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Cancer Patients' Preferences for Quantity or Quality of Life: German Translation and Validation of the Quality and Quantity Questionnaire

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Keywords

Cancer patients' preferences · Oncology · Quality of life

Summary

Background: Decision-making with patients with incurable cancer often requires trade-offs between quality and length of life. The 'Quality and Quantity Questionnaire' (QQ) is an English-language measure of patients' preference for length or quality of life. The aim of this study was to translate and validate this questionnaire. **Materials and Methods:** 1 new item was formulated to improve the 'Quality of life' scale. Construct validity including exploratory factor analysis, convergent and discriminant validity, and reliability was determined in n = 194 patients. **Results:** The acceptability of the questionnaire among patients was high. The item-non-response rate was very low (2.5–4%). The 2 QQ scales 'Quality of life' (QL) and 'Length of life' (LL) had good and acceptable internal consistency (Cronbach's = 0.71 for LL and 0.59 for QL). Convergent validity was shown by significant correlation of the QL subscale with the CCAT (Cancer Communication Assessment Tool) subscale 'Limitation of treatment' ($r = 0.37$, $p < 0.01$) and the LL scale with the CCAT subscale 'Continuing treatment' ($r = 0.24$, $p = 0.00$). **Conclusion:** The German version of 'QQ' has satisfactory psychometric properties for measuring patients' preferences for LL or QL. It can be used in all research fields that should be informed by patients' preferences: shared decision-making, palliative care, and health services.

Katsiaryna Laryionava and Halina Sklenarova contributed equally to this article.

Introduction

Decision-making with patients with incurable cancer is becoming increasingly complex and is often surrounded by medical uncertainty. When considering treatment, it is often unclear whether the potential benefits of treatment outweigh its risks and side effects. Tumor-specific therapy can potentially prolong life, but, due to its toxicity, may considerably reduce quality of life. Hence, decisions about cancer-specific therapy often require trade-offs between quality of life (QL) and length of life (LL). Evaluations of such trade-offs may vary considerably. Some patients accept treatments despite high reported toxicities and uncertain outcomes in order to increase their chances of prolonging survival. Others prioritize QL over LL [1, 2]. Thus, a prerequisite for patient-oriented decision-making is the understanding of patient preferences and their timely integration into patient care [3]. However, the identification of patients' views remains difficult in clinical practice. Evaluation of patients' preferences is an important quality parameter for clinical care. There is a need for a standardized assessment in all research fields that should be informed by patients' preferences: palliative care research, health services research, and research on shared decision-making. Most previous research on decision-making has focused on either assessment of health-related quality of life (HRQoL) or the evaluation of the utility of therapeutic options (i.e., standard gamble, time trade-off, and the visual analog scale) [1, 4]. These methods are directed at concrete therapeutic decisions and cannot be used to elicit patients' general attitudes. In contrast, the 'Quality and Quantity Ques-

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tionnaire' (QQ) is a tool for directly assessing a patient's general preference for LL or QL. It was developed for different groups of cancer patients in the Netherlands by Stiggelbout, de Haes, Kiebert, Kievet, and Leer (1996), and has shown good psychometric properties [2]. However, in German-speaking countries, there is no comparable instrument for assessing trade-offs between QL and LL. Therefore, the aim of this study was to translate the QQ into German, and study its psychometric properties with a broad group of German cancer patients.

Materials and Methods

Study Sample

To validate the German version of the QQ, patients with different types of tumors were recruited at the National Center for Tumor Diseases and the Thorax Clinic of the University of Heidelberg. Exclusion criteria for participation were a lack of proficiency in the German language, cognitive impairment, or lacking the capacity to consent. The study was approved by the institutional review board of the University of Heidelberg. Consecutive series of patients were enrolled in the study. Out of 298 patients screened for eligibility, 252 fulfilled the inclusion criteria and were asked to participate in the study. 223 patients agreed to participate, 29 (11%) declined. Of the 223 distributed questionnaires, 198 (89%) were returned. 4 questionnaires were incomplete; these were excluded from further analysis. The final sample included 194 patients (77% of the patients approached).

Validation Procedure

Quality and Quantity Questionnaire

The original version of the QQ consists of 8 items in 2 preference dimensions: QL and LL. Patients indicate how strongly they agree or disagree with a statement on a 5-point Likert scale. High scores on the quantity or quality scale indicate the importance of LL or QL, respectively. The original questionnaire showed adequate reliability; Cronbach's alphas were 0.68 for the QL scale and 0.79 for the LL scale.

Translating of the Quality and Quantity Questionnaire

Using the guidelines for the intercultural adaptation of measuring instruments [5], the QQ was translated by an interdisciplinary team (including a sociologist, psychologists, an oncologist, and an independent professional translator). 2 team members (K.L. and H.S.) independently translated the original version of the QQ into German. The translated versions were merged by discussion and consensus within the research team. Then, it was translated back into English by an independent professional translator. The team reviewed the synthesized translated version, and approval was obtained from the author of the original questionnaire.

Cognitive Pre-Test

In order to learn how the translated questionnaire was interpreted and understood by the patients, a pre-test was conducted with oncology inpatients (n = 10) at the University Hospital of Heidelberg [6]. It encompassed cognitive techniques including paraphrasing, thinking aloud, and asking questions to clarify unclear ideas. The majority of participants felt the questionnaire was clear. However, it was noticed that some items were too generally phrased and referred to abstract ideas such as 'normal life' (Item 2). 3 patients found the questionnaire to be distressing as it made them think about their dire prognosis. Finally, after evaluating the results of this pre-test, the questionnaire was modified once more based on suggestions from the patients. As a main change, a new item was added in order to include a stronger representation of balancing life span and quality of life: 'If it is doubtful whether I can extend my life with a burdensome treatment, then I would rather choose a treatment that places a special emphasis on quality of life' (Item 9).

Instruments

Socio-demographic data and health status (cancer diagnosis and stage, illness duration, and prognosis as estimated by the attending physician) were collected. Additionally, QL patient preferences in the decision-making process, cancer-related psychosocial distress, and satisfaction with relationships were assessed with the following established instruments.

Health-Related Quality of Life

HRQoL in cancer patients was assessed with a multidimensional cancer-specific instrument, namely the Functional Assessment of Cancer Therapy-General (FACT-G) [7]. The sum score of the subscales (physical well-being, social/family well-being, emotional well-being, functional well-being) was used. Low FACT values indicate a low quality of life. We supposed that quality of life and patients' preferences for LL or QL are unrelated.

Patient Preferences

The Cancer Communication Assessment Tool for Patients (CCAT-P) assesses patients' values and preferences regarding treatment and care decisions with an emphasis on the family's role in the decision-making process [8]. A modified German version of this instrument has been validated, and demonstrated acceptable reliability and validity [9]. It consists of 12 items on the following 4 subscales: 'Disclosure' (5 items, $\alpha = 0.66$), 'Limitation of treatment' (3 items, $\alpha = 0.51$), 'Family involvement in treatment decisions' (2 items, $\alpha = 0.68$), and 'Continuing treatment' (2 items, $\alpha = 0.51$). 2 subscales of this instrument reflect a trade-off between QL and LL, namely the subscales 'Limitation of treatment' and 'Continuing treatment'. We expected a positive correlation between the subscale 'Limitation of treatment' and the QL subscale, and a positive correlation between 'Continuing treatment' and the LL subscale.

Psychosocial Distress

Psychosocial distress was assessed with a 10-item screening instrument for self-assessment of psychosocial distress in cancer patients, namely the Questionnaire on Stress in Cancer Patients (QSC-R10) [10]. We expected that psychological distress and patients' preferences for LL or QL are unrelated.

Relationship Satisfaction

Relationship satisfaction was assessed with an adapted version of the Positive and Negative Quality in Marriage Scale (PANQIMS) [11]. 2 items were used to measure the satisfaction with the relationship regarding both positive and negative qualities, using an 11-point scale ranging from '0 = not at all' to '10 = extremely'. We hypothesized that satisfaction with relationship has an impact on patients' preferences.

Statistical Analysis

The acceptability of the questionnaire was assessed by calculating the percentage of missing data per item. Item analysis included assessment of the distribution of the responses in order to determine floor and ceiling effects. In this study, we refer to floor and ceiling effects if more than 15%

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of the interviewees have chosen the smallest lowest (floor effect) or biggest highest (ceiling effect) answer category, respectively. The discrimination power of items was examined using the coefficients of item discrimination.

Measure of sampling adequacy (MSA) was assessed by analysis of the anti-image correlation matrix. Variables which have MSA values of less than 0.50 should be excluded from the factor analysis.

Principal component analysis with varimax rotation was used to examine the factorial structure of the translated version. Items were included in the analysis with a factor loading above 0.30 on the factor. The exploratory factor analysis was chosen to reveal new structure as 1 additional newly formulated item was added. The internal consistency of the translated QQ was evaluated for each dimension using Cronbach's alpha coefficient.

Convergent validity, which means that the tested instrument correlates with other instruments measuring theoretically similar constructs, was assessed by Pearson's correlation with the 2 subscales of the CCAT-P. Discriminant validity, the comparison of the QQ with other instruments measuring different constructs, was assessed by correlations between the QQ subscales and the measures of psychosocial distress and HRQoL. The association between socio-demographic variables, health status, QL and LL were additionally explored using parametric tests (t-tests and one-way ANOVAs) or Pearson's correlation coefficients. All analyses were performed using SAS software, version 9.3 (SAS Institute Inc., Cary, NC, USA). Statistical significance was set for all comparisons at $p < 0.05$ (two-tailed).

Results

Socio-Demographic and Disease-Related Characteristics of the Sample

The distribution of socio-demographic and disease-related characteristics is displayed in table 1.

Table 1. Socio-demographic and disease-related characteristics of the sample (n =194)

Age	
Mean (SD), years	62.8 (10.3)
Sex, n (%)	
Total	194
Male	132 (68)
Female	62 (32)
Unknown	0
Partnership, n (%)	
Total	194
Yes	169 (87.1)
No	25 (12.9)
Unknown	0
Children, n (%)	
Total	194
Yes	170 (87.6)
No	24 (12.4)
Unknown	0
Education, n (%)	
Total	185
< 9 years	81 (43.8)
> 9 years	104 (56.2)
Unknown	0
Employment	
Total	194
Currently working	20 (10.3)
On sick leave	38 (19.6)
Unemployed	136 (70)
Pensioner	128
Home work	6
Jobless	2
Unknown	0
Duration of illness	
Total, n	191
Mean (SD, median), years	2.89 (5.0, 1.2)
Unknown	3
Disease stage at assessment, n (%)	
I–III	34 (17.5)
IV	145 (74.8)
Unclear	15 (7.7)
Unknown	0
Metastasis, n (%)	
Total	194
Yes	145 (74.7)
No	34 (17.5)
Unclear	15 (7.7)
Unknown	0
Tumor type, n (%)	
Lung	63 (32.5)
Kidney	28 (14.4)
Prostatic	19 (9.8)
Colon	18 (9.3)
Rectum	15 (7.7)
Pancreatic	14 (7.2)
Bladder	12 (6.2)
Others	25 (12.9)
Unknown	0
Estimated prognosis, n (%)	
Total	192
< 6 months	38 (19.8)
6–12 months	59 (30.7)
> 12 months	95 (49.5)
Unknown	2

Item Analyses

Acceptability of the questionnaire was investigated with the calculation of the percentage of missing values for each item. This item-non-response rate was very low (2.5–4%). The items with the highest number of missing values were Item 4 (n = 8; 4%) and Item 5 (n = 8; 4%).

Factor Analysis and Reliability

MSA was used to ensure adequacy of sampling. The MSA values for all the individual items were > 0.60 which ensured the suitability of each item for factor analysis (table 2). Exploratory factor analysis was carried out using the principle component method with varimax rotation. The factor analysis revealed 2 factors with an eigenvalue of > 1 which explained 49.9% of the total variance. The factor loads varied from 0.32 to 0.77. All items, with the exception of Item 5, had loads greater than 0.50 on the accompanying factor, which can be considered high loadings. Item 5 showed a low loading of 0.32 on the QL, unlike the original version. However, it was retained in the QL factor due to content reasons. Cronbach's alpha coefficient was used to assess internal consistency; $\alpha = 0.71$ was observed for LL and $\alpha = 0.59$ for quality of life. The extent to which each item was representative of the full scale was calculated using the coefficients of item discrimination. The discriminability of the single items ranged between $R_{it} = 0.28$ (Item 6) and $R_{it} = 0.61$ (Item 8). These R_{it} are middle-rate

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Table 2. Item and scale descriptive statistical values: mean, corrected item-total correlation, loading, and internal consistency

	Factor loading	Scale mean, M ± SD	Median	Cronbach's α	Corrected item-total correlation	MSA[b]	Explained variance 49.9%
Factor 1: Length of life (LL)		3.15		0.71			30.2%
Q8. In order to live a bit longer, I would clutch at any straw.	0.77	3.0 ± 1.4	3	0.58[a]	0.61	0.72	
Q7. I would always accept a hard to tolerate treatment, even if the chance of it prolonging my life was as little as 1%.	0.76	2.3 ± 1.4	2	0.61	0.57	0.74	
Q1. If a treatment could prolong my life, I would always accept it, whatever the side effects might be.	0.74	3.4 ± 1.0	3	0.64	0.52	0.79	
Q3. If I reached a point during treatment at which I felt like giving up, I would probably manage to find the strength to continue.	0.57	3.86 ± 0.9	4	0.74	0.33	0.74	
Factor 2: Quality of life (QL)		3.51		0.59			19.7%
Q6. If I had to endure 6 months of intensive treatment in order to live for an extra half year, then I wouldn't bother.	0.68	3.07 ± 1.3	3	0.56	0.28	0.64	
Q9. If it is doubtful whether I can extend my life with a burdensome treatment, then I would rather choose a treatment that places a special emphasis on the quality of life.	0.67	3.8 ± 0.9	3	0.54	0.34	0.72	
Q2. If a life-prolonging treatment would prevent me from leading a normal life, then I would rather not have it.	0.62	3.7 ± 1.1	4	0.54	0.32	0.61	
Q4. I can imagine some side effects being so bad that I would refuse the treatment, even if that meant a shorter life.	0.51	3.4 ± 1.0	3	0.47	0.45	0.75	
Q5. A moment might come at which I would say 'I have done my best, this is the limit'.	0.32	3.46 ± 1.3	4	0.54	0.31	0.79	

[a]Alpha if item deleted.
MSA = Measure of sample adequacy; Q = question.

[12]. The Pearson's correlation between the 2 subscales was r = –0.25, p = 0.00. In table 2, item and scale descriptive statistical values of the QQ are shown.

Associations with Socio-Demographic and Disease-Related Variables

A comparison of means (t-test) was used to assess the association of the translated QQ subscales with gender, partnership, children, and educational level. No significant differences were found for either subscale for gender, children, educational level and partner, contrary to our expectations. The variables employment and prognosis had 3 levels. Hence, one-way ANOVAs were carried out. A significant difference appeared concerning the preferences for QL between the groups by employment (working: mean = 3.0, on sick leave: mean = 3.4, unemployed: mean = 3.5; p = .01). The group of patients who were not employed had higher levels on the quality scale. No significant difference was found between prognosis and the 2 subscales. As expected, the LL subscale and satisfaction with partnership (considering positive aspects of partnership (r = 0.17; p = 0.027) and negative aspects (r = 0.16; p = 0.043)) were slightly but significantly correlated. A Pearson's correlation analysis showed no significant association between the subscales of the translated QQ and patient age as well as duration of illness. The relationship with socio-demographic and disease-related variables is presented in supplemental table 3.

Convergent Validity

The CCAT subscale 'Limitation of treatment' was highly positively correlated with the QL subscale (r = 0.37; p = 0.01) and negatively correlated with the LL subscale (r = –0.23; p = 0.01). The subscale 'Continuing treatment' was positively correlated with the LL (r = 0.24; p = 0.00). Contrary to our expectation, 'Continuing treatment' did not show a negative correlation with QL. The role of the family in decision-making about cancer treatment was correlated with the choice for LL (r = 0.17; p = 0.01). Those who valued their family's input in cancer treatment decisions and involved their family in the decision-making process showed a stronger tendency to choose LL. The correlation coefficients of QQ subscales with patients' preferences are shown in supplemental table 3.

Discriminant Validity

To evaluate the discriminant validity of the translated QQ, we correlated it with different psychometric measures (HRQoL and psychosocial distress). There was no significant relationship between patients' self-reported HRQoL and the subscales of the translated QQ (LL r = 0.04; p = 0.73 and QL r = 0.02; p = 0.74). Also, psychosocial distress did not correlate substantially with any of the subscales (LL r = 0.05; p = 0.52 and QL r = 0.01; p = 0.90).

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Discussion

Assessment of patients' preferences for LL or QL in advanced cancer is essential for all fields of research that focus on decision-making and on patients' needs and goals. For this purpose, the QQ was translated into German, and psychometric properties were assessed in this study.

The factor validity of the LL scale was replicated, although the QL scale was not as robust. The LL factor was characterized by high loads (0.57–0.77). While Item 5 ('Es kann ein Moment kommen, an dem ich sage: Ich habe mein Bestes getan, ich kann nicht mehr') loaded substantially less on the QL in comparison with the original study, it was still assigned to the QL factor.

An examination of reliability showed good results for the LL subscale (0.71). The reliability of the original questionnaire was somewhat higher (0.79). For the QL, Cronbach's alpha was not as good (0.59) but still acceptable: Cronbach's alpha values of 0.5–0.7 are generally considered as an acceptable level of internal consistency. Without the new item, however, it was only 0.54, so we decided to retain the new item. The slightly lower reliability and factorial validity found for the QL subscale compared to the original study might be explained by variations in interpreting the quality of life concept among the interviewed patients. The pre-test of the translated questionnaire indicated that participants had more questions and comments about the QL subscale. It was often pointed out that Item 5 was formulated too generally. Future studies should be conducted for further evaluation of the QL subscale.

Furthermore, the pre-test showed that some patients felt distressed while answering the questions. Similar observations were reported in the original study [4]. We would therefore advice to use this questionnaire together with an offer of an additional consultation or psycho-oncological counseling.

The German version of the QQ had few significant associations with socio-demographic or disease-related variables. Only employment status and the QL subscale were positively associated. Unemployed patients (predominantly pensioners) tended to prefer QL. The other correlation found in the original study was between LL and having children. This connection could not be found in our study, but there was a significant relation between family role in decision-making and striving for LL ($p = 0.01$). Furthermore, satisfaction with partnership was also associated with striving for LL. This confirms the validity of the questionnaire, assuming that people wish to stay alive for their partners.

In contrast to the original study [2] and the studies conducted by Vogt et al. [13] and Rietjens et al. [3], we found no correlation between patients' age and preferences for either QL or LL in our study population. In accordance with the original study, there was no correlation between prognosis and preference for LL or QL. In our study, it was not clear whether the patients were aware of their survival prognosis. Future studies should focus on the influence of the survival prognosis as perceived by patients on preference for LL or QL.

Limitations of the Study

We could not perform test-retest (reliability) measurements due to the cross-sectional design of the study. The sample did not include many young patients, which could have resulted in a lack of association between age and preference for LL or QL. Similarly, our sample included only 20% of far-advanced cancer patients with an estimated medium survival of < 6 months. No difference between estimated prognosis and patients' preferences was revealed. However, larger studies are necessary in order to assess whether prognosis may be a mediator in the choice between LL and QL.

Conclusion

The QQ was translated and validated in the present study, and psychometric results indicated that the German translation had satisfactory reliability and validity and can be used in studies with German-speaking populations. The translated QQ (supplemental fig. 1) can be used for further empirical studies of patient preferences and to improve therapeutic treatment decisions by integrating patient preferences according to QQ results into decisions about the intensity of treatment [14].

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Disclosure Statement

All authors declare that there is no conflict of interest.

Online Supplemental Material

Supplemental Fig. 1. Quality and Quantity Questionnaire.

Supplemental Table 3. Association with socio-demographic disease-related variables and correlation of QQ (Quality and Quantity Questionnaire) subscales with patients' preferences (Cancer Communication Assessment Tool for Patients, CCAT-P)

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