig. 1.

### Phase I. Scale development

#### Theoretical framework

Before developing the scale, a theoretical framework should be developed through a literature review and qualitative research.<sup>21</sup> The scale's theoretical framework is based on attributes identified through the concept analysis of the social adjustment of youth cancer survivors.<sup>22</sup> Concept analysis using the hybrid model is widely applied in the prescale development stage.<sup>23</sup> Empirical criteria in the hybrid model are presented through the phases of theoretical analysis, fieldwork, and final analysis.<sup>24</sup> At the theoretical stage, we conducted a thorough literature review to confirm the definition and attributes of the concept of “social adjustment of youth cancer survivors.” We utilized the following keywords: “(adolescent OR adolescence OR young adult\$ OR teenage\$ OR pediatric OR childhood) adj2 {(neoplasm OR cancer) AND (survivor\$ OR Off OR end)}” AND “social AND (adjustment OR adaptation OR well-being OR outcome\$1 OR functioning)” in Ovid-Medline, Ovid-Embase, and Korean databases.

Overall, 1770 documents were initially searched, and 474 duplicates were removed using the EndNote program (Clarivate™, Philadelphia, Pennsylvania, USA). Among the remaining 1296 documents, studies published in languages other than English and Korean ( $n = 9$ ), non-peer-reviewed studies ( $n = 299$ ), studies not targeting youth cancer survivors ( $n = 427$ ), and studies that did not present the concept of social adjustment in youth cancer survivors ( $n = 551$ ) were all excluded. Finally, 10 studies regarding social adjustment of youth cancer survivors were analyzed. In the fieldwork phase, the attributes of social adjustment determined in the theoretical phase were validated and confirmed by youth cancer survivors. Seven youth cancer survivors were individually interviewed with a semi-structured format. The main questions asked for the interviews were “Tell me what you experienced and felt in school and in social life after childhood cancer treatment” and “What do you think is social adjustment after childhood cancer treatment?” Interviews were conducted face-to-face for 30–70 min. Twenty themes and six attributes were derived.

Finally, the attributes identified during the previous two phases were compared and analyzed to construct the definition of social adjustment.

A multidimensional concept, youth cancer survivors' social adjustment comprises four attributes—namely, having harmonious relationships with friends, having harmonious relationships with boyfriends/girlfriends, fulfilling their present roles, and planning for and expecting future roles. Further details regarding the aforementioned processes have been described previously.<sup>22</sup>

#### Preliminary scale item development

The questions were developed through qualitative data of seven interviews collected in the field work phase mentioned above and literature review. Components of 70 initial items were revealed by qualitative inductive analysis and comprehensive review of the existing qualitative studies.<sup>3,25–29</sup> After this, 33 items were subsequently deleted owing to overlapped meanings. The remaining 37 items were confirmed as preliminary items by verifying content validity: having harmonious relationships with friends (10 items), having harmonious relationships with boy/girlfriends (8 items), fulfilling their present roles (9 items), and planning for and expecting future roles (10 items).

The preliminary items were designed to be rated on a four-point Likert scale (0 = *not at all*, 1 = *largely not*, 2 = *mostly*, 3 = *very*) to avoid neutral responses. The neutral response option was designed with the intention of reducing the number of false responses; however, previous studies have recommended against using it because several respondents tend to use it as a refuge for ambiguous responses.<sup>30</sup> The total score was calculated as the sum of all items. Higher scores indicated better social adjustment.

#### Content validity testing

Content validity was tested by six experts (a professor specializing in scale development, a nursing manager in a pediatric cancer department, a childhood cancer coordinator, a clinical nurse experienced in care of patients with cancer, a pediatric oncologic physician, and a parent of a youth cancer survivor). Theoretical and operational definitions of the concepts were presented to the six experts and, thereafter, they were asked to rate the clarity and relevance of each item on a four-point scale (1 = *not at all*, 2 = *largely not*, 3 = *mostly*, and 4 = *very*). Two items with an item content validity index of 0.78 or less<sup>31</sup> were deleted: “I have similar hobbies with my friends” and “I do not think my cancer will affect my child's health.” One item was revised to reflect the recommendation of the experts—from “I do not think my cancer will affect marriage” to “My future spouse will understand my experience of cancer treatment.” The appropriateness of the revised item was later confirmed by two youths who had completed their cancer treatment. Additionally, the wording of the six aforementioned items was revised for clarity.

#### Cognitive interviews

Two youth cancer survivors participated in cognitive interviews using verbal probing for the remaining 35 items. Interview transcripts were prepared for each item, and the interpretations of the items were summarized. Thereafter, the researchers checked whether any parts differed from their intentions, and if necessary, the preliminary items were revised appropriately. Through this process, 35 preliminary items were refined and confirmed.

### Phase II. Psychometric properties of the SAS-YCS

#### Participants and procedures

An online survey was administered among youths admitted to follow-up care centers at two medical institutions in Seoul, South Korea. Participants were recruited through recruitment posters and referrals for eligible participants from nurses. The inclusion criteria were cancer survivors aged 15–24 years who had been diagnosed with childhood cancer, had completed treatment at least 6 months earlier, and had not been treated for any psychiatric illness. The United Nations defines youth as one's transition from a dependent child to an independent adult, which occurs between 15 and 24 years of age. Adolescence and early adulthood

are often considered distinct developmental stages; however, the boundaries between them are typically indistinct. Therefore, it was recommended that adolescents and early adults be considered and named collectively as “youths.” Thus, we targeted those aged 15–24 years for participation.<sup>6</sup>

The target sample size was set at 190, derived from the ratio criterion of 5:1 between the number of participants and number of items (ie, 35)<sup>32</sup> and the nonresponse rate of 10%. Data were collected from 168 participants: Overall, 136 were included in analyses, excluding 21 participants with total nonresponse, 5 participants with significant missing item responses, and 6 patients undergoing follow-up owing to aplastic anemia. It takes approximately 10 min to complete SAS-YCS and approximately 25 min to complete all surveys, including the SAS-YCS, K-MMQL, and general characteristics. Data were collected from November 28, 2017, to April 3, 2018.

To assess test-retest reliability, the survey link was resent after 2 weeks to those who participated in the first test. We considered that the 2-week interval would allow enough time for participants to forget the first survey results; however, the concept being measured would remain relatively stable.<sup>33</sup> Sixty-four participants responded to the retest. There were 1.8 participants per item in the test-retest analysis.

### Measurement

The online survey comprised the SAS-YCS and KMMQL-AF. The validity and reliability of KMMQL-AF have been verified for South Korean adolescent cancer survivors.<sup>19</sup> We used the KMMQL-AF after obtaining approval for its use. The KMMQL-AF comprises 46 items pertaining to the following seven domains: (1) physical functioning, (2) psychological functioning, (3) social functioning, (4) cognitive functioning, (5) body image, (6) outlook on life, and (7) intimate relations. Higher scores indicate minimal negative impact and, thus, greater health-related QoL.<sup>19</sup> The Cronbach's  $\alpha$  ranged from 0.78 to 0.92 previously<sup>19</sup> and was 0.96 in this study.

For convergent validity testing, KMMQL-AF was chosen as a comparator instrument. Based on previous studies,<sup>4</sup> we hypothesized that social adjustment and QoL measured by the SAS-YCS and KMMQL-AF would be positively correlated.

### Data analysis

Data were analyzed using PASW SPSS 21.0 (IBM, Armonk, NY, USA). During the item analysis, items with a total correlation coefficient of  $< 0.30$  and  $> 0.70$ , skewness of  $> \pm 3$ , kurtosis of  $> \pm 10$ , and a missing data rate greater than 5% were deleted,<sup>33–35</sup> and the mean and standard deviation of each item were calculated. Next, an exploratory factor analysis (EFA) was performed using principal component analysis with varimax rotation. Kaiser–Meyer–Olkin (KMO) and Bartlett's test of sphericity were used to determine whether the data were appropriate for factor analysis. Items with a communality of less than 0.4 were reviewed and deleted.<sup>36</sup> For factor retention, parallel analysis, the eigenvalue greater than 1 rule, and the scree plot were used. Parallel analysis assumes larger eigenvalues in real dataset than in randomly generated datasets if nonrandom factors exist.<sup>37</sup> We used parallel analysis with 1000 random datasets and 95th percentile eigenvalues. Convergent validity was assessed by the correlations between the scores obtained on the SAS-YCS and KMMQL-AF. Cronbach's  $\alpha$  coefficient was calculated to test internal consistency, and intraclass correlation coefficient was calculated between the scores in the first and second surveys to assess test-retest reliability.

### Ethical considerations

This cross-sectional study was approved by the Institutional Review Board (IRB) of Severance Hospital at Yonsei University (IRB No. 4-2017-0923) and Seoul National University Hospital (IRB No. 1801-094-916). A researcher explained the purpose and content of the study to each youth and their parent(s). Those who presented an interest in the study were

provided with an online survey link and asked to indicate their intention to participate. The consent procedure for the parents of participants aged younger than 19 years was performed at the recommendation of the IRB of each medical institution. At one institution, a detailed explanation of the study was provided to the parents of the adolescents who wished to participate, and a link to the survey was delivered to parents' cell phones. The other institution recommended obtaining written informed consent from parents and adolescents, which was duly followed.

## Results

### Participants' characteristics

Participants included 84 boys/men (61.8%) and 52 girls/women (38.2%). Notably, 79 (58.1%) were aged 15–19 years and 57 (41.9%) were aged 20–24 years. Most participants had been diagnosed with cancer between the ages of 7 and 12 years, and more than half had completed cancer treatment 5 years ago or earlier. Leukemia was the most frequent diagnosis, and 64 (47.1%) participants had received combined treatment, including stem cell transplantation. The response rate to the period of academic interruption caused by disease and/or treatment was high—in the order of 1–2 years, 2 years or more, and none. At the time of the survey, 79.4% of participants were attending school (Table 1).

### Item analysis

There were no items with more than 5% of the missing data. The mean, standard deviation, skewness, and kurtosis of each item were examined for the item analysis. The mean and standard deviation of each item ranged from 1.77 to 2.70 and 0.61 to 1.04, respectively. The skewness value ranged from  $-2.42$  to  $-0.25$ , and the kurtosis value was between  $-1.15$  and  $5.74$ , meeting the normality criteria (Supplemental Table A). As items with an item–total correlation coefficient less than 0.30 are considered to have a low level of contribution in the scale domain,<sup>38</sup> one item with a corrected item–total correlation coefficient of 0.29 (“I do not think I can continue to rely on my parents”) was deleted after examination, and 34 items were retained (Supplemental Table A).

### Factor structure

Bartlett's test of sphericity showed that the item correlation coefficient matrix was not a unit matrix ( $\chi^2 = 2876.432$ ,  $P < 0.001$ ), and the KMO value was 0.893. These results supported the data as appropriate for factor analysis.

From the initial EFA for the 34 items, six factors were identified with eigenvalues greater than 1.0. The scree plot showed that five factors were appropriate. After the parallel analysis, there were four factors for which the eigenvalues analyzed in the actual data were greater than the eigenvalue values of the randomly generated data (Fig. 2). Applying these multiple factor extraction strategies yielded four factors. Two items with a communality of less than 0.4 were further deleted: “I can perform leisure activities (such as watching a movie or going to a coffee shop) that my friends enjoy” and “There will be a solution even if cancer treatment affects my future pregnancy.” Consequently, four factors with 32 items were confirmed and together explained 58.83% of the accumulated variance (Table 2).

Factor 1 (11 items)—“role achievement in one's present position”—included attributes such as confidence, performance level, and satisfaction in achieving a given role as a student or worker. Factor 2 (9 items)—“harmony in relationships”—represented harmonious socialization and includes peer and romantic relationships. Factor 3 (6 items)—“disclosure and acceptance of cancer history”—included items related to feelings of being understood without being intimidated about disclosing one's own cancer history. Factor 4 (6 items)—“preparation and expectation for future roles”—represented the discovery of one's aptitude and making efforts to achieve one's dreams, and preparation and expectations for independence and marriage.



**Table 1**  
Demographic characteristics of participants ( $N = 136$ ).

Variable	Category	$n$ (%)
Gender	Male	84 (61.8)
	Female	52 (38.2)
Age	15–19 years	79 (58.1)
	20–24 years	57 (41.9)
Age at diagnosis <sup>a</sup>	≤ 6 years	36 (26.7)
	7–12 years	49 (36.3)
	13–15 years	32 (23.7)
	16–18 years	18 (13.3)
	≥ 5 years	12 (9.0)
Duration after treatment <sup>b</sup>	≤ 6 months–< 1 year	11 (8.3)
	≤ 1 year–< 2 years	36 (27.1)
	≤ 2 years–< 5 years	74 (55.6)
	≥ 5 years	67 (49.3)
Diagnosis	Leukemia	28 (20.6)
	Lymphoma	16 (11.8)
	Brain tumor	25 (18.4)
	Solid tumor/Other	31 (22.8)
	Only chemotherapy	38 (27.9)
Treatment <sup>a</sup>	Combined therapy that included chemotherapy	64 (47.1)
	Combined therapy that included transplantation	2 (1.5)
	Other	30 (22.2)
	None	14 (10.4)
Duration of academic interruption due to disease and/or treatment <sup>a</sup>	≤ 1 month–< 1 year	49 (36.3)
	≤ 1 year–< 2 years	42 (31.1)
	≥ 2 years	108 (79.4)
Currently attending school	Yes	28 (20.6)
	No	

M, mean; SD, standard deviation.

<sup>a</sup> With missing value ( $n = 1$ ).

<sup>b</sup> With missing value ( $n = 3$ ).

Raw data eigenvalues, mean, and percentile of random data eigenvalues

Root	Raw data	Means	Percentile
1.000000	12.681114	2.095198	2.239837
2.000000	2.588300	1.938553	2.046640
3.000000	2.161500	1.825310	1.917096
4.000000	2.034247	1.731008	1.812779
5.000000	1.370646	1.645220	1.718093
6.000000	1.073384	1.568945	1.632735

**Fig. 2.** Parallel analysis results.

### Validity and reliability

Cronbach's  $\alpha$  for the total scale was acceptable at 0.95. All domains had satisfactory Cronbach's  $\alpha$  ranging between 0.83 and 0.93. The intraclass correlation coefficient also showed high stability at 0.94 ( $P < 0.001$ ; Table 3). To test the convergent validity, the correlations between the SAS-YCS and KMMQL-AF scores were calculated. The total score between the two scales had a significant positive correlation ( $r = 0.82$ ,  $P < 0.001$ ). The higher the social adjustment of the participant, the higher the QoL. Since the correlation between the two scales was more than 0.50 and supported the hypothesis formulated in the "Measurement" section,<sup>39</sup> the convergent validity of SAS-YCS was established (Table 3). The relationship between participants' characteristics and final SAS-YCS scores is presented in Supplemental Table B.

### Discussion

#### Development and psychometric properties of the SAS-YCS

We developed a scale that objectively measures the level of social adjustment in youth cancer survivors in South Korea. Several steps were systematically followed: concept analysis through literature review and in-depth interviews, cognitive interviews, and validity and reliability testing. In this process, a unique domain representing the developmental

tasks of youths such as planning for and expecting future roles was included, which had not been captured by existing instruments. The final version of the 32-item self-reported SAS-YCS is valid, feasible, and easy and quick to complete.

Four factors were derived by applying this multifactor extraction strategy. Factor 1—"role achievement in one's present position"—with the largest loading, contained attributes such as confidence, performance level, and satisfaction in achieving one's current role as a student or worker. This construct was frequently described by participants in the interviews and seems to reflect high school performance pressure among South Korean youths. In general, academic achievement is measured through education completion and special education requirements<sup>40</sup>; however, the interviewees may apply relative standards for role achievement through comparison with other youths. When they returned to school after treatment, they had a "feeling of being relatively behind," and unique items reflecting these statements as the characteristics of childhood cancer survivors were constructed. This factor can contribute to long-term impacts stretching into adulthood, including financial difficulties.<sup>41</sup> Although many children reintegrated to school well, the process required ample effort from them.<sup>42</sup> In particular, in the case of children with brain tumors, "educational pain" is severe when they return to school after treatment<sup>43</sup>; thus, it is necessary to promote the adjustment of youths through close cooperation between healthcare providers, educators, youth cancer survivors, and their parents in advance.

Next, the construct of "harmony in relationships" concerned harmonious socialization and includes peer and romantic relationships. Hocking et al.<sup>44</sup> suggested that the perception of one's social relationship is an aspect of social adjustment, and the second factor of this study may reflect this aspect. Considering that many youths experience difficulty establishing relationships owing to school closures and distancing in the era of COVID-19, the development of social relationships among childhood cancer survivors is expected to undergo greater difficulties.<sup>45</sup> Therefore, understanding the context of social relationships in youth cancer survivors is critical during the COVID-19 pandemic. During the interviews with youth cancer survivors, some participants used the term "opposite sex." Thus, we used the same term. Although questionnaires have been developed using the term "opposite sex" for several items pertaining to youths' romantic relationships, we did not want lesbian, gay, bisexual, transgender, and queer or questioning youths to be excluded from the survey or experience difficulties in responding to these items. As focusing on the romantic relationship with others—irrespective of sex—is important, future studies suggest use the terms "lover" or "romantic relationship" instead of "opposite sex."

The third factor of "disclosure and acceptance of cancer history" was related to feelings of being understood without being intimidated about disclosing one's own cancer history. This study provides novel insights on how social adjustment is perceived in childhood cancer survivors by identifying the factor of "disclosure and acceptance of cancer history." Finding answers to the question "Who am I?" is often seen as a main objective of adolescence.<sup>46</sup> The discrepancy between reality and their ideal identity can be stressful for youth cancer survivors; however, seemingly, this stress can be reduced by being open and accepting of their cancer history. Childhood cancer survivors tend to be reluctant to disclose their medical history because they do not want to be distinguished from others<sup>47</sup> and may even experience social isolation when their medical history is disclosed, leading to tension in their relationships.<sup>48,49</sup> This factor may reflect the related stigma as youth cancer survivors may have to hide their cancer history to avoid negative perceptions by—or discrimination from—others.<sup>47</sup> Among adolescents with chronic heart disease, patients who tried hiding their disease exhibited difficulty forming intimate and meaningful relationships with their peers, which increased school maladjustment.<sup>50</sup> This problem is not limited to South Korean youth cancer survivors.<sup>51,52</sup> Seemingly, this factor is also applicable to other cultures. To disclose one's cancer history to others, one must be able to accept cancer first. Therefore, facilitating

**Table 2**Factor analysis of the SAS-YCS (*N* = 136).

Item No.	Items	Mean $\pm$ SD <sup>a</sup>	Factor 1	Factor 2	Factor 3	Factor 4	Communality
Factor 1: Role achievement in one's present position (11 items)							
19	It is not difficult to keep up with studies/work.	2.01 $\pm$ 0.94	<b>0.87</b>	0.16	0.10	0.14	0.81
21	I can study/work as well as people who did not suffer from childhood cancer.	2.18 $\pm$ 0.91	<b>0.80</b>	0.16	0.07	0.15	0.70
23	Changes (such as physical strength, lethargy, depression, pain, memory decline) due to cancer treatment are not problematic for my academic or work life.	2.10 $\pm$ 0.98	<b>0.76</b>	0.18	0.27	0.23	0.73
24	I do not find it difficult even if I do not take more rest than others while studying/working.	1.85 $\pm$ 0.96	<b>0.75</b>	0.10	0.16	0.20	0.63
20	I am not afraid to compete with friends/colleagues.	2.25 $\pm$ 0.86	<b>0.73</b>	0.16	0.16	0.13	0.61
18	I can concentrate on my studies/work.	2.18 $\pm$ 0.89	<b>0.67</b>	0.40	0.09	0.19	0.66
22	I am satisfied with my grades/achievements.	1.90 $\pm$ 0.91	<b>0.64</b>	0.22	0.14	0.22	0.52
17	There is no difficulty in sustaining school/work life.	2.26 $\pm$ 0.96	<b>0.60</b>	0.37	0.08	0.07	0.51
1	I am as normal as my friends of the same age.	2.34 $\pm$ 0.84	<b>0.57</b>	0.51	0.13	0.04	0.60
25	I actively participate in group activities (athletic competitions, school trips, dinner parties, etc.) at my school or workplace.	2.20 $\pm$ 0.97	<b>0.56</b>	0.37	0.07	0.15	0.47
16	The changes in me (appearance, physical strength, etc.) due to cancer treatment do not affect my romantic relationship with the opposite sex.	2.08 $\pm$ 0.94	<b>0.51</b>	0.30	0.48	0.12	0.59
Factor 2: Harmony in relationships (9 items)							
2	I am not afraid to make new friends.	2.20 $\pm$ 0.97	0.24	<b>0.74</b>	0.04	0.00	0.60
10	I do not avoid meeting an opposite-sex friend.	2.29 $\pm$ 0.78	0.28	<b>0.71</b>	0.27	0.17	0.68
5	I have a friend with whom I can share my secrets.	2.40 $\pm$ 0.86	0.12	<b>0.70</b>	0.16	0.14	0.55
12	I express my feelings frankly to my opposite-sex friend.	2.06 $\pm$ 0.85	0.12	<b>0.69</b>	0.08	0.33	0.60
11	I am confident when I deal with a friend of the opposite sex.	2.08 $\pm$ 0.85	0.20	<b>0.68</b>	0.22	0.34	0.67
4	I feel comfortable when I am with my friends.	2.49 $\pm$ 0.66	0.24	<b>0.61</b>	0.18	−0.03	0.46
13	I can adequately manage conflicts with a friend of the opposite sex.	2.23 $\pm$ 0.73	0.21	<b>0.59</b>	0.16	0.36	0.55
9	I have an interest in the opposite sex.	2.17 $\pm$ 0.76	0.13	<b>0.55</b>	0.19	0.21	0.40
3	I often spend time with my friends.	2.25 $\pm$ 0.83	0.41	<b>0.54</b>	−0.01	0.02	0.46
Factor 3: Disclosure and acceptance of cancer history (6 items)							
14	I do not hesitate to talk about my cancer with my opposite-sex friend.	1.77 $\pm$ 1.04	0.07	0.10	<b>0.84</b>	0.03	0.72
7	I do not hesitate to tell my friends about my cancer.	1.89 $\pm$ 0.99	0.10	0.13	<b>0.81</b>	0.04	0.69
15	My opposite-sex friend understands the changes in me (appearance, physical strength, etc.) due to cancer treatment.	2.29 $\pm$ 0.68	0.16	0.20	<b>0.68</b>	0.06	0.53
29	I will not hesitate to disclose my cancer treatment experience in the future at work.	2.27 $\pm$ 0.95	0.13	−0.01	<b>0.66</b>	0.35	0.56
8	My friends understand the changes in me (appearance, physical strength, etc.) due to cancer treatment.	2.49 $\pm$ 0.67	0.22	0.40	<b>0.60</b>	−0.18	0.59
34	My future spouse will understand my experience of cancer treatment.	2.44 $\pm$ 0.70	0.18	0.26	<b>0.53</b>	0.30	0.47
Factor 4: Preparation and expectation for future roles (6 items)							
27	I have a plan for my future life.	2.19 $\pm$ 0.68	0.19	0.17	0.06	<b>0.84</b>	0.77
28	I am trying to achieve my dreams.	2.24 $\pm$ 0.72	0.21	0.12	−0.01	<b>0.72</b>	0.57
26	I know what I do well.	2.20 $\pm$ 0.77	0.14	0.19	0.11	<b>0.72</b>	0.58
32	I am confident of being economically independent of my parents in the future.	2.12 $\pm$ 0.80	0.51	0.14	0.12	<b>0.53</b>	0.57
33	I look forward to my future marital life.	2.20 $\pm$ 0.83	0.17	0.41	0.22	<b>0.48</b>	0.47
31	I am confident of being emotionally independent of my parents in the future.	2.40 $\pm$ 0.70	0.42	0.09	0.32	<b>0.47</b>	0.50
Eigenvalue			6.36	5.30	3.75	3.42	
Explained variance (%)			58.83 <sup>b</sup>	19.88	16.55	11.71	10.69

Bold indicates the factor loading &gt; 0.40; SAS-YCS, Social Adjustment Scale for Youth Cancer Survivors; M, mean; SD, standard deviation.

<sup>a</sup> The score range for all items is 0–3.<sup>b</sup> Total.

**Table 3**  
Descriptive statistics, reliability, and convergent validity of the SAS-YCS ( $N = 136$ ).

SAS-YCS (range)	M $\pm$ SD	Skewness	Kurtosis	Cronbach's $\alpha$	ICC <sup>a</sup>	KMMQL-AF (Pearson correlation)					Total	
						Physical functioning	Psychological functioning	Body image	Social functioning	Cognitive functioning		Intimate relations
Factor 1 (0–33)	23.35 $\pm$ 7.74	−0.80	0.10	0.93	0.94***	0.72***	0.59***	0.56***	0.55***	0.73***	0.70***	0.56***
Factor 2 (0–27)	20.16 $\pm$ 5.28	−0.46	−0.62	0.89	0.91***	0.49***	0.43***	0.46***	0.72***	0.44***	0.73***	0.51***
Factor 3 (0–18)	13.16 $\pm$ 3.77	−0.55	−0.31	0.83	0.86***	0.27**	0.34***	0.25**	0.35***	0.27**	0.40***	0.33***
Factor 4 (0–18)	13.35 $\pm$ 3.30	−0.57	0.49	0.83	0.86***	0.55***	0.40***	0.38***	0.44***	0.44***	0.62***	0.45***
Total (0–96)	70.03 $\pm$ 16.49	−0.51	−0.11	0.95	0.94***							0.82***

\*\* $P < 0.01$ , \*\*\* $P < 0.001$ .

Factor 1, Role achievement in one's present position; Factor 2, Harmony in relationships; Factor 3, Disclosure and acceptance of cancer history; Factor 4, Preparation and expectation for future roles.  
SAS-YCS, Social Adjustment Scale for Youth Cancer Survivors; KMMQL-AF, Korean version of Minneapolis–Manchester quality of life instrument-Adolescent form; M, mean; SD, standard deviation; ICC, intraclass correlation coefficient.

<sup>a</sup> Test-retest reliability (number of participants = 64).

this process through education, counseling, and support activities for youth cancer survivors is necessary.

The fact that disclosure and acceptance of cancer history is an important part of social adjustment means that youth cancer survivors can rely heavily on peer feedback in their self-assessment. It is important to youth cancer survivors that others do not perceive them as different.<sup>49</sup> The role of parents and healthcare providers in supporting a positive sense of self during and after treatment is crucial. Individuals' prejudice against childhood cancer also develops within a cultural context.<sup>46</sup> For example, if characteristics such as pale skin, weak physical strength, and strange appearance are emphasized and exposed in the media, we may inadvertently project prejudice against childhood cancer survivors. Therefore, to promote the social adjustment of childhood cancer survivors, it is necessary to create a sociocultural atmosphere in which childhood cancer survivors can disclose their cancer history without hesitation and accept it without prejudice.

Lastly, the factor of "preparation and expectation for future roles" contained attributes of discovering one's aptitude and making efforts to achieve one's dreams, as well as preparation and expectations for independence and marriage. During their youth, childhood cancer survivors look for career paths but feel that they lag behind at their job/workplace and have to change their occupational goals because of cancer.<sup>53</sup> Thus, this study added unique elements that are not included in existing tools through realistic on-site interviews. The impacts of childhood cancer are ongoing, and some survivors manage to identify the positive aspects of these impacts in their life. As such, integrating the cancer experience into one's daily life as well as anticipating and preparing for the role of adulthood with flexible thinking is an important part of social adjustment for childhood cancer survivors.

Correlations with the KMMQL-AF indicated good convergent validity, and internal consistency and test-retest reliability of the SAS-YCS were also verified. These evaluations suggest that the SAS-YCS has acceptable reliability and validity. The time required to complete the questionnaire is less than 10 min, it is easy to calculate the total score, and the interpretation of the results is clear. The SAS-YCS could be used to identify youths facing difficulty in adjusting to society after treatment and to investigate the effect of interventions implemented to promote social adjustment among youth cancer survivors.

This scale was developed in Korean but translated into English. Although each item was initially developed with the intention to be universally applicable, researchers should consider the context wherein it is validated. Future research should examine this scale's psychometric properties with participants from diverse cultural backgrounds to assess its applicability for youth cancer survivors worldwide.

### Limitations

This study had some limitations. First, we analyzed data from 136 childhood cancer survivors. Considering our specific inclusion criteria, tracking childhood cancer survivors and obtaining consent was challenging, though we tried recruiting potential participants from the two largest tertiary hospitals in South Korea. The sample size ( $n = 190$ ) was calculated to include a 10% attrition rate, indicating that about 175 participants were needed for the EFA. Generally, a factor analysis needs a ratio of 5:1 for the number of participants and number of items<sup>32</sup>; however, it is suggested not to apply extremely strict criteria in an exploratory analysis.<sup>54</sup>

Second, regarding the relatively low response rate for test-retest reliability, we compared demographic variables and social adjustment scores between a sample that participated in the retest ( $n = 64$ ) and a sample that did not ( $n = 72$ ; Supplemental Table C). No significant differences between the two groups were found except for the type of treatment. In future studies, to assess the stability of questionnaires, efforts should be invested to increase the participation rate in the retest.

Third, we developed a questionnaire to measure the level of social adjustment in childhood cancer survivors aged 15–24 years. However, youths may need to achieve different developmental tasks depending on

where they are placed within these age continuums. Therefore, a limitation of the tool that we developed is that it may not cover all aspects of social adjustment in childhood cancer survivors in this age group, and this tool is expected to be supplemented by the use of mix-methods through in-depth interviews.

Finally, in item analysis, a group of items showed average values close to the extremes or had small standard deviations—possibly owing to socially desirable behavior. Future studies are needed to refine the scale by adding or revising items that can distinguish the responses reflecting social desirability.

## Conclusions

Social adjustment is a multidimensional concept that includes preparing for various developmental tasks that individuals expect to achieve. We developed an instrument that can assess social adjustment from various perspectives. The SAS-YCS, comprising 32 items across four domains, was valid and reliable. Calculation of the total score is easy, and interpretation of the results is clear. Therefore, the instrument can be used to measure the level of social adjustment among youth cancer survivors in clinical and research settings. Future research is needed to examine the applicability of scale in patients across diverse cultural backgrounds and healthcare systems.

## CRediT author statement

**Sumi Oh:** Conceptualization, Methodology, Data curation, Formal analysis, Writing. **Hyejung Lee:** Conceptualization, Methodology, Formal analysis, Writing - Original and Revised draft preparation, Supervision. **Sue Kim:** Conceptualization, Methodology, Formal analysis, Writing - Original and Revised draft preparation. **Sanghee Kim:** Conceptualization, Methodology, Formal analysis, Writing - Original and Revised draft preparation. **Chuhl Joo Lyu:** Conceptualization, Methodology, Formal analysis, Writing - Original and Revised draft preparation. **Chang Gi Park:** Conceptualization, Methodology, Formal analysis, Writing - Original and Revised draft preparation. **Hyoung Jin Kang:** Methodology, Investigation, Formal analysis, Writing - Original and Revised draft preparation. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

## Declaration of competing interest

The authors declare no conflict of interest.

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## Ethics statement

The study was approved by the IRB of the Severance Hospital at Yonsei University (IRB No. 4-2017-0923) and Seoul National University Hospital (IRB No. 1801-094-916). All participants and their parent(s) provided written informed consent.

## Data availability statement

The data that support the findings of this study are available from the corresponding author, [H.L.], upon reasonable request.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.apjon.2023.100241>.

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