



Original Article

Pilot Study for the Psychometric Validation of the Sheffield Profile for Assessment and Referral to Care (SPARC) in Korean Cancer Patients

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Purpose This study aimed to validate the Sheffield Profile for Assessment and Referral to Care (SPARC) as an effective tool for screening palliative care needs among Korean cancer patients.

Materials and Methods The English version of the SPARC was translated by four Korean oncologists and reconciled by a Korean language specialist and a medical oncologist fluent in English. After the first version of the Korean SPARC (K-SPARC) was developed, back-translation into English was performed by a professional translator and bilingual oncologist. The back-translated version was reviewed by the original author (S.H.A.), and modifications were made (ver. 2). The second version of the K-SPARC was tested against other questionnaires, including the Functional Assessment of Cancer Therapy-General (FACT-G) and the Edmonton Symptom Assessment System (ESAS).

Results Thirty patients were enrolled in the pilot trial. Fifteen were male, and the median age was 64.5 years. Six patients had an Eastern Cooperative Oncology Group performance status of 2 or more. All patients except one were receiving chemotherapy. Regarding internal consistency, the Cronbach's α scores for physical symptoms, psychological issues, religious and spiritual issues, independence and activity, family and social issues, and treatment issues were 0.812, 0.804, 0.589, 0.843, 0.754, and 0.822, respectively. The correlation coefficients between the SPARC and FACT-G were 0.479 ($p=0.007$) for the physical domain and -0.130 ($p=0.493$) for the social domain.

Conclusion This pilot study indicates that the K-SPARC could be a reliable tool to screen for palliative care needs among Korean cancer patients. A further study to validate our findings is ongoing.

Key words Sheffield Profile for Assessment and Referral to Care, Cancer, Holistic, Palliative care, Korean

Introduction

Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. Palliative care prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual [1]. Moreover, early palliative care, when combined with usual oncology care, led to the improvement of mood and longer survival of non-small-cell lung carcinoma patients [2]. Based on many randomized clinical trials, several guidelines recommend the

initiation of palliative care in advanced cancer patients at the early stage of their disease trajectories and the integration of concurrent palliative care into disease-directed, life-prolonging therapies [3-5].

To implement early referral to palliative care, there is a need to assess symptoms and identify the unmet needs of advanced cancer patients [6]. In addition, palliative care teams also need comprehensive assessments of patients' needs to provide holistic care. The Sheffield Profile for Assessment and Referral for Care (SPARC) was developed over a 5-year period by the Academic Unit of Supportive Care at the University of Sheffield. The SPARC is a holistic multidimensional

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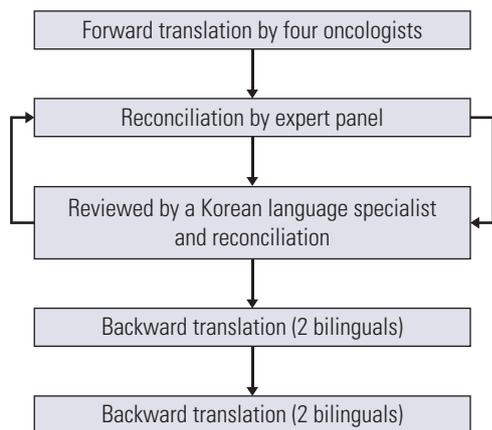


Fig. 1. The translation and back-translation processes.

screening questionnaire regarding supportive and palliative care needs regardless of the diagnosis. The SPARC is a self-rated questionnaire with a total of 45 questions under the following eight subscales: communication and information issues, physical symptoms, psychological issues, religious and spiritual issues, independence and activity, family and social issues, treatment issues, and personal issues. The SPARC helps healthcare professionals to identify patients and families that would benefit from a referral to specialist supportive and palliative care [7]; it was translated into Polish and then validated by Leppert et al. [8]. The aim of this study was to develop a Korean version of the SPARC (K-SPARC) and validate the K-SPARC for the evaluation of palliative care needs among Korean cancer patients.

Materials and Methods

In this study, we translated and back-translated the SPARC and then conducted a pilot study of the K-SPARC by conducting semistructured debriefing interviews. To evaluate the reliability of the K-SPARC, we measured the internal consistency by calculating the Cronbach's alpha coefficients of six of the subscales. We evaluated the criterion validity through correlation analysis of the K-SPARC with other tools such as the physical well-being and social well-being domains of the Functional Assessment of Cancer Therapy-General (FACT-G).

1. Translation and back-translation process

Ahmed et al. [7] provided approval for the translation of the SPARC into Korean. The translation and back-translation processes are detailed in Fig. 1. Four Korean oncologists fluent in English (S.K.B., J.H.K., Y.J.K., M.A.L.) independently translated the 45 items of SPARC, including the response

options and questionnaire instructions. The expert panel which consisted of five oncologists including four primary translators reviewed each translation and reconciled the translations to create the first version of the K-SPARC. The first version of the K-SPARC was reviewed by a Korean language specialist (J.C.S.), and the items were modified to reflect the layperson's perspective in the second version of the K-SPARC. The expert panel reviewed the second version of the K-SPARC, and a professional translator and a bilingual oncologist back-translated it into English. This translation was reviewed by S.H.A. and was found to be consistent with the original English: a few minor discrepancies were discussed and allowed for linguistic or cultural differences and for variations in healthcare systems.

2. Pilot study

The pilot study was performed with the translated version of the SPARC (Supplementary Material), and two rounds of semistructured debriefing interviews were conducted with 15 patients in each round. Patients were asked if the instructions were clear and easy to understand, if there were any word that were difficult to understand, if the order of items was appropriate, if the questionnaire was easy to complete, if they needed help completing the survey and if there were additional suggestions. The debriefing interviews were performed by a palliative care nurse who had been trained for interviewing.

3. Patients

Patients who were 20 years old or older, who had advanced cancer and who understood written Korea were included. Patients with symptomatic brain metastasis, a psychologic condition that could not be controlled or that affected cognition, or cognitive problems such as dementia or delirium were excluded. The following patient demographics were collected from the patient's medical record upon enrollment: age, sex, Eastern Cooperative Oncology Group (ECOG) performance status, diagnosis, stage of cancer, current cancer treatment, duration of disease, admission status, and education level. Patients completed the initial questionnaires including the SPARC, Edmonton Symptom Assessment System (ESAS), and FACT-G, on the same day.

4. Instruments used in the study

The instruments used in this study were the Korean version of the ESAS (K-ESAS), the Korean version of the FACT-G (FACT-G Korean), and the ECOG performance status; these instruments were used as comparative tools, as well as to test the feasibility of survey set.

1) Sheffield Profile for Assessment and Referral for Care (SPARC)

The SPARC is a self-rated questionnaire to screen for supportive and palliative care needs and contains a total of 45 questions under the following eight subscales: communication and information issues (1 question), physical symptoms (21 questions), psychological issues (9 questions), religious and spiritual issues (2 questions), independence and activity (3 questions), family and social issues (4 questions), treatment issues (2 questions), and personal issues (3 questions). Among the 45 items, four are yes/no questions, and the other items are scored on a four-point Likert scale with the following options: not at all, a little bit, quite a bit, and very much. For the Polish version of the SPARC, the Cronbach's alpha coefficients for physical symptoms, psychological issues, religious and spiritual issues, independence and activity, and family and social issues were 0.68, 0.86, 0.65, 0.77, 0.80, and 0.62, respectively [8].

2) Other instruments to evaluate the quality of life of cancer patients

The instruments used in this study were the K-ESAS, the FACT-G Korean, and the ECOG performance status; these instruments were used as comparative tools, as well as to test the feasibility of the survey set. The ESAS uses numerical scales ranging from zero to 10 to assess the average intensity (10 indicates highest intensity) of symptoms experienced during the previous 24 hours, namely, pain, fatigue, nausea, depression, anxiety, drowsiness, loss of appetite, decreased well-being, dyspnea, and sleep disturbance [9,10]; the K-ESAS has been validated [11].

The FACT-G scale, which was developed and validated by Cella et al. [12] in the United States, consists of a total of 27 Likert-type items formulated into separate subscales, i.e., physical (seven items), emotional (six items), social/family (seven items) and functional (seven items) well-being; it is widely used to measure health-related quality of life in cancer patients [12]. The FACT-G has also been translated into Korean and validated [13].

Physical activity was evaluated by the ECOG performance status. The performance status is indicated on a scale from 0-5 according to a chart of activities of daily life and is an indicator that is widely used by researchers and clinicians.

5. Statistical analysis

Descriptive statistics were used to summarize the data. The reliability of the K-SPARC was measured in this study based on the internal consistency of the SPARC using Cronbach's alpha coefficients, and it will be assessed in a future study based on the test-retest reliability. The internal test-retest reliability of the Cronbach's alpha coefficients for 41 items under

six factors will be evaluated with the correlation coefficients between the measured values at the beginning of the first seven days and 3 days later. Cronbach's alpha is the most commonly used measure of internal consistency. Internal consistency is generally considered good if the coefficient is 0.60 or higher [14]. Validity was evaluated in terms of the construct validity and the criterion validity. The construct validity was evaluated for six areas (physical symptoms, psychological issues, religious and spiritual issues, independence and activity, family and social issues, and treatment issues) from the English version. We analyzed the factors of the K-SPARC by conducting a factor analysis of the translated Korean version. A correlation analysis with the FACT-G, as the gold standard, was also conducted. Of the four factors of the FACT-G (physical well-being, social/family well-being, emotional well-being, and functional well-being), correlation analysis of the physical well-being and social well-being dimensions with the SPARC was conducted. The statistical analysis was performed with the SPSS ver. 23.0 statistical software package (IBM Corp., Armonk, NY). A p-value less than 0.05 was considered significant in the statistical analysis.

Results

1. Modification of items based on cultural differences

In the translation and back-translation process, the modification of the items was not permitted except for changing "b. community nurse" and "c. hospital nurse" to "nurse" in the communication and information issues section because of the differences in the healthcare system between the UK and Korea. Several items also needed to be modified due to the constraints of the Korean language. It was difficult to find an appropriate translation for "sore mouth" in Korean. We decided to modify this phrase as "oral pain" (Gugang Tongjeung) in the physical symptoms section. The phrase "feeling as if you are in a low mood" was used in the original version to avoid making respondents feel negative or embarrassed; however, in Korean feeling depressed (WooUlham) is different from depression (WooUljeung) itself, so we decided to use "WooUlham". No patients expressed embarrassment or annoyance with the word "WooUlham". The phrase "feeling that life is not worth living" was translated into "feeling that life is meaningless" because the expert panel decided that "not worth living" (Sal Ga Chiga Eopseum) seemed more aggressive than "meaningless" (Saneun Geosi Uimi Eopneun Geotgateum) and more related to suicide in Korean. The phrase "thoughts about ending it all" is a soft expression for suicide in the original version, and the expert panel had difficulty determining a soft, metaphorical expression in Korean. We ultimately decided on "Modeun Geoseul Kkeutnaeya

Table 1. Demographic characteristics of the patients

Characteristic	No. (%)
Age, median (range, yr)	64.5 (52-69.3)
Sex	
Male	15 (50)
Female	15 (50)
Performance status	
0, 1	24 (80)
2, 3	6 (20)
Diagnosis	
Gastrointestinal tumor	8 (27)
Head and neck cancer	7 (23)
Breast cancer	5 (17)
Lymphoma/Myeloma	4 (13)
Lung cancer	2 (7)
Hepatobiliary tumor	2 (7)
Other	2 (7)
Stage	
I/II/III	6 (20)
IV	24 (80)
Metastasis	
Present	18 (60)
Absent	12 (40)
Current treatment	
Chemotherapy	29 (97)
Palliative care	1 (3)
Duration of disease, median (range, mo)	9 (5-23)
Setting	
Inpatient	26 (87)
Outpatient	4 (13)
Education	
Less than high school	10 (33)
High school or more	19 (63)
Other	1 (3)

getdaneun Saenggak". Finally, we discussed the term "distress" in Korean at great length. There is no exact word for distress in Korean, and a previous validation of the Korean version of the Distress Thermometer used the English term itself [15]. We also decided to use the English term "distress" itself and included a description of the term as referring to total pain (Jeonbanjeokin Gotong) in parentheses next to it.

2. Two rounds of a pilot study of the SPARC survey

A total of 30 patients were included in the pilot trial between 10 December 2018 and 21 February 2019. In the first round of the study, 15 patients were enrolled. Only one patient expressed difficulties with several words, including urinary problems (Banggwang Munje), sex life (SeongSaenghwal), sore mouth (Gugang Tongjeung), and feeling weak (Soeyakgam), and the other patient expressed difficulty with

Table 2. Internal consistency of each domain using Cronbach's α coefficients

Characteristic	Cronbach's α score	
	Current pilot study	Polish version
Physical symptoms	0.812	0.68
Psychological issues	0.804	0.86
Religious and spiritual issues	0.589	0.65
Independence and activity	0.843	0.77
Family and social issues	0.754	0.80
Treatment issues	0.822	0.62

Table 3. Correlation between the physical domain of the SPARC and FACT-G

	FACT-Physical		FACT-Social	
	r	p	r	p
K-SPARC-Physical	0.479	0.007		
K-SPARC-Social			-0.130	0.493

FACT-G, Functional Assessment of Cancer Therapy-General; K-SPARC, Korean SPARC; SPARC, Sheffield Profile for Assessment and Referral to Care.

the word "distress." Others had no difficulties to understand each item. We conducted a second round with an additional 15 patients. The pilot study was complete after the second round because patients no longer expressed difficulties in completing the survey. Of all the patient, 19 indicated that the difficulty level of the questions was easy and clear, and 10 patients indicated a moderate difficulty level. Twenty-seven patients agreed with the order of the questionnaire. The expert panel reviewed the questionnaire, and the response of one patient was concluded to be an outlier. Two patients expressed additional problems, including with information on patient advocacy, cancer rehabilitation, and new cancer drugs. The median time to respond to the survey, including the SPARC, FACT-G, and K-ESAS, was 20 minutes (Q1-Q3, 20-35 minutes), and the median time to complete only the SPARC was 5 minutes (Q1-Q3, 10-15 minutes; minimum-maximum, 5-25 minutes). The median difficulty score of the SPARC was 2 (on a Likert scale from 1, very easy, to 5, very difficult; Q1-Q3, 2-3).

Of the 30 patients in the study, 50% were men, and the mean age was 61.6 years (range, 52 to 69.3 years). Gastrointestinal tumors were the most common primary cancers, followed by head and neck cancers, breast cancer, and lymphoma/myeloma. Of all the patients, 80% had stage IV cancer, and 97% were receiving chemotherapy. The patients' demographics are detailed in Table 1. The reliability of the

SPARC was assessed by Cronbach's alpha coefficients with the following results: 0.812 for physical symptoms, 0.804 for psychological issues, 0.589 for religious and spiritual issues, 0.843 for independence and activity, 0.754 for family and social issues, and 0.822 for treatment issues. Table 2 shows the comparison of the Cronbach's α scores of the Korean and Polish versions of the SPARC. Table 3 shows the correlation between the physical and social domains of the SPARC and FACT-G. The correlation coefficient was significant at 0.479 ($p=0.007$); however, the functional well-being domain of the FACT-G and the independence and activity domain of the SPARC ($r=0.307$, $p=0.099$) were not significantly correlated, and neither were the psychological domain of SPARC and the emotional well-being domain ($r=0.175$, $p=0.356$).

Discussion

The SPARC is a holistic multidimensional screening instrument for supportive and palliative care needs. It has also been used to capture the holistic needs of newly diagnosed lung cancer patients [16]. In this study, we developed a Korean translation of the SPARC and conducted a linguistic validation for cancer patients. The Korean version was first translated using the forward-back procedure. After the first version of the K-SPARC was created, it was back-translated into English and reviewed; minor variations from the original English version were discussed and agreed for linguistic and cultural reasons and because of difference in healthcare systems. Subsequently, the validity and reliability of the K-SPARC (Supplementary Material) were assessed, and the tool was used with a sample of 30 patients with advanced cancer. During the pilot study, participants expressed an accurate understanding of the concepts.

In this pilot study, the internal consistency of the total scale and the subscales was assessed, with Cronbach's alpha values for the subscales ranging from 0.589-0.843. The Cronbach's alpha values of 5 of the subscales, including physical symptoms, psychological issues, independence and activity, treatment issues, and family and social issues, were over 0.75, and good or acceptable internal consistency was found when comparing the Korean and Polish versions. This finding indicates that the K-SPARC has high structural validity. However, although it was not unacceptable, the Cronbach's alpha value of the religious and spiritual issues subscale was poor at 0.589. The religious and spiritual issues subscale comprises two questions with conflicting thoughts about death and dying and religious or spiritual needs not being met. In Korea, there are many obstacles and taboos regarding discussions of death, as in other Asian nations. There are differences among patients, family members, and physicians not only in terms

of the disclosure of an incurable cancer diagnosis but also in terms of end-of-life discussion when death is imminent [17,18]. For example, a study used semistructured interviews to compare meaning-making in coping among cancer patients in Sweden and South Korea [19]. The study found that Korean patients hardly mentioned "spirituality" in the interviews, whereas cancer patients in Sweden were familiar with the construct of spirituality and used the term "spirituality" in their daily communication. This finding was attributed to Koreans' difficulty in expressing issues related to spirituality in the Korean language rather than to Koreans' intrinsic lack of spiritual consciousness. There is no consensus about the definition of spirituality among the general public in Korea, and spirituality can be defined in one's own way. As a result, it is not unexpected that the Cronbach's score would be poor for religious and spiritual issues, which included two questions about death and spirituality that Koreans are not used to discussing due to cultural obstacles to talking about death and unclear definitions of spirituality.

The correlations between the K-SPARC and FACT-G varied. The K-SPARC was moderately correlated with the physical well-being domain of the FACT-G but weakly correlated with the social domain of the FACT. As mentioned above, this finding might be a result of cultural differences among nations. In addition, there were some differences between the FACT-G and K-SPARC in how social questions were asked. Questions from the social domain of the FACT-G focus on intimacy with and the care of family members or friends due to disease. However, the K-SPARC tends to focus on the impact of disease on family members and patient concerns. The low correlation between the K-SPARC and FACT-Social might be related to cultural differences between nations or the emphasis of questions, but this was difficult to conclude due to the small number of patients. An ongoing study is expected to clarify this issue.

There are several limitations to our study. First, our sample was small (30 patients). Second, we did not evaluate test-retest reliability. Finally, this study was a pilot study providing preliminary evidence of the validity of the K-SPARC. However, this study represents a fundamental step in the development of a Korean version of the SPARC, and future research to support further reliability and validity evidence is ongoing.

The present study developed K-SPARC and validated linguistically. However, there are possible differences in culture or language use, and some problematic translations might be present. We are conducting another study to validate the psychometric properties of the K-SPARC, including the test-retest reliability, convergent/divergent validity, and prognostic value for Korean cancer patients.

Electronic Supplementary Material

Supplementary materials are available at Cancer Research and Treatment website (<https://www.e-crt.org>).

Ethical Statement

This pilot study was reviewed and approved by the institutional review boards at Kangdong Sacred Heart Hospital (2018-08-014). All patients provided written informed consent; the informed consent form was approved by the institutional review board.

Author Contributions

Conceived and designed the analysis: Kwon JH, Baek SK, Kim DY, Kim YJ, Lee MA, Choi HJ, Byun JM, Jeong JY, Ahmedzai SH, Jang GD.

Collected the data: Kwon JH, Ahmedzai SH.

Contributed data or analysis tools: Kwon JH, Jeong JY.

Performed the analysis: Kwon JH, Jeong JY.

Wrote the paper: Kwon JH, Baek SK, Kim DY, Kim YJ, Lee MA, Choi HJ, Byun JM, Jeong JY, Ahmedzai SH, Jang GD.

Translation: Baek SK, Kwon JH, Kim YJ, Lee MA.

Back translation: Byun JM.

Conflicts of Interest

Conflicts of interest relevant to this article was not reported.

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