ORIGINAL ARTICLE

Assessing patient–caregiver communication in cancer—a psychometric validation of the Cancer Communication Assessment Tool (CCAT-PF) in a German sample

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Abstract

Purpose The recently introduced Cancer Communication Assessment Tool (CCAT-PF) measures congruence in patient–caregiver communication and was initially validated in lung cancer patients. Contributing to a greater proportion of the variance in the conflict scores, primary caregivers were hypothesized to experience greater stress. For a detailed understanding of conflicting communication patterns of cancer-affected families, our study aimed for psychometric validation of the CCAT-PF in a sample covering heterogeneous tumor entities.

Methods Subsequent to a cross-sectional survey of 189 pairs of cancer patients (31 % gastrointestinal, 34 % lung, and 35 % urological) and their caregivers' exploratory factor analysis with principal component condensation and varimax rotation was conducted (response rate, 74.2 %). Reliability and construct validity were assessed calculating Cronbach's α and Pearson correlation coefficients for CCAT-P and CCAT-F scales and related constructs, respectively.

Results Cancer-related communication according to the CCAT-PF can be subdivided into four factors including the scales *Disclosure*, *Limitation of treatment*, *Family involvement in treatment decisions*, and *Continuing treatment*. Reliability ranged from $\alpha=.51–.68$. The Disclosure scale, describing poor cancer-related communication of the patient, was correlated with patient's distress (QSC-R10: $r=.30$, $p<.0001$), unmet needs in several areas (SCNS-SF-34: $r=.25–.32$, $p<.001$), and negatively with social/family well-being (FACT: $r=-0.31$, $p<.0001$). Higher scores on the scale were significantly associated with considerable decrements in emotional well-being especially for caregivers perceiving patients' disclosure as problematic.

Conclusions The Disclosure scale originating from the CCAT-PF emerged as a short, valid, and reliable stand-alone instrument for identifying conflicting communication in patient–caregiver–dyads at risk.

Keywords Cancer · Communication · Caregiver · Questionnaire · Validation · Distress

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Introduction

There is wide agreement that cancer may impact an entire family causing "fears, uncertainty, disrupted life plans, rearranged schedules and routines, changed interpersonal communication, existential worries, alterations in household members' functioning, and heightened household tension" [1, 2]. For example, Burns and colleagues identified fluctuating awareness of treatment goals among 163 cancer patients and their principal family caregivers [3]. It was figured that discrepancies in patient–caregiver–dyads might complicate the delivery of effective care at the latest when patients are seriously ill. However, valid and reliable instruments to assess types and quality of conflict in communication to specify key aspects for psychosocial interventions remain scarce. Recently, the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) was introduced as a measure of congruence in patient–family caregiver communication [4]. Construction was aimed at finding a clinical screening tool for family discord in cancer. Validation was conducted with a sample of 190 advanced stage non-small cell lung cancer patients and their primary caregivers [5]. The final scale comprised 18 items within eight domains, "a high sum total of the 18-item absolute difference scores indicating disagreement between patient and caregiver" [4]. Significantly, higher CCAT-PF conflict scores were exhibited by younger caregivers, adult children caregivers, and patients with lower income. Different domains of disagreement did not correlate with each other, underscoring the importance of separate examination of domain scores in addition to the CCAT-PF total score. As a greater proportion of the variance in the conflict scores that was contributed by caregivers, it was concluded that family caregivers are more aware of deviations from an open dialogue. Caregivers may therefore be experiencing greater stress. For a detailed understanding of conflicting communication patterns of cancer-affected families, our study aimed for German translation and psychometric reassessment of the CCAT-PF in a sample covering heterogeneous tumor entities.

Methods

Study design and sample Initial sample size calculation indicated that 134 subjects were necessary to test for sufficient reliability (Cronbach's α=.80) [6]. Psychometric validation was conducted in a cross-sectional survey of 189 pairs of patients with diverse malignancies (31 % gastrointestinal, 34 % lung, and 35 % urological) and their primary caregivers. The patient sample was treated either as out- or inpatients at the National Centre for Tumour Diseases and the affiliated Thoraxklinik in Heidelberg. Caregivers, defined as nearest lay care providers, were determined by patients themselves, as in

the initial study that developed the CCAT-PF. Data was collected on July/August 2012. Sociodemographic data was provided by patients and medical data was obtained from medical records and the attending physician. The study was approved by the Ethical Commission of Heidelberg Medical School (Ethic Approval/Registration Number: S-287/2012).

Measurement The German version of the CCAT-PF was based on a back translation by two independent translators. As there is no nationwide hospice care established in Germany and since most people are still unfamiliar with the idea [7], we excluded item 18 ("I would feel uncomfortable if the doctor began to talk to me about hospice care.") from the German version of the CCAT-PF. Furthermore, to assess construct validity, the questionnaire set comprised instruments assessing disease-related distress (Questionnaire on Distress in Cancer Patients-Short Form, QSC-R10) [8], depression and anxiety (Patient Health Questionnaire-4, PHQ-4) [9], and unmet needs (Supportive Care Needs Survey, SCNS-SF34/SCNS-P&C-G) for patients and caregivers [10]. Additionally, patients completed the Functional Assessment of Cancer Therapy (FACT-G/FACT-L for lung cancer patients respectively) [11, 12], while caregivers completed the Caregiver Strain Index (CSI) [13].

Statistical analysis Only complete pairs of questionnaire sets were included in the analyses. Four sets in which >40 % of CCAT-P and/or CCAT-F items were missing were excluded from the analysis. Descriptive statistics was computed for sample characteristics and item analysis. Evaluation of scale structure exploratory factor analysis with principal component condensation and varimax rotation was conducted [14]. The number of factors to be retained was determined according to Kaiser–Guttman criteria and the scree plot criteria. Assessment of reliability included estimation of internal consistency (Cronbach's α). Construct validity was investigated using Pearson product–moment correlations. To identify differences between subgroups, the Student's *t* tests and analyses of variance (ANOVA) were used. Non-responder analysis was conducted to test for representativeness of the sample regarding gender, age, and tumor type.

Results

Sociodemographic and medical data Three hundred thirty-one patients were screened for eligibility, 64 of whom were not eligible (no relative/caregiver present, *n*=20; insufficient German language proficiency, *n*=8; too recently diagnosed, *n*=5; poor general condition; assessed by attending physician, *n*=2; patient subjectively too distressed, *n*=29). Most of the patients who declared themselves as too distressed for

participation were feeling too weak after high-dose chemotherapy treatment earlier on the same day. From the remaining 267 pairs, 44 declined participation and 25 did not return one of the two questionnaire sets (response rate, 74.2 %). Subjects refusing participation or not returning questionnaires did not differ significantly with respect to age ($p=.60$) or gender ($p=.66$) from those who did. However, lung cancer patients were more likely to refuse participation than subjects with urological or gastrointestinal tumors ($p<.001$). Enrolled patients were predominantly male (68 %), had a mean age of 63 years, and had a post-secondary education level (56 %).

The majority was suffering from late-stage (metastasized) disease (75 %), had undergone chemotherapy in the last 2 months before the survey (78 %), and had a WHO-ECOG performance status below 2 when assessed (91 %). Caregivers were predominantly female (73 %) and most commonly spouses (84 %), followed by adult children (12 %). Mean age of caregivers was 58 years with 57 % of them having a post-secondary education level.

Item analysis and evaluation of the scale structure Extreme skew distribution ($g=2.86$ for the CCAT-P and 2.98 for

Table 1 Scale and item characteristics for CCAT-P and CCAT-F questionnaires

			CCAT-P		CCAT-F	
Scale 1	Disclosure Cronbach's $\alpha=.66$ Explained variance, 21.04 %	Factor loading	Mean	SD	Mean	SD
		–	2.00	.87	1.96	.86
2	I hesitate to mention treatment side effects to my doctors or nurses.	.53	1.84	1.27	1.98	1.32
13	My family does not really listen when I talk about my cancer.	.51	1.57	1.25	1.42	0.98
14	I avoid talking about cancer to my family because I don't want to upset them.	.74	2.08	1.37	1.83	1.22
15	I don't tell my family about my problems because there is nothing they can do to help.	.74	1.95	1.29	2.17	1.40
16	I am frustrated when my family is overprotective of me because of my cancer.	.66	2.56	1.47	2.40	1.47
Scale 2	Limitation of treatment Cronbach's $\alpha=.51$ Explained variance, 12.52 %	Factor loading	Mean	SD	Mean	SD
		–	3.26	1.18	2.52	1.06
5	If treatment caused financial hardship for my family, I would not take it.	.63	3.01	1.75	1.53	1.11
7	If treatment made me sick every day, I would not take it.	.79	2.82	1.57	2.85	1.54
8	I could see that there could come a point when taking treatment would not be worth the discomfort it causes.	.46	3.96	1.72	3.22	1.79
Scale 3	Family involvement in treatment decisions Cronbach's $\alpha=.68$ Explained variance, 12.06 %	Factor loading	Mean	SD	Mean	SD
		–	4.90	1.18	4.53	1.33
1	My family plays a big role in the decisions I make about my cancer treatment.	.62	5.03	1.38	4.30	1.79
10	I value my family's judgement about treatment decisions.	.75	4.77	1.34	2.38	1.66
Scale 4	Continuing treatment Cronbach's $\alpha=.51$ Explained variance, 11.04 %	Factor loading	Mean	SD	Mean	SD
		–	4.33	1.21	4.44	1.23
3	In general, side effects are not really important when I consider my larger goals of treatment.	.59	4.05	1.49	3.85	1.61
4	Medical science may find a cure for cancer so I am willing to take any treatment now to stay alive.	.67	4.59	1.45	5.00	1.42
Total explained variance, 56.66 %						
	Items without clear factor loading/excluded items		Mean	SD	Mean	SD
			–	–	–	–
6	My family and I have different views about the goal of treatment.		1.53	1.12	1.70	1.29
9	I am willing to take treatment that causes me a significant amount of pain if I can live a few months longer.		2.83	1.67	2.35	1.49
11	My family's acceptance of my treatment decisions depends on how much they like my doctor(s).		2.24	1.56	2.38	1.66
12	It is important to base decisions about my cancer treatment on sources of information other than my doctor.		2.48	1.56	2.92	1.64
17	My family blames my cancer on my not having taken better care of myself. [excluded due to extreme skewness]		1.29	0.73	1.39	0.94
18	I would feel uncomfortable if the doctor began to talk to me about hospice care. [excluded a priori]		–	–	–	–

the CCAT-F) of item 17 ("My family blames my cancer on my not having taken better care of myself.") for patient and caregiver ratings led to its exclusion from further evaluation. First, CCAT-PF as patient/caregiver discrepancy score was computed according to the original scoring instructions (see Table 1) [4]. However, correlation of CCAT-PF discrepancy score did not yield any correlation with other theoretically related measures applied in the study. Assuming different subdomains of familial cancer-related communication, analysis continued with investigating the discrepancy scores between CCAT-P and CCAT-F by factor analysis. Scree plot and Kaiser–Guttman criteria suggested a five-factor solution. However, the fifth factor, covering items 13 and 14, was dropped due to low-content validity and very poor reliability ($\alpha=.31$). In addition, items 15 and 16 were excluded, lacking distinct loadings on a factor. The final model led to four scales that were named 'Disclosure', 'Limitation of treatment,' 'Family involvement in treatment decisions,' and 'Continuing treatment' (see Table 1). These scales explained

56 % of the total variance with substantial factor loadings >.45 throughout.

Assessment of reliability and validity Scales demonstrated Cronbach's alphas in the range $\alpha=.51—.68$ (see Tables 1 and 2). Regarding construct validity, the Disclosure scale (patient version), describing poor cancer-related communication of the patient, was correlated with patient's distress (QSC: $r=.30$; $p<.0001$), unmet needs in several areas (SCNS-SF-34: $r=.25–.32$; $p<.001$), and negatively with social/family well-being (FACT: $r=-0.31$; $p<.0001$). In contrast, the latter was positively associated with Family involvement in treatment decisions and Continuing treatment. For caregivers, correlations for the Disclosure scale (caregiver version) were more pronounced with regard to anxiety (GAD-2: $r=.32$; $p<.0001$) and psychological needs (SCNS-P&C-G: $r=.35$; $p<.0001$). A lack of open communication from the caregiver's perspective was also associated with higher disease-related distress (QSC-R10: $r=.32$; $p<.0001$) and strain (CSI: $r=.29$; $p<.0001$) on the caregiver's side.

Table 2 Pearson correlation coefficients for CCAT-P and CCAT-F scales and related constructs

	Disclosure	Limitation of treatment	Family involvement in treatment decisions	Continuing treatment
Patient (CCAT-P)				
SCNS—Psychological	0.29*	0.21	−0.10	−0.07
SCNS—Heath system and information	0.32**	0.09	−0.05	−0.11
SCNS—Physical and daily living	0.21	0.16	−0.06	−0.16
SCNS—Patient care and support	0.26*	0.03	−0.13	−0.15
SCNS—Sexuality	0.25*	0.17	−0.14	−0.14
PHQ−2	0.09	0.11	−0.07	−0.09
GAD−2	0.18	0.13	−0.04	−0.09
QSC−R10	0.30**	0.21	−0.18	−0.23
FACT—Physical well-being	−0.12	−0.08	0.07	0.22
FACT—Social/Family well-being	−0.31**	−0.06	0.26*	0.27*
FACT—Emotional well-being	−0.16	−0.20	0.13	0.14
FACT—Functional well-being	−0.13	−0.11	0.12	0.29**
FACT—Total	−0.13	−0.10	0.11	0.28**
Caregiver (CCAT-F)				
SCNS-P&C—Psychological and emotional	0.35**	0.10	−0.21	−0.12
SCNS-P&C—Health care service	0.22	0.21	−0.21	−0.15
SCNS-P&C—Work and social needs	0.30**	0.20	−0.09	−0.09
SCNS-P&C—Communication and family	0.26*	0.11	−0.18	−0.09
PHQ-2	−0.01	−0.01	−0.05	−0.13
GAD-2	0.32**	0.10	−0.18	−0.15
QSC-R10	0.32**	0.13	−0.12	−0.18
CSI	0.29**	0.20	−0.07	−0.15

*$p<.001$; **$p<.0001$

Subgroup analysis Subgroup analyses were conducted for gender, age group, caregiver type, tumor site, and WHO-ECOG performance status. Spouses of patients scored higher on Continuing treatment than other family members (Δ mean [SD], 0.63 [1.22]; $p<.05$). Patients scored significantly higher on Family involvement in treatment decisions if either they (Δ mean [SD], 0.75 [1.13]; $p<.0001$) or their caregiver (Δ mean [SD], 0.47 [1.16]; $p<.01$) were aged 60 years or older.

Discussion

This study aimed for a deeper insight in conflictual communication patterns of cancer patients and their families. We therefore undertook a psychometric reassessment of the CCAT-PF using a German version with special regard to evaluation of the scale structure. Whereas the original score covers a wide range of content areas where families might disagree, we aimed for higher content validity in this study using subdomains of CCAT-PF separately. Conceptualizing communication as a multidimensional construct, our exploratory factor analysis revealed a four-factor model with scales demonstrating sufficient internal consistencies to allow for content-specific interpretation. Higher social quality of life in the patient–caregiver–relationship went along with the wish to continue treatment besides low chances and/or high side effects. In this case, greater family involvement in decisions regarding treatment was also observed. When considering disclosure, a lack of dialogue was associated with higher distress and consequently higher needs by both parties, but for the caregiver, it also entailed a significantly higher degree of anxiety and strain. We could not confirm a significant association between communication and depression, as previously reported [4]. Overall, the Disclosure scale originating from the CCAT-PF emerged as a short, valid, and reliable tool to assess risks for impaired affective adjustment in patients and caregivers dealing with cancer. Higher scores on the scale as an indicator for low cancer-related communication were significantly associated with considerable decrements in emotional and social well-being for caregivers; this association was more pronounced in caregivers than for patients. This observation is in accordance with the notion that caregivers especially might be negatively affected when patients choose to withhold communication [15–17]. In accordance with the original work [4] emphasizing the necessity of separate examination of individual domain scores, in addition to the CCAT-PF total score, we propose the Disclosure subscale as a stand-alone instrument for identifying patient–caregiver–dyads at risk. Tailoring psychosocial interventions to improve open communication may help patients and their caregivers better adjust to a cancer diagnosis [18].

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