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ORIGINAL ARTICLE

Development and validation of self- and caregiver-report of a distress screening tool for pediatric cancer survivors

Soo Jin Yoon[1] · **Kyong-Mee Chung**[1] · **Jung Woo Han**[2] · **Seung Min Hahn**[2] · **Sun Hee Kim**[3] · **Chuhl Joo Lyu**[2,4]

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Abstract

Purpose To develop and validate the Distress Screening Tool (DST) for child and adolescent cancer survivors.

Methods In part 1, items of the DST were generated through literature search and group interviews. Initially, the DST was tested on pediatric cancer survivors and their caregivers. In part 2, the modified version of the DST was retested with a different set of participants. Lastly, the psychometric properties and cutoff scores of the DST were evaluated on a separate set of survivors and caregivers.

Results In part 1, six items of the DST self- and caregiver-report versions were generated. The initial 6 DST items of both versions showed acceptable internal consistency, but low inter-item correlation. Following the item modification, both versions of the DST showed improved inter-item correlation. In part 2, the modified DST had acceptable internal consistency and convergent validity, with acceptable psychometric properties. Cutoff scores were also generated.

Conclusions The DST could be a useful tool for pediatric cancer survivors.

Keywords Pediatric cancer · Survivors · Distress screening · Psychosocial services

Introduction

With the advancement in treatment technology and supportive care, the survival rate of individuals with pediatric cancer has been increasing steadily. In Korea, the 5-year survival rates have increased from approximately 58.9% in the early 1990s to almost 85% in 2010 [1], acknowledging cancer as a chronic condition rather than a fatal disease. A considerable amount of research is focusing on the psychosocial functioning of the pediatric cancer population, which generally reports that the level of quality of life (QOL) and prevalence of psychiatric disorders are comparable to that of age-matched healthy individuals [2, 3]. However, a critical subset is found to be at risk of developing significant psychosocial problems. Factors identified as influencing the survivors' status include medical, familial, and demographic factors. The time since treatment [4], experience of late effect [3, 5], treatment intensity [2], and diagnosis of Central Nervous System (CNS) tumors [6] are consistently reported to be associated with worse psychological functioning of the survivors. Having parents who are divorced, have psychological issues, exhibit low socioeconomic status [7], and provide insufficient social support [8] are also related to depression in the survivor. Moreover, school-age youths [9] who are female [10] are known to be at greater risk.

To identify vulnerable survivors and provide them with appropriate care, regular monitoring of survivors' distress [11, 12] is recommended. *Distress* is an umbrella term that describes physical, emotional, and social challenges relating to cancer experience; as it encompasses a wide range of difficulties while using a non-stigmatizing term [13], it is frequently used in oncology settings. Distress experienced in childhood and adolescence is known to have a negative impact on the prognosis of cancer [14] and may persist through

✉ Kyong-Mee Chung
kmchung@yonsei.ac.kr

✉ Chuhl Joo Lyu
cj@yuhs.ac

[1] Department of Psychology, Yonsei University, 50 Yonsei-Ro, Seodaemun-Gu, Seoul 120-749, Republic of Korea

[2] Department of Pediatric Hematology and Oncology, Yonsei Cancer Center, Yonsei University Health System, Seoul, Republic of Korea

[3] Department of Nursing, Yonsei Cancer Center, Yonsei University Health System, Seoul, Republic of Korea

[4] Department of Pediatrics, Yonsei University College of Medicine, Yonsei University Health System, CPO Box 8044, 50 Yonsei-Ro, Seodaemun-Gu, Seoul 120-752, Republic of Korea

adulthood [15]. It can also negatively influence the caregivers of the survivors, causing family conflict, parental distress [16], and post-traumatic symptoms among mothers [17]. Thus, identification of distress in survivors and their family is a crucial task for clinicians to prevent possible long-term physical and psychological consequences.

Despite its importance, assessment of survivor's psychosocial distress is rarely conducted as routine care in clinical settings due to insufficient time, high cost, and lack of professionals to interpret the results [18]. Standardized measures that are used in clinical settings are mostly narrowband scales designed to measure certain psychological symptoms, for example, depression [19] and anxiety [20]. The problem with using these measures as a screening device is that the overall psychosocial experience of the respondent is difficult to assess as they focus on a specific issue and require considerable time to administer, therefore giving additional burden to the clinicians [21]. Distress Thermometer (DT) [22], a single-item measure of global distress, is a widely used screening tool that complements these problems. DT has been found to be reliable and valid across diverse cancer populations [21–24], suggesting high applicability.

There have been few efforts to establish the psychometric properties of DT for the pediatric cancer population. One of the first studies to apply DT in the pediatric population reported that it has an acceptable interrater agreement and convergent validity for individuals aged between 2 and 18 years [25]. More recently, the validity of DT and its diagnostic utility were more firmly established using numerous validated measures, such as the Brief Symptom Inventory and Children's Depression Inventory. In this study, the accompanying problem checklist that provides information on the specific areas of distress was also validated [26]. Despite the positive reports, concerns of using ultra-short measures, like DT, remain the same, in clinical practice. Being short and precise are among the important qualities a screening tool should have, but at the same time, tools with less than four items may be insufficient in capturing the full experience of the respondent [18]. For example, DT was found to be only modestly effective in ruling in mood disorders, like depression and anxiety. Although the *National Comprehensive Cancer Network* emphasizes the need for administering DT with the accompanying problem checklist to clarify areas of distress, this is rarely done in clinical practice; in one study that examined the accuracy of DT, the checklist was found to be administered in only 2 of 21 publications [27]. When it comes to children and adolescents, evaluation of distress can be a more complicated process. This is because distress comes from diverse environments surrounding the youths, including familial, academic, and interpersonal. Thus, as the World Health Organization emphasizes, children and adolescents' emotional distress should be evaluated at a multidimensional level that considers one's physical, mental, and social health [28]. Recognizing the importance of developing a screening tool for pediatric cancer population, the current study aimed to develop and validate a six-item Distress Screening Tool (DST) that measures diverse aspects of distress experienced by Korean child and adolescent survivors of cancer in two parts. In part 1, items were generated and preliminary testing was performed. In part 2, the DST modified from results of part 1 was retested, and then the finalized DST was validated along with generation of cutoff scores.

Development and preliminary testing of the DST

Participants and procedure

In order to identify domains of distress experienced by pediatric cancer survivors, MEDLINE, PubMED, and PSYCINFO databases and relevant reference lists were searched, using a combination of various terms (e.g., "pediatric cancer," "psychological," and "screen" or "assess"). Additionally, six survivors, eight of their caregivers, and five mental health professionals running the Long-Term Follow-Up Clinic (LTFUC) were invited in the discussion and encouraged to talk about some of the core areas of distress experienced by the child and adolescent survivors. All the participants were recruited from the LTFUC of a cancer hospital in Seoul. Survivors of pediatric cancer and their caregivers visit LTFUC regularly for physical, developmental, and psychosocial checkup. The eligibility criteria for participation were as follows: (1) being aged between 10 and 18 years, (2) being off medical treatment for the last 2 years, and (3) currently not having any severe physical or psychiatric difficulties in participating in the interview or completing questionnaires. For the initial testing of the DST, a set of 48 survivors (male = 28, female = 20, average age [*SD*] 12.42 [*1.87*] years), and their 48 caregivers completed the self- and caregiver-report of the six-item DST, respectively.

Data analysis

Descriptive data, internal consistency, and inter-item correlations were examined for the initial items using IBM SPSS 21.0. For internal consistency, Cronbach's α values were examined; α higher than .70 is regarded as satisfactory and that higher than .80 is regarded as good [29]. Inter-item correlations were examined using Pearson's correlation coefficients.

Results

Item generation

Literature search and group interviews revealed that child and adolescent cancer survivors experience various psychosocial difficulties; of all, the most frequently reported were depressive and anxious symptoms, physical fatigue, peer relationship problems, academic difficulties, and overall low life satisfaction. The six items on the frequency of each of the above symptoms experienced in the last 2 weeks were generated (e.g., for the last 2 weeks, I have been depressed) on a 5-point Likert scale (never~almost always). In order to minimize acquiescent response bias, both negatively and positively worded items (nos. 1, 2, and 6 and 3, 4, and 5, respectively) were included. Additionally, caregiver-report regarding the survivor's distress and self-report version were produced, to reduce self-report bias of distress that has been reported in youths with the chronic condition [30].

Evaluation of the initial DST

Internal consistency of the initial DST was good for both self-report ($\alpha = .82$) and caregiver-report ($\alpha = .84$). However, some of the inter-item correlations were not statistically significant in both versions of the DST (i.e., items 4 and 2, and items 4 and 6). To resolve this issue, negatively worded items were positively reworded based on the findings that suggest that a combination of positively and negatively worded items may create more problems than that they prevent [31], such as weakening the internal consistency [32] and creating response acquiescence [33].

Testing the modified DST and its validation

Participants and procedure

The modified DST was tested with another set of participants; 93 survivors (male = 53, female = 40, average age [*SD*] 13.28 [*2.4*] years) and 77 caregivers visiting the LTFUC who met the same eligibility criteria, participated. This time, the participants additionally completed the Pediatric Health-Related Quality of Life (PedsQL), for testing the convergent validity. PedsQL was chosen as a comparative measure as the items concern the similar areas of distress as the DST (i.e., emotional, social, academic, physical, and overall functioning), and it is the most frequently used measure for pediatric patients with a chronic disease [34].

For evaluation of psychometric properties of the finalized DST, another 180 survivors (male = 100, female = 80, average age [*SD*] 14.05 [*2.57*] years) and 201 caregivers visiting the LTFUC were recruited. Survivors and their caregivers completed the DST along with the set of other scales for testing the reliability and validity of the DST. Among them, 50 survivor-caregiver pairs completed the DST again within 2 weeks of their initial visit for the test-retest reliability of the DST. Participants received a summary of the test results for their participation.

Measures

DST

The DST (Table 5) is a screening tool for survivors of pediatric cancer aged between 10 and 18 years, and has both self-report and caregiver-report versions. It comprises six items asking the respondents to rate survivors' distress (depression, anxiety, physical fatigue, peer relationship, academic difficulties, and overall life satisfaction) experienced in the last 2 weeks on a 5-point Likert scale, from 1 (never) to 5 (almost always). The DST was developed in Korean. The items presented in Table 5 were translated into English by two researchers fluent in both languages for the purpose of this paper.

PedsQL generic core scales

Health-related quality of life (HRQOL) is conceptualized as how the patient perceives his/her functioning during or after the treatment, in various contexts, including physical, mental, and social domains [34]. The PedsQL Generic version was developed to measure the HRQOL of children and adolescents in the physical, emotional, social, and school domains. The respondents are asked to rate 23 items on a 5-point Likert scale ranging from 0 (never a problem) to 4 (almost always a problem). The scores are calculated to yield four subscale scores (i.e., emotional, social, school, and physical) and a total score, with higher scores reflecting greater QOL. The PedsQL was originally developed in English and has been translated into many languages including Korean. The Korean version of the PedsQL was used in this study upon approval from the Mapi institute (https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory#languages). The Korean version used in this study has strong reliability and validity [35]. The Cronbach's α of the PedsQL used as a comparison to modify the DST was .91 for self-report and .93 for parent-proxy report. The internal consistency of the PedsQL used for evaluating psychometric properties of the DST was Cronbach's $\alpha = .91$ and $\alpha = .94$ for self- and parent-proxy report, respectively.

DT

DT [22] is a measure of distress originally developed for adult cancer patients, but has also been applied to pediatric patients;

the respondents are asked to rate the level of their distress on a single scale from score 0 (no distress) to 10 (extreme distress).

Children's depression inventory

Children's depression inventory (CDI) [19] is a measure of depressive symptoms among youths aged between 7 and 17 years. Children are asked to rate symptoms experienced in the past 2 weeks on a scale of 0 (absence of the symptom) to 2 (severe form of the symptom), with higher scores representing higher levels of depression. CDI comprises 27 items. The Korean version of CDI has high internal consistency ($r = .88$) and validity [36]. The Cronbach's α of the CDI in the current study was .85.

Revised Children's manifest anxiety scale

Revised children's manifest anxiety scale (RCMAS) [20] is a self-report measure of trait anxiety in youths aged between 6 and 19 years. It has 37 items, and children are asked to respond with either "Yes" or "No" to each symptom. In the current study, the Total Anxiety scores were used. The Korean version of RCMAS [37] has strong internal consistency ($r = .80$) and validity. The Cronbach's α of the RCMAS in the current study was .78.

Child behavior checklist (6–18)

The child behavior checklist (CBCL) [38] is a caregiver-report measure to evaluate emotional and behavioral problems of youths aged between 6 and 18 years. Caregivers are asked to rate the frequency of each symptom on a 3-point Likert scale (0 = Not true, 1 = Somewhat or Sometimes true, 2 = Very true or Often true). In the current study, items of three subscales (depressed/anxious, withdrawn/depressed, and somatization subscale) were used. The three subscales were summed up to yield an internalization score. As recommended by the author [39], raw scores reflecting greater differentiation than the T scores were used for analyses. The Korean version of CBCL [40] has acceptable internal consistency with Cronbach's $\alpha = .62$~.86 and strong validity. The Cronbach's α of the CBCL items used in the current study was .87.

Data analysis

For the modified DST, internal consistency with Cronbach's α and inter-item correlations were reexamined. Convergent validity was evaluated using Pearson's correlation coefficients with the DST and the scores of the PedsQL.

For evaluation of psychometric properties of the modified DST, descriptive analysis was conducted on the demographic and cancer-related variables of the survivors. Univariate analyses were conducted to investigate whether these variables are significantly associated with the DST scores. Internal consistency was examined using the Cronbach's α for the self- and caregiver-report versions. For convergent validity, correlations between the total and item scores of the DST and the subscale and/or total scores of relevant measures were assessed using Pearson's product moment correlation coefficients. Discriminant validity of the DST was assessed by comparing scores of the survivors with PedsQL scores within the average and below average range based on the national norm score. To do this, scores of PedsQL through self- and parent-proxy reports were divided into two groups: scores within the mean range ($M \pm 1SD$) and those below the mean range ($M - 1SD >$). Independent samples t test was performed to compare the mean scores of the DST between the two groups. Finally, M and SD for each self- and caregiver-report of the DST were calculated and scores that were $1.5SD$ above the mean score were selected as the cutoff scores of the DST.

Results

Modified DST

As the analysis of the initial items of the DST resulted in low internal consistency, items were reworded such that they were all positively worded. Analyses of the modified DST yielded improved internal consistency for both self-report ($\alpha = .83$) and caregiver-report ($\alpha = .85$). The inter-item correlation coefficients also increased for self-report ($r = .29$~.65) and caregiver-report ($r = .30$~.70) and became statistically significant (all $p < .001$). Correlations between the DST and the relevant subscales of the PedsQL (i.e., item 1, 2 and emotional subscale, item 3 and social subscale, item 4 and school subscale, item 6 and physical subscale, and item 5 and total DST score and total PedsQL score; see Table 2) were statistically significant (all $p < .001$), for both self-report ($r = -.39$~$-.68$) and caregiver-report ($r = -.42$~$-.79$), demonstrating convergent validity.

Psychometric properties of the modified DST

Participant characteristics

Among 180 survivors and 201 caregivers who were contacted, 168 survivors and 162 caregivers agreed to participate in the study. Of the 50 survivor-caregiver pairs who were additionally requested to complete the DST for a second time, 27 pairs returned their responses. Demographic and cancer-related data are shown in Table 1. None of the demographic or cancer-related variables were shown to significantly affect survivors' DST scores. To investigate age and sex differences in the DST scores, analysis of variance for three age groups and independent samples t test for sex were performed with

Table 1 Demographic and cancer-related characteristics of the survivors

Survivor variables	Cases (*N* = 168) *N* (%)
Age (years)	
10–12 (elementary school)	60 (35.7%)
13–15 (middle school)	43 (25.6%)
16–18 (secondary school)	65 (38.7%)
Sex	
Male	100 (59.5%)
Female	68 (40.5%)
Diagnosis	
Leukemia	70 (41.7%)
Lymphoma	13 (7.7%)
Abdominal tumor	28 (16.7%)
Brain tumor	18 (10.7%)
Others	39 (23.2%)
Time since diagnosis (years)	
1–4	18 (10.7%)
5–9	81 (48.2%)
10–15	59 (35.1%)
> 15	7 (4.2%)
Missing data	3 (1.8%)
Time since treatment completion (years)	
2–4	50 (29.8%)
5–9	79 (47.0%)
10–15	36 (21.4%)
> 15	3 (1.8%)

the self- and caregiver-reports of the DST. No significant differences were found in the DST scores among groups.

Reliability

Internal consistency The Cronbach's α of the DST used in part 2 was .86 for self-report and .84 for caregiver-report, representing good internal consistency. These values are in-between the values for two validated psychological screening tools used with adult cancer patients in Korea [41, 42].

Test-retest reliability Correlation coefficients of the total scores of the DST over the 2-week period were $r = .70$ for survivor- and $r = .85$ for caregiver-reports (both $p < .001$), showing sufficient test-retest reliability (Table 2).

Validity

Convergent validity Each item and the total score of the DST self-report version were compared with the CDI, RCMAS, DT, and PedsQL self-report version. The correlations were performed considering the relevance of contents. For example, item 1 (depression) and item 2 (anxiety) were correlated with CDI and RCMAS, respectively. Also, they were each correlated with the emotional subscale of the PedsQL(See Table 2 for other correlations that were made). All the correlations were statistically significant. The DST caregiver-report version was compared with the CBCL and the PedsQL parent-proxy report version. The total DST score showed significant correlations with the depressed/anxious, withdrawn/depressed, and somatization subscale scores and the total internalization score of the CBCL. Caregiver-reported DST scores were significantly correlated with subscale and total scores of the parent-proxy report of PedsQL (see Table 2, all $p < .001$).

Discriminant validity The mean DST score of the survivors with the PedsQL scores below the average range was significantly higher than that of the survivors with the PedsQL scores within the average range, on both self-report, $t(100) = 6.63$, $p < .05$, and caregiver-report, $t(166) = 9.57$, $p < .001$(Table 3).

Cutoff scores of the DST

The cutoff scores of the DST in both versions were calculated using the *M* and the *SD* (Table 4). This method has been used to generate cutoff scores for several scales of psychological distress, including the State-Trait Anxiety Inventory and CBCL, where the scores of the clinical population are expected to fall 1.5~2*SD* above the mean [20, 38]. As the DST scores showed no significant differences among age groups, a single cutoff score was generated for both versions. A score of 15 on self-report and 16 on caregiver-report were identified as cutoff scores. The rates of distressed survivors who scored above the cutoff were 10.7% for self-report and 10.1% for caregiver-report.

Discussion

The purpose of the present study was to develop and validate the two versions of the DST for pediatric cancer survivors. In part 1, six items were generated based on literature review and interviews, and internal consistency, and inter-item correlations of the items were evaluated. The results were satisfactory except for the inter-item correlation coefficients across six items, which were low. To resolve this, negatively worded items were rearranged positively. In part 2, the modified DST was retested and its psychometric properties were evaluated. Inter-item correlation coefficients had improved and all became statistically significant following modification. Reliability and validity of the DST were found to be acceptable. Additionally, cutoff scores for the self- and caregiver-report versions were calculated. The results of the current

Table 2 Correlations of survivor- and caregiver-report of the Distress Screening Tool (DST) with validated measures

	DST													
Validated measures	Self-report							Caregiver-report						
	1 Dep	2 Anx	3 Rel	4 Sch	5 Gen	6 Phy	Total	1 Dep	2 Anx	3 Rel	4 Sch	5 Gen	6 Phy	Total
CDI ($n = 72$)	$.47^{**}$						$.66^{**}$							
RCMAS ($n = 65$)		$.59^{**}$					$.61^{**}$							
DT ($n = 89$)							$.48^{**}$							
PedsQL ($n = 168$ for self-report, $n = 162$ for caregiver-report)														
Emotional	$-.55^{**}$	$-.60^{**}$						$-.52^{**}$	$-.56^{**}$					
Social			$-.68^{**}$							$-.73^{**}$				
School				$-.50^{**}$							$-.60^{**}$			
Physical						$-.17^{**}$							$-.44^{**}$	
Total					$-.59^{**}$		$-.73^{**}$					$-.61^{**}$		$-.74^{**}$
CBCL ($n = 44$)														
Depressed/anxious														$.58^{**}$
Withdrawn/depressed														$.42^{**}$
Somatization														$.48^{**}$
Internalization score														$.61^{**}$
Test-retest reliability ($n = 27$)	$.70^{**}$							$.85^{**}$						

All values show significance of $^{**}p < .001$

study suggest that the DST is a psychometrically sound screening tool with several advantages.

First, psychometric properties of the DST showed that it is a reliable and valid measure for assessing distress among pediatric cancer survivors. Unlike adult survivors, little efforts have been made to develop a screening tool for psychological functioning of pediatric cancer population. This may be partly due to the fact that they experience subtle adjustment difficulties that are hard to detect [43]. However, both clinical and research findings suggest that neglect of early signs could result in serious psychological disorders in some of the patients. Thus, it is necessary to develop a valid screening tool to detect psychological problems of pediatric cancer patients and survivors for prevention purposes. Until now, narrowband scales such as the measure of depression or anxiety have been commonly used for this population. They are rarely administered unless significant symptoms are reported or observed, and require professionals to administer and score. Conversely, the newly developed DST assesses diverse aspects of distress (i.e., emotional, school, peer relationship, and physical fatigue-related problems) which are commonly reported among pediatric cancer patients, and takes only a few minutes to complete, which lessens the respondents' burden. To ensure the use of the DST as a screening tool of distress in practice, continuous efforts to examine its psychometric properties across diverse pediatric cancer groups and countries is necessary.

Second, the DST has both self- and caregiver-report versions, which have several benefits in both clinical and research settings. PedsQL, which is being widely used in oncology settings to measure the respondent's perceived QOL, is a representative measure that has both self-report and parent-proxy versions; however, the discrepancy between self- and parent-reported distress of youths with chronic illness has been reported while using this tool, especially regarding adolescents' internalizing problems [44]. Although researchers recommend assessing adolescents' status based on self-reported data and using parent's data as supplemental information [45], given

Table 3 Results of *t* test for total Distress Screening Tool score by level of quality of life (QOL) in the survivors

	M(*SD*)		*T*	df
	Average QOL group	Low QOL group		
Self-report	7.94 (3.03)	12.67 (4.11)	6.63^{*}	100
Caregiver-report	7.67 (2.25)	12.63 (4.18)	9.57^{***}	166

Health-related quality of life was dummy coded "1" for below average group and "0" for within the average group, $^{*}p < .05$, $^{***}p < .001$

Table 4 Suggested cutoff scores of Distress Screening Tool

Versions	M ± 1.5*SD*	Cutoff score	Above cutoff (%)
Self-report	8.99 ± *5.87*	15	10.7%
Caregiver-report	9.81 ± *6.03*	16	10.1%

that a considerable number of survivors of pediatric cancer suffer from physical or neurological late effects, obtaining information from the caregivers should be continued. The caregiver-report version of the DST could be useful in this case. Moreover, in future studies, having two versions will support the studies that investigate inter-rater reliability in perceiving survivors' distress.

Finally, cutoff scores of the DST were suggested. The cutoff score is useful as it guides clinicians to decide whether respondents need additional attention. For routinely used screening tools, like the DST, having cutoff scores will save time and unnecessary costs for the patients and caregivers. However, several considerations should be made regarding the cutoff score of the DST. Above all, specificity and sensitivity were not determined used to generate the cutoff scores. In the current study, the national norm for score on PedsQL was used as a standard to define the average range score of the DST. The mean scores of PedsQL of our participants indicated that their QOL was in the average range of national data [35]. Thus, it was not considered necessary to recruit participants without a history of cancer to generate cutoff scores. Additionally, age-specific cutoff scores were not suggested as there was no difference in the mean score of the DST across age groups. However, as these cutoff scores have not been validated, future studies should consider generating cutoff scores based on clinical outcomes.

The limitation and suggestions for further study are as follows. First, diverse cancer-related factors such as types of cancer, treatments received, and the severity of late effects, were not investigated. The pediatric cancer population is known to have a great heterogeneity, and cancer-related factors are known to interact in complicated ways to affect the survivors' adaptation [2–5]. Thus, future studies should investigate how these factors affect survivors' distress, in order to represent the population more accurately and provide useful information on psychosocial care for different cancer populations. Second, although the DST may be useful in gathering information about the survivors' distress experience, whether reported scores correspond to the actual presentation of clinical symptoms cannot be inferred. For example, the DST scores may guide the clinicians in knowing that the survivor has emotional problems, but whether these symptoms are clinically significant cannot be inferred from the current cutoff scores. Again, future studies should include survivors with clinically significant symptoms for this reason. Lastly, participants were recruited from only one site, limiting the generalization of the results. It is necessary to use a multisite approach to recruit a large group of participants in future studies.

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Compliance with ethical standards

Ethics Institutional Review Board (IRB) of Severance Hospital, Yonsei University College of Medicine (IRB No. 4-2015-0919).

Conflict of interest The authors declare that they have no conflict of interest.

Appendix

Table 5 Distress Screening Tool

Item	Check (V) the box that applies to the state, your own or your child's, in the last 2 weeks. Survivors (I am…)/Caregivers (My child is…)	1(never)~5(almost always)				
		1	2	3	4	5
1	Depressed (e.g., sad, withdrawn, lonely, uninterested in activities)					
2	Anxious (e.g., tense, scared, pursuing perfectionism, restless)					
3	Having problems in relationship with friends					
4	Having problems in school life (e.g., attending school, catching up in class)					
5	Not satisfied with overall life					
6	Having physical symptoms (e.g., chest pain, vomiting, breathing, fatigue)					

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