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Cross-cultural validation of Cancer Communication Assessment Tool in Korea

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ABSTRACT

***Background*: Communication between cancer patients and caregivers is often suboptimal. The Cancer Communication Assessment Tool for Patient and Families (CCAT-PF) is a unique tool developed to measure congruence in patient–family caregiver communication employing a dyadic approach. We aimed to examine the cross-cultural applicability of the CCAT in the Korean healthcare setting.**

***Methods*: Linguistic validation of the CCAT-PF was performed through a standard forward–backward translation process. Psychometric validation was performed with 990 patient–caregiver dyads recruited from 10 cancer centers.**

***Results*: Mean scores of CCAT-P and CCAT-F were similar at 44.8 for both scales. Mean CCAT-PF score was 23.7 (8.66). Concordance of each items between patients and caregivers was low (weighted kappa values <0.20 for all items and Spearman's rho <0.18 for scale scores). Scale scores did not differ significantly across a variety of cancer types and stages. The CCAT-P or CCAT-F score was weakly associated with mental health and quality of life outcomes. The CCAT-PF was correlated weakly with both patient-perceived and caregiver-perceived family avoidance of cancer care scales.**

***Conclusion*: The CCAT-PF Korean version showed similar psychometric properties to the original English version in the assessment of communication congruence between cancer patient and family caregivers.**

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Introduction

With the recent trend toward greater reliance on outpatient care, the role of the family caregiver in cancer care is increasing. Family caregivers provide not only emotional support but also instrumental support for patients to adhere to treatment regimens. In addition, as most care decisions are made within the family context, they also act as key participants in treatment decision making [1,2]. Family caregivers often convey information between patients and physicians; they frequently affect the decision-making process regarding patient care; sometimes, they need to make surrogate decisions as the patient's condition worsens. Indeed, patients themselves usually want their family caregivers to be involved in treatment decision making, including advance care planning for end of life [1].

In the light of the critical role of family caregivers in cancer care, the importance of communication between cancer patients and caregivers is increasingly recognized [3]. Open, frequent, and supportive communication between cancer patients and caregivers is known to be beneficial for information sharing, reducing conflicts, better adjustment, and overall well-being of patients and caregivers [1,4–7]. In addition, most patients and caregivers themselves want more communication with each other [8], and a substantial minority needs help with this issue. In Korea, around 40% of family caregivers reported moderate to high need for help with communication with the patient and/or other family members [9].

Many studies found that communication between cancer patients and caregivers is suboptimal among 10–30% of patients [10,11]. They do not communicate openly about the cancer and hide their concern and fear from each other in an effort to avoid disagreement and reduce one's partner's upset and burden, which is also known as 'protective buffering' [12]. Identification of the families at risk of communication difficulty would be vital to supporting families to improve communication and ultimately improve patient outcomes [13]. However, oncologists often could not detect families experiencing conflicts regarding treatment decision making [14].

To make actual progress in patient–caregiver communication, the availability of a quality tool that can be easily administered in clinical and research setting is paramount. However, little attention has been paid to the conceptualization of family communication regarding cancer care, and few instruments have been developed for the measurement of communication difficulty between patients and family caregivers [15]. Some instruments were designed to measure patient-perceived openness or avoidance of communication about cancer within the family [11,16], which may be different from actual communication or caregivers' perception of it [11,17]. This potential incongruence in patient–caregiver communication may increase communication difficulties and psychological distress for both parties, which may ultimately hinder optimal care for the patient.

Recent theories of cancer communication perceive the dyad as a unit, instead of as two separate individuals, and focus on how interaction between them helps enhance closeness and facilitate the adjustment of both parties throughout the cancer experience [13]. The Cancer Communication Assessment Tool for Patient and Families (CCAT-PF) is a unique tool developed to measure congruence in patient–family caregiver communication and employs a dyadic approach [18,19]. It identifies a range of sources of family conflict and has potential as a clinical screening tool to assess level of family risk for communication problems [18]. It has been developed through a rigorous process of item generation, item reduction, and psychometric validation with 190 patients with advanced stage nonsmall cell lung cancer and their caregivers, recruited from a single area in the USA. To our knowledge, no similar scale is available in Korea.

To examine the cross-cultural applicability in the Korean healthcare setting and to expand the applicability of such tools in an oncology setting in general, we sought to test the psychometric properties of the CCAT-PF Korean version in a wider array of cancer types and various stages of disease.

Methods

Data for this analysis were collected as part of a larger study, named CaPE (cancer patient experience) study, which is an annual nationwide survey of cancer patient experience in Korea. In 2011, the study was conducted with patient–caregiver dyads. The details of the study have been published elsewhere [1]. The National Cancer Center and the nine government-designated Regional Cancer Centers in Korea participated in the survey. Patients accompanied by family caregivers in outpatient waiting areas and inpatient wards were recruited by research assistants who explained the purpose and procedures of the survey. Eligible patients were those who were (a) older than 18 years, (b) diagnosed with cancer, (c) currently receiving cancer treatment or follow-up care, and (d) physically and mentally healthy to complete the questionnaire. Inclusion criteria for caregivers were (a) an accompanying family member of a patient with cancer and (b) older than 18 years.

Patient–caregiver dyads were enrolled when both the patient and family member agreed to participate. We approached 1299 dyads and enrolled 990 (participation rate 76.2%). Consenting patients and their family members were instructed to independently complete the questionnaires in a separate area to avoid influencing their answers. In addition to the survey, we reviewed the medical records of the participants to collect information about their cancer stage and treatments. Ethical approval for this study was obtained from the Institutional Review Board of the National Cancer Center.

Instruments

Written consent was obtained from Professor Siminoff, the author of the original English version of CCAT-PF [18,19]. Linguistic validation of the CCAT-PF was performed through a standard forward–backward translation process. Forward translation was performed by two independent translators who are bilingual, reconciliation of two versions was performed by the coordinator (D. W. S.) in discussion with other researchers and translators, and backward translation was performed by another two independent translators. The original and back-translated versions were compared, and linguistic parity was confirmed. Finally, a pilot test with 30 patients with cancer and their caregivers was performed by a research assistant. This confirmed that the questions and response options were clearly understood by the subjects.

The CCAT-PF is composed of two parts: the CCAT-P and CCAT-F. Each part is completed by the patient or caregivers about their preferences, values, and experiences in making treatment and care decisions, with an emphasis on how family caregivers or patients fit into this process. The CCAT-PF consists of 18 items in eight-content categories: general communication and interaction style (one item), reluctance to report side effects (two items), treatment and care goals (three items),

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trade-off between side effects and quality of life (three items), family support of decisions (one item), patient and family perspectives about physicians' decisions and communication (two items), family communication (five items), and hospice care (one item). A simple raw sum for patients' and caregivers' responses on a 6-point Likert scale (1 = strongly agree or all the time, 6 = strongly disagree or never) produced patient-specific and caregiver-specific scales of CCAT-P and CCAT-F. A high sum total of the 18-item absolute difference scores (CCAT-PF) indicated disagreement between patient and caregiver. The possible range of CCAT-PF is 0–90, with higher scores indicating greater discordance or conflict.

Concurrent and discriminant validity was assessed by analysis of correlation with several measures. The Family Avoidance of Communication about Cancer (FACC) Scale consists of five items that measure the patient's perception of the extent to which family members avoid talking about the cancer experience [11]. Each item is measured on a 5-point Likert scale (1 = less avoidance, 5 = more avoidance), and the mean score is calculated and transformed to range from 0 to 100 in order to produce a scale score. The Cronbach's alpha values of original and current data are 0.92 and 0.88, respectively. The Hospital Anxiety and Depression Scale was used to measure both patient and caregiver depression and anxiety. The European Organization on Research and Treatment on Cancer Quality of Life Questionnaire core module-C30 [20] and the Caregiver Quality of Life Scale [21] were used to measure the quality of life of patients and caregivers, respectively.

Statistical analyses

Mean and standard deviation of patients' and caregivers' responses, as well as absolute difference between dyads, were calculated to produce CCAT-P, CCAT-F, and CCAT-PF scores. Correlations between patients and caregivers were assessed with weighted kappa value for each item and with Spearman's rho for the domain scores. To assess internal consistency, we separately calculated the Cronbach's alpha coefficients for the CCAT-P, CCAT-F, and CCAT-PF measures. Mean scores of each scale were compared by the analysis of covariance across the cancer stage and cancer types.

To assess concurrent and discriminant validity, we calculated Pearson's correlation coefficients between scale scores and anxiety, depression, quality of life, and family avoidance of cancer care scores, as appropriate for patients and caregivers. All the statistical analyses were performed using STATA 12.1 (StataCorp, College Station, TX, USA). We defined statistical significance as $p \leq 0.05$ for two-tailed analyses.

Results

Study participants

The socio-demographic characteristics of these participants are shown in Table 1. The mean age of the caregivers was 50 years (standard deviation [SD] = 14.5 years), and patients' mean age was 63.4 years (SD = 10.8 years). Breast cancer was most common among patients ($n = 226$; 22.8%) followed by stomach cancer ($n = 111$; 11.28%). The mean time since diagnosis was 1.6 years (SD = 2.3). More than half of the caregivers were spouses of the patient ($n = 544$; 54.9%), and 18.7% ($n = 185$) were their children. Caregivers were predominantly women ($n = 615$; 62.1%).

Descriptive statistics and internal consistency

The mean scores of CCAT-P and CCAT-F were similar at 44.8 for both scales. Mean CCAT-PF score was 23.7 (SD = 8.66). The greatest absolute difference between dyads was seen for the following items: 'If treatment caused financial hardship for my family, I would not take it' (1.89), 'I am willing to take treatment that causes me a significant amount of pain, if I can live a few months longer' (1.79), 'My family's acceptance of my treatment decisions depends on how much they like my docdtor (s)' (1.66), 'In general, side effects are not really important when I consider my larger goals of treatment' (1.63), and 'I would feel uncomfortable if the doctor began to talk to me about hospice care' (1.59). The concordance of each item between patients and caregivers was low (weighted kappa values <0.20 for all items and Spearman's rho <0.18 for scale scores). Internal reliability coefficients (Cronbach's alpha) for the CCAT-P, CCAT-F, and CCAT-PF were 0.52, 0.50, and 0.60, respectively (Table 2). Scale scores did not differ across various cancer stages and cancer types (Table 3).

Concurrent and discriminant validity

The CCAT-P score was moderately positively correlated with patient-perceived FACC ($\gamma = 0.376$, $p < 0.01$) and weakly correlated with anxiety ($\gamma = 0.179$, $p < 0.01$), depression ($\gamma = 0.149$, $p < 0.01$), and lower quality of life of the patients. Similar correlations were observed for CCAT-F and corresponding scales for the caregivers. The CCAT-PF was correlated weakly with both patient-perceived ($\gamma = 0165$, $p < 0.01$) and caregiver-perceived FACC scales ($\gamma = 0.143$, $p < 0.01$), caregiver's anxiety ($\gamma = 0.088$, $p < 0.01$), and depression ($\gamma = 0.081$, $p < 0.05$) and with caregiver's positive adaptation ($\gamma = 0.117$, $p < 0.01$) (Table 4).

Discussion

The mean CCAT-PF score of 23.7 in our study population was slightly lower than that reported in the original study

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Table 1. Characteristics of the 990 dyads of patients and caregivers

Patients ($n = 990$)	***N***	**%**	**Caregivers ($n = 990$)**	***N***	**%**
Age, mean (SD)	59.5 (12.9)		Age, mean (SD)	50.0 (14.5)	
Sex			Sex		
Male	459	46.4	Male	375	37.9
Female	531	53.6	Female	615	62.1
Marital status			Marital status		
Married	820	82.8	Married	793	80.1
Unmarried	169	17.1	Unmarried	197	19.9
Missing	1	0.1	Missing	0	0.0
Education			Education		
Less than high school (<9 years)	454	45.9	Less than high school (<9 years)	246	24.8
High school and above (≥9 years)	532	53.7	High school and above (≥9 years)	740	74.7
Missing	4	0.4	Missing	4	0.4
Monthly income			Monthly income		
<2 million KRW	574	58.0	<2 million KRW	465	47.0
≥2 million KRW	406	41.0	≥2 million KRW	520	52.5
Missing	10	1.0	Missing	5	0.5
Cancer type			Relationship with patient		
Stomach	111	11.2	Spouse	544	54.9
Lung and bronchus	108	10.9	Son/daughter	185	18.7
Liver	47	4.7	Son-in-law/daughter-in-law	47	4.7
Colorectal	163	16.5	Parent	146	14.7
Breast	226	22.8	Sibling	42	4.2
Cervix and uterus	58	5.9	Other	14	1.4
Other	277	28.0	Missing	12	1.2
SEER cancer stage (current)			Living with patient		
In situ and local	279	28.2	Yes	737	74.4
Regional	295	29.8	No	253	25.6
Distant	383	38.7			
Unknown/missing	33	3.3			
Time since diagnosis, year, mean (SD)	1.6 (2.3)				
<1	594	60.0			
1–5	327	33.0			
>5	69	7.0			
Current treatment status					
Under initial treatment	562	56.8			
On regular follow-up after treatment	196	19.8			
On regular follow-up after cure	26	2.6			
Under treatment for metastasis or recurrence	198	20.0			
Not sure	4	0.4			
Other (e.g., treatment for second primary cancer)	4	0.4			

(26.4, $p < 0.001$). Direct comparison between the original study and ours may not be appropriate but could be partly explained by cancer stage, cancer type, and cultural difference. However, contrary to our expectation [9], our data show that cancer stage and cancer type do not affect communication difficulty, suggesting that some patients and caregivers experience communication difficulty even in earlier stages and regardless of cancer type [11,22]. The original authors reported that mean scores for nonsmall cell lung cancer were very similar to those for hematological cancer, implying general applicability of this tool [18]. Cultural differences may have played a role, as people from non-Western cultures tend to be more family oriented and have stronger relationships between family members. In an Israeli study, caregivers from Europe or the USA displayed more communication difficulties with patients than those from Israel and Asia/North Africa [4].

Internal consistency of the CCAT-PF and each individual scales was relatively low, when the criterion was Cronbach's alpha greater than 0.70. Lower values were expected and consistent with those found in the original study, as the CCAT-PF does not represent a typical summed scale of a single construct. It has eight independent content categories, and different content areas did not correlate well with each other [19].

The low kappa values (<0.20) of the correlation item statistics are consistent with the findings from the original validation study [18] and indicate that patients and caregivers disagree in rating each item. This was intended in the development process of the original scale, as items with high correlation coefficients were not useful measures of discordance and were deleted during the item reduction process [18]. However, it is also notable that there is profound disagreement regarding each item of

Table 2. Concordance of cancer communication assessment between patients and their family caregivers

	Patient response		Caregiver response		Absolute difference between patient and caregiver*		Correlation between dyads	
CCAT items	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Weighted κ**	***p*-value**
1. My family plays a big role in the decisions I make about my cancer treatment	1.90	1.21	2.57	1.41	1.34	1.28	0.10	<0.001
2. I hesitate to mention treatment side effects to my doctors or nurses	1.75	1.39	1.70	1.18	1.04	1.41	0.08	<0.001
3. In general, side effects are not really important when I consider my larger goals of treatment	3.31	1.66	3.76	1.51	1.63	1.37	0.12	<0.001
4. Medical science may find a cure for cancer so I am willing to take any treatment now to stay alive	2.02	1.19	1.95	1.18	0.99	1.1	0.17	<0.001
5. If treatment caused financial hardship for my family, I would not take it	3.13	1.66	2.04	1.32	1.89	1.51	0.00	0.539
6. My family and I have different views about the goal of treatment	1.66	1.31	1.71	1.15	1.02	1.39	0.04	0.026
7. If treatment made me sick everyday I would not take it	3.05	1.7	2.86	1.51	1.72	1.39	0.05	0.0069
8. I could see that there could come a point when taking treatment would not be worth the discomfort it causes	4.04	1.4	3.87	1.25	1.38	1.22	0.07	<0.001
9. I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer	3.40	1.83	3.11	1.58	1.79	1.45	0.09	<0.001
10. I value my family's judgment about treatment decisions	2.15	1.41	2.68	1.42	1.33	1.28	0.15	<0.001
11. My family's acceptance of my treatment decisions depends on how much they like my doctor(s)	3.70	1.64	3.43	1.63	1.66	1.38	0.12	<0.001
12. It is important to base decisions about my cancer treatment on sources of information other than my doctor	2.96	1.7	3.13	1.61	1.64	1.42	0.12	<0.001
13. My family does not really listen when I talk about my cancer	1.59	1.32	1.58	1.19	0.90	1.45	0.08	<0.001
14. I avoid talking about cancer to my family member because I don't want to upset him/her.	1.84	1.38	2.27	1.55	1.29	1.47	0.13	<0.001
15. I avoid talking about cancer to my family because there is nothing they can do to help	1.50	1.11	1.53	1.01	0.72	1.17	0.15	<0.001
16. I am frustrated when my family is overprotective of me because of my cancer	1.76	1.19	1.65	0.99	0.88	1.12	0.13	<0.001
17. My family blames my cancer on my not having taken better care of myself	1.75	1.32	1.72	1.18	0.91	1.27	0.19	<0.001
18. I would feel uncomfortable if the doctor began to talk to me about hospice care	3.28	1.66	3.23	1.54	1.59	1.36	0.12	<0.001
Total score	44.8	8.65	44.8	7.87	23.7	8.66	0.18**	<0.001

Total score: CCAT-P (for patient), CCAT-F (for family), and CCAT-PF (for dyads).
Higher score denotes difficulty in communication between patient and caregivers.
Internal reliability coefficient (Cronbach's α) for the CCAT-P = 0.52, CCAT-F = 0.50, and CCAT-PF = 0.60.
SD, standard deviation; CCAT, Cancer Communication Assessment Tool.
*Each of the 18-item mean difference scores >0 ($p < 0.001$).
**Spearman's correlation coefficient.

the scale. This might be due to avoidance of communication from the patient or caregiver side due to the fear of causing the other distress and wishing to protect the other [23].

Concurrent validity of the CCAT-PF and each individual score was evidenced by moderate correlation with the FACC scale. This is consistent with the findings of the original validation study that high conflict scores were associated with lower scores on expressiveness scale of the family environment scale [24], which measures the extent to which family members are encouraged to express their feelings directly. The strength of our study is that we used a cancer-specific measure.

The CCAT-PF was generally not or very weakly associated with mental health and quality of life of patients or caregivers, indicating discriminant validity. This is also consistent with the original validation study and in contrast to higher correlations between patient-specific or caregiver-specific scores and their own mental health and quality of life. It suggests that CCAT-PF is not strongly affected by patients' or caregivers' own mental health and quality of life and by their evaluation of communication and is more indicative of communication discord itself. High CCAT-PF scores were weakly but significantly correlated with greater burden, greater disruptiveness, and less positive adaptation. This is consistent with the weak statistical association between high conflict scores, which were associated with poorer caregiver outcomes, such as social functioning, and caregiver-perceived family cohesion in the original validation study [18].

Table 3. Cancer Communication Assessment Tool scale scores by current cancer stage and by cancer types

	CCAT-P			CCAT-F			CCAT-PF		
	Mean	**SD**	***p*-value**	**Mean**	**SD**	***p*-value**	**Mean**	**SD**	***p*-value**
Total sample	44.8	8.7		44.8	7.9		23.7	8.7	
By cancer stage									
In situ and local	43.9	7.5		44.9	7.9		23.6	8.9	
Regional	45.0	9.5		44.4	7.9		23.9	8.7	
Distant	45.1	8.6		45.1	7.9		23.7	8.4	
Unknown/missing	45.8	10.4	0.24	44.6	7.4	0.69	23.1	8.8	0.93
By cancer types									
Stomach	45.5	10.0		45.5	8.4		23.6	7.9	
Lung and bronchus	44.4	8.9		46.5	7.8		23.5	7.9	
Liver	46.3	8.6		45.5	8.6		24.9	7.6	
Colorectal	43.9	9.2		44.9	8.3		24.0	8.6	
Breast	45.4	8.7		44.6	7.1		23.6	7.9	
Cervix and uterus	45.9	6.9		44.1	8.5		24.2	9.2	
Other	44.2	7.8	0.27	44.0	7.7	0.15	23.4	8.8	0.95

p-value by analysis of covariance.
CCAT-PF, Cancer Communication Assessment Tool for Patient and Families.

Table 4. Concurrent validity of Cancer Communication Assessment Tool

	CCAT-PF	**CCAT-P**		**CCAT-PF**	**CCAT-F**
EORTC QLQ C30			Caregiver QOL		
Physical function	−0.029	−0.062	Burden	−0.098**	−0.211**
Role function	−0.033	−0.104**	Positive adaptation	0.117**	−0.089**
Emotional function	−0.060	−0.221**	Disruptiveness	−0.072*	−0.280**
Cognitive function	−0.058	−0.191**	Financial concern	−0.022	−0.171**
Social function	−0.024	−0.183**	Total score	−0.059	−0.304**
Patients' mental health			Caregivers' mental health		
Anxiety	0.058	0.179**	Anxiety	0.088**	0.280**
Depression	−0.013	0.149**	Depression	0.081*	0.283**
Family avoidance of cancer communication			Family avoidance of cancer communication		
Patient scale	0.165**	0.376**	Caregiver scale	0.143**	0.381**

CCAT-PF, Cancer Communication Assessment Tool for Patient and Families; EORTC QLQ, European Organization on Research and Treatment on Cancer Quality of Life Questionnaire core module-C30; QOL, Quality of Life Scale.
*$p < 0.05$.
**$p < 0.01$.

High CCAT-P score was weakly associated with mental health and quality of life outcomes, except for physical functioning. The original validation study also showed similar level of association with depression score and quality of life domain scores, except for physical well-being [18]. High CCAT-F score was associated with mental health, consistent with the original validation study. Although the original validation study did not show a significant association with quality of life measured by generic SF-20, the use of a cancer caregiver-specific measure in our study revealed significant associations with all domains of caregivers' quality of life.

There is one significant limitation in this study. We could not examine how the CCAT-PF persisted or changed over time. The original validation study showed that the average conflict between patient and caregiver decreased on a follow-up after 2 months, and the correlation between periods was 0.35 [18].

In conclusion, CCAT-PF Korean version showed similar psychometric properties to the original English version in the assessment of communication congruence between cancer patients and family caregivers. Although previous assessments of family communication during cancer trajectory have relied on patients' or caregivers' interpretation of it, CCAT-PF provides information on family discord in communication. This scale would help understand communication between patient and caregivers as a unit. Further studies are required to test the utility of CCAT-PF as a clinical screening tool and as a follow-up instrument after interventions to improve communication processes within the family in Korean population, as well as in English-speaking population.

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Conflict of interest

The authors have declared no conflict of interest.

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