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Original Article

Measure of perceived social support from family, friends, and healthcare providers for Korean adolescents and young adults with cancer

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A B S T R A C T

Objective: Assessing the perceived social support (PSS) that adolescents and young adults (AYAs) with cancer receive from family, friends, and healthcare providers is critical to promoting their adjustment. This study developed a reliable and comprehensive self-report PSS assessment tool that measures various aspects of social support by translating existing measurements into Korean.
Methods: The translation was completed in accordance with international guidelines. To focus on cultural adaptation, the main ideas associated with items were translated to reflect the differences between Western and Eastern culture. In total, 144 Korean AYAs with cancer (mean age: 17 years; 46% female) completed the translated version. A separate principal component analysis (PCA) with an orthogonal quartimax rotation, a minimum eigenvalue of 1.0, and minimum factor loadings of 0.50 was used for each subscale. Cronbach's alpha coefficients were calculated for each PCA-derived subscale.
Results: Four subscales with 46 items were identified. Two subscales represented perceived emotional support within the family (PSS-ESF, 14 items) and the AYA's perceived helpfulness within the family (PSS-HWF, 3 items). The third scale represented the perceived support of friends (PSS-Friends, 14 items). The final scale represented the perceived support of healthcare providers (PSS-HCPs, 15 items). Excellent reliability per subscale was demonstrated (Cronbach's alpha: 0.93 for PSS-ESF, 0.73 for PSS-HWF, and 0.92 each for PSS-Friends and PSS-HCPs).
Conclusions: A culturally adapted and reliable Korean version questionnaire with four independent subscales was developed. Further assessment of the Korean PSS is required and will contribute to the development of culturally adapted and tailored interventions.

Introduction

Recent advances in treatments are expected to result in better patient outcomes among childhood cancer patients and survivors.[1] This progress, however, has had unanticipated effects on the quality of life of adolescent and young-adult (AYA) cancer survivors. Due to their unique characteristics, AYA cancer patients/survivors often experience intensified physical and psychological burdens during their developmental transition.[2–5] These bring a variety of psychosocial disruptions, resulting in emotional, interpersonal, existential, and spiritual unmet needs.[6,7] Specifically, extensive research has shown that AYAs with cancer suffer from ongoing uncertainty and fear of recurrence,[8,9] in addition to

unpleasant symptoms, changes in physical appearance, identity issues, dependence on parents, disrupted schooling, social isolation, and decreased cognition and academic abilities.[10–12]

In this context, extensive research has been conducted to help AYAs adjust in positive ways to their diagnoses. Researchers have emphasized the role of social support in helping AYA cancer patients/survivors make such positive adjustments.[13–15] However, Korean AYAs may need more attention from researchers regarding social support in order to adjust better to cancer diagnoses. Korean AYAs with cancer have reported a higher prevalence of psychological distress than their American peers, due to their unique sociocultural characteristics.[16–19] At worst, Korean AYAs have reported an inability to cope in healthy or positive ways with

their cancer diagnoses.[20] This finding underlines the need for a further assessment of perceived social support (PSS) in this population. Despite the wide range of definitions of social support, the existence and availability of necessary help and compassion offer a coherent understanding of social support.[21]

Three main types of PSS exist in the childhood-cancer context. First, PSS from family is a strong predictor of AYA cancer patients/survivors' positive adjustment to cancer diagnoses.[22,23] In addition, AYAs with cancer value the perceived support of peers, which influences their ability to adjust in better ways across the illness trajectory.[22,24] The PSS received from healthcare providers is another type of support, closely related to patient satisfaction, adherence to the treatment regimen,[25] an ability to cope with cancer-related distress and uncertainty.[26] It is, therefore, essential to assess the PSS that AYAs receive from family, friends, and healthcare providers.

In recent years, various measurements have been used to assess PSS in the Korean population. These measures include the Norbeck Social Support Questionnaire (NSSQ),[27] Part 2 of the Personal Resource Questionnaire (PRQ),[28] the Interpersonal Support Evaluation List (ISEL),[29] the Korean Social Support Questionnaire (KSSQ),[30] the Social Support Scale (SSS),[31] and the Multidimensional Scale of PSS (MSPSS).[32] In particular, the MSPSS has been widely used to assess PSS among Korean cancer patients, including breast cancer survivors and AYAs with cancer.[32] However, the MSPSS does not provide a holistic assessment of PSS from family, friends, and healthcare providers, especially among AYAs with cancer. The aim of this study is thus to translate the existing PSS measures into Korean and develop a culturally adapted and reliable PSS assessment tool to measure perceived support from family, friends,[33–35] and healthcare providers[36] among Korean AYAs with cancer.

Methods

Design, setting, and sample

The present study is a cross-sectional, psychometric analysis of the PSS received from friends, family, and healthcare providers, following translation into Korean. AYAs were recruited from a university-affiliated hospital in Seoul, Korea, and from the Korean Leukemia Foundation (KLF) via an online survey. In both settings, the AYA inclusion criteria were as follows: (1) 11–26 years of age; (2) having a cancer diagnosis at any stage (newly diagnosed, in treatment, a survivor in remission, or relapsed ["survivor" refers to an AYA who has completed treatment and is not on hospice]); (3) being fully informed about their cancer diagnoses; (4) having the ability and willingness to complete the required measures on an iPad or laptop computer; and (5) being able to communicate in Korean. From both sites, data were collected using convenience sampling from a total of 144 AYAs diagnosed with cancer and treated at a university-affiliated hospital in Seoul, Korea. Of the 144 AYAs studied, 31 (21.5%) were recruited through the KLF mechanism. Sensitivity analyses indicated no significant differences between the characteristics of AYAs recruited at the hospital and through the KLF, apart from the fact that fewer KLF patients had higher education and one or more comorbidities. There was no significant difference in the number of female AYAs.

Data collection

Data were collected between June 25, 2019, and August 31, 2020. In the hospital setting, the study coordinator explained the study purpose and process. In the online-survey setting, a flyer was posted on the KLF homepage, introducing the study and its purpose, inclusion criteria, expected risks/benefits, and processes. This flyer included a URL link to enable participants to provide informed consent. Researchers obtained written parental consent and permission (for minor adolescents) and assent and written consent from participants who were 19 or older, as required by the institutions. In the hospital setting, questionnaires were distributed in the waiting areas, while consenting participants were

waiting to see their healthcare providers. In the online setting, once the consent form was received, researchers contacted potential study participants via telephone to confirm their consent and determine whether they met the inclusion criteria. Once it was confirmed that all potential study participants met the inclusion criteria, the researchers sent the survey link to all who had agreed to participate. The survey included a 60-item Korean version of the PSS questionnaire, which incorporated the translated measures of PSS from family (PSS-Family), friends (PSS-Friends) and healthcare providers (PSS-HCPs). Each measure consisted of 20 items.

Procedure

The translation process used to develop a Korean version of the PSS questionnaire for assessing the social support from family, friends, and healthcare providers perceived by Korean AYAs with cancer was conducted systematically by applying the forward and back-translation method, as widely recommended.[37,38] The process involved three native Korean speakers who were fluent in English and a bilingual researcher who blindly translated the preliminary initial instrument into English. During the process, the researchers met regularly, discussed every discrepancy, and reached a consensus in each case. In translating the measures, they focused on two main areas: (1) enhancing cultural adaptation by translating the main ideas in the items in each measure, rather than translating them word-for-word; and (2) understanding Western and Eastern cultural differences when developing culturally appropriate measures. Specific examples included the use of different possessive cases, such as translating "my" or "mine" into "our" in Korean. The frequency of "our" rather than "my" also reflected the influence of collectivism in traditional Korean society.[39] The generational gap was another important issue in the translation. For example, the researchers had to consider variations in vocabulary across generations in order to translate items into vocabulary that would be familiar to AYAs. Items with minor semantic and idiomatic discrepancies between the languages were revised during the discussion with the research team, who reached a consensus on each item. Finally, the translated instrument was tested on several monolingual Korean AYAs with cancer to detect any unclear expressions or expressions that were difficult to understand.

Measures

The original English version of the PSS questionnaire included two sections: the first assessed PSS from family and the second measured PSS from friends.[33] An additional PSS questionnaire was later developed to specifically assess PSS from healthcare providers by adapting the two existing measures of family and friends.[36,40] All three PSS assessment tools were used to evaluate PSS among AYAs with cancer.[40,41] Thus, these three PSS tools were used to assess the extent to which the AYAs perceived themselves to have the support, information, and feedback they needed from PSS-Family, PSS-Friends, and PSS-HCPs.

The original English-language version of the PSS-Family and PSS-Friends tools have excellent reliability, as well as predictive and construct validity, when used with diverse subpopulations, including healthy college students and patients with chronic illnesses, such as chronic mental-health disorders and diabetes.[33,34] Importantly, all three tools have shown excellent reliability among AYAs with cancer in previous studies,[40,41] with Cronbach's alpha internal consistency values $\geq$ 0.84 (PSS-Family = 0.91; PSS-Friends = 0.84 to 0.92; and PSS-HCPs = 0.86 to 0.96).

All three assessment tools were translated into Korean for this study, as described above. These three tools were used to create a single 60-item PSS questionnaire for AYAs, consisting of three sections (PSS-Family, PSS-Friends, PSS-HCPs). Each section included 20 items from the Korean version of each respective assessment tool. Each item included in each tool was rated using a 5-point Likert-scale, with responses ranging from 1 = totally disagree to 5 = totally agree. Negatively worded items were

reverse scored. Total scores were derived by adding up the items comprising each assessment tool; they ranged from 20 to 100, with higher scores indicating greater PSS from the source indicated.

Data analysis

Data were analyzed via SAS 9.4 software (Cary, NC). Descriptive statistics were used to summarize the AYA characteristics and to detail key variables in the analysis. The goal was to develop a single Korean version of the PSS questionnaire with an orthogonal factor structure, from which PSS subscales could be derived. The Korean-translated items comprising each tool were expected to yield a factor structure similar to that reported for the English version of each assessment tool (PSS-Family, PSS-Friends, and PSS-HCPs). Rather than conducting an analysis of the 60-item Korean-translated PSS questionnaire, a separate analysis of each tool comprising the questionnaire was conducted, replicating the approach applied during the development of the English version of each tool.[33]

A principal component analysis (PCA) was used in place of a confirmatory factor analysis (CFA) for the initial evaluation of the Korean-translated PSS-Family, PSS-Friends, and PSS-HCPs tools. The PCA applied to each assessment tool allowed us to reduce the larger set of 20 variables (items) into one or more small sets of items, each set representing a different PSS dimension (component). Furthermore, no CFA approach was applied at this juncture, due to the small sample size of 144.[42] Reflecting the general recommendation of 10–20 participants per item, a sample size of 200 or more was needed for a CFA with 20 items. Finally, the focus at this stage of developing the Korean version of the instrument was to identify various components of PSS in Korean AYAs with cancer, from which subscales assessing each component construct could be derived.

A separate PCA was conducted on the 20 Korean-translated items for (1) PSS-Family; (2) PSS-Friends; and (3) PSS-HCPs, resulting in three sets of model results. For each PCA, an orthogonal quartimax rotation method was applied with a scree plot, and a minimum eigenvalue of 1.0 was used to determine the factor structure.[43] The final rotated factor structure included only items with a minimum factor loading of 0.50 on one factor. Items with a crossloading of ≥ 0.50 on more than one factor were omitted to obtain a noncorrelated factor structure.[44] The variance explained by the final factor structure was determined. Subscale scores were derived by adding up the item scores comprising each component identified by the final rotated factor structure. As a final step, the internal consistency of items comprising each PSS subscale was assessed using standardized Cronbach's alpha coefficients. A Cronbach's alpha of 0.70 or higher was determined to indicate the adequate reliability of items.[45]

Ethical considerations

Prior to data collection, the principal investigator (PI) obtained approval from the Institutional Review Board (IRB) at the Korean study sites (IRB No. 4-2018-0932) and a North American site (for data transfer and analysis; IRB No. Pro00093767). The hospital IRB approved both onsite and online data collection and the consent process at both sites.

Results

AYA characteristics

Table 1 presents the characteristics of the 144 AYAs. The mean age was 17.0 years (range: 11–26); 45.8% were female and 54.6% reported a religious affiliation. Their levels of education ranged from elementary school to college/university attendance. The most common cancer diagnosis was solid tumors (61.9%) and 23.9% were recently diagnosed with cancer (less than one year). Of the 116 AYAs with available treatment-status data, 42.2% were currently receiving active cancer treatment, which included chemotherapy, radiation, surgery, and hematopoietic stem-cell transplantation.

Table 1
AYA characteristics ($N = 144$).

Characteristics	n (%)
Age, years, mean $\pm$ SD	17.0 $\pm$ 3.8
Gender (female)	66 (45.8)
Religious ($n = 141$)	77 (54.6)
Educational level ($n = 138$)	
Elementary school	19 (13.8)
Middle school	36 (26.1)
High school	42 (30.4)
College or university	41 (29.7)
Time since diagnosis ($n = 142$)	
Less than 1 year	34 (23.9)
1–3 years	39 (27.4)
4–6 years	40 (28.1)
Over 6 years	29 (20.4)
Cancer diagnosis ($n = 139$)	
Hematologic malignancy	38 (27.3)
Solid tumor	86 (61.9)
Brain tumor	13 (9.35)
Not specified	2 (1.44)
Having relapsed cancer diagnosis ($n = 143$)	23 (16.1)
Currently receiving cancer treatment ($n = 116$)	49 (42.2)
One or more comorbidities ($n = 120$)	41 (34.2)

Perceived social support—Family

A three-factor solution was predicted from the PCA of the 20 items comprising the PSS-Family tool, based on a published CFA of the English version.[35] The three factors were previously labeled as follows: (1) receives support from family (items 1, 2, 3, 5, 6, 8, 9, 10, 11, 13, 14, 17, 20); (2) provides support to family (items 5, 7, 12, 15. 17, 18); and (3) family intimacy (items 4, 16, 19, 20). Thus, the original English version yielded three subscales (constructs) related to perceived support within the family, with some items cross-loading on more than one scale.

The final PCA model for the Korean version of PSS-Family, which included 17 of the 20 items, indicated a two-factor solution and explained 92% of the total variance (Table 2). From the initial 20 items, three items (items 3, 11, 17) were removed due to a factor loading < 0.50. No item was removed from any of the models due to cross-loading. Factor l represented emotional support from family (PSS-ESF, items 1, 2, 4, 5, 6, 8, 9, 10, 12, 13, 14, 16, 19, 20), and Factor 2 represented the AYA's perception of his/her own helpfulness within the family (PSS-HWF, items 7, 15, 18). Two family-support subscales were derived by adding up the items comprising the respective factors, with higher subscale scores indicating greater perceived support from family. The Cronbach's alpha coefficient was 0.93 for the 14-item subscale of PSS-ESF and 0.72 for the 3-item subscale of PSS-HWF.

Perceived social support—Friends

A one-factor solution was expected from the PCA, with 20 items comprising the Korean version of the PSS-Friends tool.[35] From the initial 20 items, six items (items 2, 6, 10, 15, 18, 20) were omitted due to factor loadings < 0.50. No items were eliminated because of cross-loadings. The final 14-item PCA indicated a one-factor solution, explaining 87.8% of the total variance (Table 3). The "AYA's perceived support from friends" subscale was derived by adding up the 14 items comprising the single factor, with higher subscale scores indicating greater perceived support. The Cronbach's alpha of 0.92 confirmed the reliability of the subscale items.

Perceived social support—Healthcare providers

A one-factor solution was expected from the PCA, with 20 items comprising the Korean version of the PSS-HCPs tool. Five items (items 2, 6, 15, 18, 20) were eliminated due to factor loadings under 0.50. No items were eliminated because of cross-loadings. The final 15-item EFA

Table 2
Korean PSS-Family subscales: Final principal components ($N = 144$).

No	Items	Factor loadings	
		Factor 1	Factor 2
01	My family gives me the moral support I need	0.82	
02	I get good ideas from my family about how to do things or make things	0.67	
04	When I confide in the members of my family who are close to me, I get the idea that it makes them uncomfortable	0.61	
05	My family enjoys hearing about what I think	0.65	
06	Members of my family share many of my interests	0.70	
07	Certain members of my family come to me when they have problems or need advice		0.55
08	I rely on my family for emotional support	0.72	
09	There is a member of my family I could go to if I were just feeling down, without feeling funny about it later	0.80	
10	My family and I are very open about what we think about things	0.82	
12	Members of my family come to me for emotional support	0.65	
13	Members of my family are good at helping me solve problems	0.79	
14	I have a deep sharing relationship with a number of my family members	0.72	
15	Members of my family get good ideas from me about how to do things or make things.		0.61
16	When I confide in members of my family, it makes me uncomfortable	0.64	
18	I think that my family feels that I'm good at helping them solve problems.		0.50
19	I don't have a relationship with a member of my family that is as close as other people's relationships with family members	0.76	
20	I wish my family were much different	0.64	

Italicized items did not load at the 0.50 or higher level any one factor and were not retained in final PSS-Family model. Cronbach's alpha was 0.93 for Factor 1 (AYA's percent emotional support from family) and 0.72 for Factor 2 (AYA's perception of on helpfulness within the family). PSS, perceived social support; AYAs, adolescents and young adults.

Table 3
Korean PSS-Friends subscale: Final principal component analysis ($N = 144$).

No.	Items Factor Loadings	Factor loadings
		Factor 1
01	My friends give me the moral support I need	0.73
03	My friends enjoy hearing about what I think.	0.76
04	Certain friends come to me when they have problems or need advice.	0.67
05	I rely on my friends for emotional support	0.69
07	I feel that I'm on the fringe in my circle of friends.	0.53
08	There is a friend I could go to if I were just feeling down, without feeling funny about it later.	0.62
09	My friends and I are very open about what we think about things	0.79
11	My friends come to me for emotional support.	0.84
12	My friends are good at helping me solve problems.	0.76
13	I have a deep sharing relationship with a number of friends.	0.68
14	My friends get good ideas from me about how to do things or make things.	0.70
16	My friends seek me out for companionship.	0.68
17	I think that my friends feel that I'm good at helping them solve problems.	0.70
19	I've recently gotten a good idea about how to do something from a friend.	0.55

Italicized items did not load at the 0.50 or higher level on any factor and not retained in final PSS-Friends model. Cronbach's alpha as 0.92 for Factor 1 (AYA's perceived support from friends). PSS, perceived social support; AYAs, adolescents and young adults.

indicated a one-factor solution, which explained 85.3% of the total variance (Table 4). A subscale of "AYA's perceived support from healthcare providers" was derived by adding up the 15 items comprising the single factor, with higher subscale scores indicating greater perceived support from healthcare providers (Cronbach's alpha = 0.92).

Korean PSS assessment tool

A final Korean version of the PSS (Korean PSS) was developed, consisting of the four subscales derived from the final three PCA model results previously described. The Korean PSS, a single assessment tool designed to assess perceived support from the family, friends, and healthcare providers of AYAs with cancer diagnoses, includes 46 total items divided into three sections (Table 5). The family section includes two family-related subscales (17 items), one friend-related subscale (14 items), and one healthcare provider-related subscale (15 items).

Furthermore, the items within each subscale align well with similar subscale items reported for the English version of the PSS instruments. The Pearson correlation coefficient for the two family-related subscales was 0.50, less than $r = 0.80$ or a higher indicative of collinearity.[46] The remaining intercorrelations among the subscales ranged between 0.28 and 0.46, further suggesting that the subscales measured different dimensions of PSS. Table 5 presents descriptive statistics for the four subscales derived from the PCAs. For each subscale, higher scores indicated greater perceived support. The median score for the observed scores was higher than the midpoint of the possible range of scores for each subscale. In particular, the median scores from the subscales of PSS-ESF and PSS-Friends diverged most from the midpoint of the possible range of scores.

Discussion

The existing PSS assessment tools were translated into Korean and a reliable single self-report PSS questionnaire was developed to meet the need for a culturally-tailored, comprehensive measure of perceived

Table 4
Korean PSS-HCPs subscale: Final principal components analysis ($N = 144$).

No.	Items	Factor loadings
		Factor 1
01	My healthcare providers give me the moral support I need	0.66
03	My health care providers want to hear about what I think.	0.61
04	I have certain health care providers I can go to when I have problems or need advice.	0.69
05	I rely on my health care providers for emotional support.	0.66
07	I feel that my health care providers are interested in me.	0.68
08	There is a health care provider I could go to if I were just feeling down, without feeling funny about it later.	0.76
09	My health care providers and I are very open about what we think about things.	0.75
10	My health care providers are sensitive to my personal needs.	0.63
11	Health care providers share things about themselves with me.	0.54
12	My health care providers are good at helping me solve problems.	0.71
13	I have a deep sharing relationship with a number of health care providers.	0.73
14	My health care providers use my ideas about how to do things.	0.60
16	I have fun with my health care providers.	0.73
17	I think that my health care providers feel that I'm good at helping them solve problems.	0.57
19	I've recently gotten a good idea about how to do something from a health care provider.	0.64

Italicized items did not load at the 0.50 or higher level on any factor and not retained in final PSS-HCP model. Cronbach's alpha of 0.92 for Factor 1 (AYA's perceived support from healthcare providers). PSS, perceived social support; AYAs, adolescents and young adults; HCPs, healthcare providers.

Table 5
Final Korean version of the PSS assessment tool (Korean PSS): Descriptive statistics.

PSS section	PSS subscale	# of items	Possible range	Possible range midpoint	Observed scores: Range	Observed scores: Median (P25, P75)
Family	AYA's perceived emotional support from family	14	14 to 70	42	20 to 70	57.0 (52.0, 65.0)
Family	AYA's perceived own helpfulness within the family	3	3 to 15	9	3 to 15	10.0 (9.0, 12.0)
Friends	AYA's perceived support from friends	14	14 to 70	42	14 to 70	55.0 (50.0, 61.0)
HCP	AYA's perceived support from health care providers	15	15 to 75	45	21 to 74	50.0 (42.0, 56.0)

Higher subscale score indicates greater PSS, perceived social support.

support from family, friends, and healthcare providers among Korean AYAs with cancer. The final Korean PSS questionnaire consists of four subscales, which measure the AYAs' perceived emotional support from family, perception of their own helpfulness within the family, perceived support from friends, and perceived support from healthcare providers.

The PCA of the Korean PSS questionnaire yielded a different factor structure (four subscales) from the original English version, which yielded three PSS-Family subscales and one subscale each from PSS-Friends and PSS-HCPs. The process also reduced the number of items from 60 to 46 items for the Korean PSS. However, this is not surprising because different factor structures are common in original and translated measures in different cultures.[47] Cultural differences between Korea and North America constitute one possible explanation for the different factor structures and reduced number of items. For instance, it is widely understood that cultural beliefs can influence the perception of friendships and peer relationships.[48]

Specifically, most items removed from the original PSS-Friends focused on feelings of AYA intimacy with friends or beliefs about the help they provided to friends, rather than the support they received. In the original English version of the tool, a feeling of intimacy was defined as a form of social support from friends. However, Korean AYAs may view social support from friends in more functional ways. For example, they may view physical assistance and emotional support as forms of social support, rather than emotional connection (eg, intimacy). Similarly, the Korean PSS-HCPs resulted in 15 items, after omitting original items that described feeling intimate with healthcare providers as a form of social support. Taken together, the findings suggest that Korean AYAs with cancer may have different expectations and definitions of social support from healthcare providers and friends.

An additional example supports the argument that cultural differences generate gaps in the perception of perceived support from healthcare providers. As the Korean healthcare provider—patient relationship is hierarchical,[49] due to the influence of confucianism,[50] it may be considered disrespectful and inappropriate for AYAs to develop intimate feelings for their healthcare providers. In addition, the differences between primary healthcare systems in Korean and Western cultures may affect AYAs' perceived relationships with healthcare providers. For example, in the United States, American patients have family doctors, who are responsible for managing their health conditions. Patients can contact their physicians directly. The Korean medical system does not have the same concept of the "family doctor." Instead, Korean patients can come to the hospital for in-patient services or admission without direct contact. The absence of a direct method of communication may affect the way Korean AYAs perceive close relationships with their physicians. The fact that the original authors adapted the original PSS-HCPs tool from PSS-Friends by reflecting the characteristics of healthcare providers in Western cultures supports this possible difference.[36,40]

Korean AYAs show different patterns of perceived support from family. It is worth noting that the Korean AYAs defined perceived support differently, based on relationship type. Korean AYAs saw intimacy or the provision of help to family members as relevant to their PSS. The fact that Korean society is traditionally family-centered may explain why Korean AYAs perceive intimacy among family members as social support.[16,51] Further studies are needed to understand how PSS may differ in different

relationships; this could provide better insight into how family, friends, and healthcare providers can support AYAs with cancer in Korea.

The AYAs' median score on each subscale was greater than the midpoint values for the possible range of scores for each subscale, suggesting that the subscale scores for each aspect of PSS for Korean AYAs with cancer tended to fall on the side of higher levels of perceived support. In particular, the fact that the PSS-ESF subscale was one of the subscales with the most deviant score aligns with the published results, which show that AYAs rank family as one of the most meaningful sources of support across the illness trajectory.[20,52] However, the current findings related to greater perceived support from friends contradict previous studies, which have suggested a lack of peer support for Korean AYAs with cancer.[53,54]

The internal consistency reliability of each PSS measure was good to excellent. Specifically, three of the four subscales (PSS-ESF, PSS-Friends, and PSS-HCPs) had excellent levels of internal consistency, manifested by Cronbach's alpha of 0.92–0.93. The one subscale of PSS-HWF had good reliability (Cronbach's alpha of 0.73).

Limitations

Several limitations provide directions for future research and should be considered. Despite our recruitment efforts through KLF, most participants were recruited from one university-affiliated hospital in Seoul, Korea. These results may not be generalizable to all Korean AYAs with cancer. Although the original PSS measures have been used to assess PSS among North American AYAs with cancer, they were initially developed for an adult population. We, therefore, encountered challenges when translating some items related to interpersonal relationships among family members. One of these items was, "Members of my family get good ideas from me about how to do things or make things" from PSS-Family.[33] It may be hard for Korean AYAs to envision family members, especially their parents, asking for their advice or opinions, given the hierarchical structure prevalent in Korean families.[55] If necessary, the additional items could be developed to better reflect PSS from family, friends, and healthcare providers, based on Korean interpersonal relationships.

Most of the negatively phrased items were not included in the Korean PSS questions because of their low factor loadings (< 0.50). In general, negatively phrased items are recommended for developing measurements to prevent response bias.[56] Here, the researchers found that negatively worded or reverse items did not affect reliability.[57] However, there is a concern that mixing negatively and positively worded items can adversely affect measure consistency or dimensionality, especially in translated measures when conducting cross-cultural studies.[58] Researchers must be aware that the translation process can undermine consistency and dimensionality. Finally, a larger, separate sample of AYAs with cancer is recommended for a future study, which could use a CFA to confirm the factor structure of the 46 items in the Korean PSS questionnaire and adequately evaluate the goodness-of-fit of the final model.

Conclusions

Evidence is mounting to support the importance of assessing the social support needs of AYAs to improve their adjustment and patient

outcomes.[14,26,59] The present study has developed a Korean PSS questionnaire in order to assess the PSS of family, friends, and healthcare providers. Our findings suggest that Korean AYAs may have different definitions and/or expectations of the support they receive from family, friends, and healthcare providers from their North American counterparts. In addition, these findings suggest that Korean AYAs with cancer tend to receive more PSS than those who surround or care for them. The Korean PSS questionnaire is a reliable tool for Korean AYAs, offering several advantages: (1) it reduces the burden on AYAs, as it has only 46 items; (2) it reflects cultural differences in PSS and (3) each tool can be applied independently, with established reliability. Taken together, this tool can be useful in assessing PSS levels and needs among Korean AYAs, providing insights that can be used to develop interventions that provide essential social support to Korean AYAs.

CRediT author statement

Heeyeon Son: Conceptualization, translation of the measurement, data collection, analysis, and writing- original draft preparation and revising based on feedback. Sungsil Hong: Conceptualization, translation of the measurement, and data collection. Michin Hong: translation of measurement and reviewing and editing. Susan Silva: Methodology, data analysis, writing-original draft preparation, and reviewing and editing. 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.

Ethics statement

This study was approved by the Ethics Committee of Duke University (IRB No. Pro00105744) and Severance Hospital, Seoul Korea (IRB No. 2019-0263-003). All participants provided written informed consent.

Data availability statement

Data is available upon request from the authors.

Declaration of competing interest

All authors have none to declare.

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