Reliability and validity of the caregiver quality of life index-cancer (CQOLC) scale in Turkish cancer caregivers

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Aims and objectives. The aim of this study was to translate the Caregiver Quality of Life Index-Cancer into Turkish and test the reliability and validity of the Turkish version of the Caregiver Quality of Life Index-Cancer in Turkey.
Background. Cancer is a chronic illness that affects the entire family and deteriorates the quality of life of cancer caregivers. The Caregiver Quality of Life Index-Cancer is a widely used instrument to measure quality of life in cancer caregivers. Therefore, identifying and increasing quality of life benefits of cancer caregivers.
Design. Methodological research design.
Method. This study describes the translation process of The Caregiver Quality of Life Index-Cancer into Turkish and testing its reliability and validity on quality of life in cancer caregivers. The questionnaire was translated using a back-translation technique. The statistical analysis was carried out using Cronbach's alpha to test the internal consistency of the Caregiver Quality of Life Index-Cancer scale while confirmatory and exploratory factor analyses were carried out using principal component analysis with varimax rotation and Kaiser Normalization to test its construct validity.
Results. The Cronbach's alpha was found to be reliability for the total scale was 0·88 and subscale alpha coefficients ranged from 0·73–0·83. Confirmatory factor analysis resulted in four factor structure: burden, distruptiveness, positive adaptation and financial concerns.
Conclusion. The effects of providing care for patients with cancer on caregiver quality of life have not yet been adequately explored in Turkey. The results of this study suggest that the Turkish version of the Caregiver Quality of Life Index-Cancer is a reliable and valid supplementary measure of the quality of life in cancer caregivers in Turkey.
Relevance of clinical practice. In research and practice, valid measurement instruments are needed to assess Quality of Life in Turkish cancer caregivers. The Caregiver Quality of Life Index-Cancer scale is simple to administer and nurses by using this equipment in routine appointments will be able to better identify caregiver at risk for developing cancer related distress and worse Quality of Life.

Keywords: caregiver, Caregiver Quality of Life Index-Cancer, Quality of Life, reliability, validity

Introduction

Cancer is the second highest cause of death among adults and the mortality rate from cancer had increased to nearly 130 per 100,000 population in 2000 and 2003 in Turkey. Based on the latest report of the Turkish Statistical Institute, 23·681 were dead in 2000 and 23·775 were dead in 2003 because of cancer (Turkish Statistical Institute 2006). These numbers imply that more and more families in Turkey have to live with and care for a relative suffering from cancer. Family caregivers play a central role in managing all aspects of the patient's care. The diagnosis of cancer is a traumatic event that has a significant impact on patients and their familys' Quality of Life (QoL) (Northouse 2005). Learning to live

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with cancer is not an easy task. Learning to live with a loved one who has cancer can also be immensely difficult. Caregiving is demanding and overwhelming and can be a very stressful experience, affecting all aspects of caregiver QoL. It changes their everyday lives in various ways (Yates 1999, Kinsella *et al.* 2000, Edwards & Ung 2002, Glajchen 2004).

Moreover, caring for patients with cancer also affects family functioning and places burdens on caregivers (Siegel *et al.* 1991, Edwards & Ung 2002). As medical management of cancer becomes more complex, family caregivers must perform a variety of activities (i.e. meeting the survivor's multidimensional needs, coordination of medical appointments, including treatment monitoring, treatment-related symptom management, provision of physical and emotional care, providing transportation, shopping, homemaking services, nursing care, emotional, financial and spiritual support, assistance with personal and instrumental care), which can have a negative impact on their psychological, mental, social, physical, spiritual and emotional health (Nijboer *et al.* 1999, Given *et al.* 2001, Kim & Given 2008). The negative consequences of caregiving may manifest as physical (ie, pain, sleep disturbance, headache, raised blood pressure, stomach pains, loss of appetite, fatigue and a sense of weakness) and psychological (ie, worry, shock, uncertainty, hopelessness, grief, anxiety, nervous distress and depression, reduced self-esteem and somatic health problems) symptoms may have a negative impact on family caregivers QoL, as well as on their ability to provide care to the patient (Steele & Fitch 1996, Nijboer *et al.* 2001, Schumacher *et al.* 2006, Fletcher *et al.* 2008). Studies have found that family caregivers report various problems from their caregiving experiences, including conflict among their social roles, restrictions of activities, strain in marital and family relationships, psychological distress and diminished physical health (Weitzner *et al.* 1999, Given *et al.* 2001, Kim & Given 2008).

There is increased emphasis on health-related Quality of Life (QoL), which the World Health Organization defines as a multidimensional self-perceived construct including social, physical and emotional functioning of the person (Bhatia *et al.* 2004). However, much less is known about the profile scores or the relevance of QoL measures in carers, although this may also be an important clinical issue. The amount of time and effort involved in developing a new local language QoL instrument is considerable. A better option is to translate existing validated tools. The validation of translated scales improves cross-cultural utility of the source tool. The Caregiver Quality of Life Index-Cancer (CQOLC) measurement system is a collection of QoL questionaires (Weitzner *et al.* 1999). Weitzner *et al.* (1999) showed that the English version of the CQOLC scale would be a practical, reliable and valid instrument for cancer caregivers as well.

Over the past two decades, Turkey has made remarkable progress in improving health outcomes among its population, particularly among cancer patients. No reports on translation or validation of CQOLC to any Turkish language has been reported earlier. The need is felt for a concentrated, well-defined attempt to identify the QoL determinants among cancer caregivers in Turkey. We therefore conducted this study to translate the CQOLC into Turkish and to test the reliability and validity on QoL in cancer caregivers.

The purpose of this study was to test whether or not to be the Turkish version of the CQOLC is a relevant, valid and reliable instrument for determining the QoL of cancer caregivers in Turkey. The present study was done to translate the CQOLC into Turkish and to test the reliability and validity of QoL in cancer caregivers.

Methods

Translation

The study was initiated after the researchers first obtained written permission from Michael A. Weitzner to adapt the CQOLC and make changes found to be necessary for Turkish culture. After obtaining a written consent from the authors' of CQOLC, employing standard 'forward–backforward' translation procedure, the English-language version of the questionnaire was translated into Turkish-language by experts. The double back-translation procedure was performed as follows (Bonomi *et al.* 1996): Step (1) independent forward translation by four native Turkish speakers (One oncologist, one psychologist, one English lecturer, one nursing lecturer). Step (2) reconciliation of the forward translations by another native Turkish speaker not involved in the forward translation process. Step (3) back translation of the reconciled version by three native English speaker (two nursing lecturer, one English lecturer) fluent in Turkish, allowing for comparison with the source document by CQOLC developers. Step (4) review by four bilingual experts, including linguists and health professionals, who selected the most appropriate translation for each item from the reconciled or independent forward translations or provided alternative translations to improve items with inadequate pre-existing translations and to determine the cultural appropriateness of the tool. Step (5) spelling and grammatical verification of the new forward translation in preparation for pre-testing with native caregivers in Turkey. Then, a provisional version of the Turkish questionnaire was provided. After a consensus by all authors the final version

was developed. Then, the cross-cultural equivalence the translated questionnare was reviewed, pre-tested, revised and the form was approved by the 'multi-disciplinary' committee before and after pre-testing and subsequently it was used in this study.

Questionnaire

The original version of the CQOLC developed by Michael A. Weitzner and it is a self-administered rating scale designed to assess QoL issues in family caregivers of patients with cancer, especially to evaluate the broader impact of caregiving on QoL. The scale measured four conceptual domains of QoL: physical functioning, emotional functioning, family function-ing and social functioning. The CQOLC consists of 35 items that have a five-point Likert format that ranged from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much): ten items relate to burden, seven to distruptiveness, seven to positive adaptation, three to financial concerns and eight single items to additional factors (distruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, man-agement of patient's pain and family interest in caregiving) (Weitzner *et al.* 1997).

Individual CQOLC factor scores obtained by summing the responses to the items that load on that particular factor. Total CQOLC score obtained by summing scores for all 35 items. Not all 35 items load on a factor; items 2, 4, 13, 15, 23, 30 and 32 do not load on any factor, but are included in total CQOLC score. The CQOLC scale is scored by adding up the score on each item to yield a total score for the instrument and scores can range from 0–140. For all items and domains that measure QoL, a higher score represents a better QoL (Weitzner *et al.* 1997).

In the validity–reliability study of the original instrument (CQOLC) developed by Weitzner *et al.* (1999), the internal consistency for total instrument, burden, distruptiveness, positive adaptation and financial concerns was found to be, respectively, $\alpha = 0.90$, $\alpha = 0.89$, $\alpha = 0.83$, $\alpha = 0.73$ and $\alpha = 0.81$. The CQOLC has been shown to be both valid and reliable and part of it is cancer specific (Weitzner *et al.* 1999). The Korean version of the CQOLC has been validated (Rhee *et al.* 2005).

Patients, data collection and statistical analysis

This study was planned to adapt the CQOLC culturally to the Turkish language and to evaluate of validity and reliability of the Turkish version. The study was performed in daily chemotherapy unit of university hospital which is the only daily chemotherapy hospital in Antalya, in the Mediterranean region in Turkey. There are several guidelines for sample size. To have confidence in our statistics, we need to have adequate sample sizes, both in terms of absolute numbers and in terms of subject-to-item ratios (5–10 subjects per item) (Shultz & Whitney 2004). A total of 280 family caregivers were approached to participate in the study. Of that total number, 18 refused to participate and 25 were deemed noncompleters. The major reasons for study refusal were (1) no time to complete and (2) already having too much stress to complete the questionnaire. The study sample was composed of 237 caregivers of patients with cancer. The percentage of the population reached and included was 80%.

The translated instrument was pilot-tested for understand-ability with a 10-cancer caregivers and at the conclusion the instrument's language and content validity were approved. In this pilot study it was determined that the questions could be understood and no changes were made. The caregivers in the pilot test were not included in the research.

After informed consent had been obtained to assess their QoL, the Turkish CQOLC was administered to each care-giver. To be eligible for the study, potential participants had to (1) have a family member with cancer, (2) be the identified or self-identified primary family caregiver, (3) be at least 18 years of age, (4) be able to complete a questionnaire or communicate with the interviewer, (5) not have a history of prior or current psychiatric or neuropsychological disorders, (6) not have a diagnosis of cancer of any type and (7) consent to participate in the study.

The CQOLC was used as a self-report tool, however, for patients who had difficulty in reading, a structured interview was carried out. As the study design required, the questionn-are was administered routinely as an interview because some patients were illiterate (4·7%). There were no incomplete questionnaires at all, nor was any missing information. Participants were interviewed in the daily chemotherapy unit during their patients' chemotherapy between September 2007 and 15 January 2008 by researchers. The avarage time required to complete the CQOLC was 15 (SD 5) minutes. Almost all caregivers found the questions easy to understand and acceptable.

All items were coded and scored and the completed questionnaires were included in the data set. Individual unanswered items were excluded from the analysis. All the data were entered, checked for missing values and analysed using SPSS version 11.0 (SPSS Ltd., Chicago, IL, USA) and SAS version 7.0 (SAS Institute, Cary, NC, USA) statistical programs. Values < 0.05 was considered statistically signifi-cant, unless otherwise stated.

Reliability analysis

To determine internal consistency, Cronbach's alpha, the corrected item total correlations, the alpha-if-item deleted procedure and the mean inter-item correlations were included in the analysis. The criterion level for coefficient alpha was set at 0·70 or above (Bonomi *et al.* 1996, Bhatia *et al.* 2004). Clark and Watson (1995) indicate that internal consistency may be a necessary condition for homogeneity or unidimensionality of a scale, but it is nevertheless possible that in spite of a satisfactory Cronbach's alpha (> 0·80) the scale is not unidimensional. They recommend using the mean inter-item correlation as the criterion for internal consistency. This should be between 0·15–0·50. They point out that this average value can be biased and that all individual inter-item correlation should be within these limits. In other words, unidimensionality is only ensured if all individual inter-item correlations are clustered closely around the mean inter-item correlation (Clark & Watson 1995).

Validity analysis

The item scores were subjected to a confirmatory factor analysis using the principal component analysis and varimax rotation with Kaiser Normalization. Factor extraction was restricted to four factors to test construct validity. To attain the best-fitting structure and correct number of factors, the following criteria were used: Eigenvalues > 1·0, factor loadings > 0·40 and the so-called elbow criterion regarding the eigenvalues. Before conducting the factor analysis, the Kaiser–Meyer–Olkin measure of sampling adequacy (KMO) and Bartlett's Test were conducted to evaluate whether the sample was large enough to perform a satisfactory factor analysis. A KMO value > 0·5 indicates that the sample size is adequate for factor analysis (Kara *et al.* 2006).

A confirmatory factor analysis with the normal theory maximum likelihood estimation method was conducted on our samples separately to confirm the exploratory model obtained by Weitzner *et al.* (1999), to determine whether their factor structure required modification and to refine the model, if necessary. In these analyses, the same model specification was used and specified four independent factors, following the model extracted by Weitzner *et al.* (1999). The model was identified by fixing factor variances at 1.

If model fit is acceptable, the parameter estimates are examined. The ratio of each parameter estimate to its standard error is distributed as a Z statistic and is significant at the 0·05 level if its value exceeds 1·96 and at the 0·01 level it its value exceeds 2·56 (Hoyle 1995). In confirmatory factor analysis, if unacceptable model fit is found, an exploratory

factor analysis can be performed. Exploratory factor analysis was used to guide the item-reduction process. Factor analysis uses the pattern of inter-item correlations to produce clusters of items that have substantial correlations with one other. Items within each cluster have low correlations with those in other clusters.

When a confirmatory analysis fails to fit the observed factor structure with the theoretical structure, the researcher can evaluate ways to improve the model by exploring which items might be freed that had been fixed and which might be fixed that had been freed. This is done by employing an exploratory factor analysis which was used for a variety of applications. In the second stage of this analysis, an exploratory factor analysis was conducted to identify a viable factor structure. An exploratory factor analysis, using principal component extraction method with varimax rotation, was conducted on all participants to determine the factor structure of the 35 items of the CQOLC. Items with factor loadings ≥0·40 (including values that rounded to 0·40) and those that did not load on more than one factor were retained. Items not meeting these criteria were removed one at a time. Factor analyses were repeated until a solution where all items included in the analysis met all criteria was attained.

Ethics considerations

Permission to translate and use the CQOLC into Turkish was granted by the developer, Michael A. Weitzner. Permission to conduct this study was received from the authors' institutional ethical committe. The informed consent was obtained from the Director of the Hospital and the head of the daily chemotherapy unit and from all study participants. The cancer caregivers were informed about the purpose of the study and what would be expected of them. Participants were assured of their rights of refusal to participate in or to withdraw from the study at any stage without any negative consequences. The anonymity and confidentiality of participants was guaranteed.

Results

Descriptive statistics and scale reliability analysis

In this study, 237 cancer caregivers were interviewed. The demographic and medical characteristics of the cancer patients are shown in Table 1. The patients of caregivers in the sample averaged 52·96 years of age (SD 12·82 years, range 18–83), included most patients were female (52·7%), married (85·7%), housewife (43·9%) and had completed

Table 1 The demographic and medical characteristics of the cancer patients (n = 237)

Variable	Category	N (%)
Age (years)	36 <	15 (6·3)
	36–45	49 (20·7)
	46–55	67 (28·3)
	56–65	72 (30·4)
	≥66	34 (14·3)
	Mean ± SD	52·96 ± 12·82
	Range	18–83
Gender	Female	125 (52·7)
	Male	112 (47·3)
Marital status	Married	203 (85·7)
	Single, divorced or widowed	34 (14·3)
Occupational status	Housewife	104 (43·9)
	Retired	53 (22·4)
	Self-employed	29 (12·2)
	Public servant	19 (8·0)
	Worker	14 (5·9)
	Farmer	14 (5·9)
	Student	4 (1·7)
Education	Illiterate	21 (8·9)
	Primary	116 (48·9)
	Secondary	26 (11·0)
	High	39 (16·5)
	University	35 (14·7)
Health insurance	Yes	229 (96·6)
Employment status	Unemployed	190 (80·2)
	Employed whole day	33 (13·9)
	Employed half day	14 (5·9)
Type of cancer	Lung	53 (22·4)
	Breast	52 (21·9)
	Colon-rectum	32 (13·5)
	Stomach	24 (10·1)
	Other cancers*	76 (32·1)
Duration of the illness	1–3 month	69 (29·1)
	4–6 month	39 (16·5)
	7–9 month	16 (6·8)
	10–12 month	28 (11·8)
	≥13 month	85 (35·8)
	Mean ± SD	21·83 ± 0·278
	Minimum–maximum	1–180 ay

*Leukemia (16), pancreas (12), lymphoma (10), kidney (6), liver (4), cervix (4), uterus (3), mesothelioma (3), brain tumour (3), multiple myeloma (2), bladder (2), skin (2), tongue (2), ovarian (1), endometrium (1), larynx (1), testis (1), prostate (1), lip (1), nasofarenx (1).

Table 2 The demographic characteristics of the cancer caregivers (n = 237)

Variable	Category	N (%)
Age (years)	36 <	89 (37·7)
	36–45	63 (26·6)
	46–55	52 (21·9)
	≥56	33 (13·8)
	Mean ± SD	40·19 ± 13·48
	Range	18–79
Gender	Women	146 (61·6)
	Men	91 (38·4)
Marital status	Married	179 (75·5)
	Single, divorced or widowed	58 (24·5)
Occupational status	Housewife	95 (40·1)
	Self-employed	34 (14·3)
	Retired	31 (13·1)
	Public servant	30 (12·7)
	Student	23 (9·7)
	Worker	19 (8·0)
	Farmer	5 (2·1)
Education	Illiterate	8 (3·4)
	Primary	78 (32·9)
	Secondary	23 (9·7)
	High	68 (28·7)
	University	60 (25·3)
Employment status	Unemployed	154 (64·9)
	Employed whole day	66 (27·9)
	Employed half day	17 (7·2)
Caregiver/patient family relationship	Spouse	97 (40·9)
	Daughters/sons	80 (33·8)
	Parents	31 (13·1)
	Sisters/brothers	22 (9·3)
	Other relatives or friends	7 (2·9)
Live with patient	Yes	169 (71·3)
	No	68 (28·7)

primary education (48·9%) and had health insurance (96·6%). The majority of the cancer sample was unemployed (80·2%), majority had lung cancer (22·4%) and had breast cancer (21·9%), duration of the illness was 21·83 months (SD 0·278 months).

The demographic characteristics of the cancer caregivers are summarised in Table 2. The caregivers in the research averaged 40·19 years of age (SD 13·48 years, range 18–79), included most caregivers were women (61·6%), married (75·5%), housewife (40·1%) and most had completed primary education (32·9%), while 28·7% had high school education, the majority of the caregiver sample was unemployed (64·9%). Spouses made up 40·9% of family caregivers; daughters and sons (33·8%) were the next most frequent relationship to the patient, 71·3% were lived with the patient.

The mean, standard deviation and internal consistency of the CQOLC for Turkish cancer caregivers are shown in Table 3. The mean score ± SD of the Total CQOLC was 71·77 (SD 16·08, range 31–116) and scores of the four subscales were as follows: Burden 14·29 (SD 7·66), distruptiveness 11·79 (SD 5·01), positive adaptation 14·82 (SD 5·13) and financial concerns 6·83 (SD 3·04). The internal consistency of the CQOLC as measured by the Cronbach's alpha coefficient has been found to be 0·88 for the cancer caregivers

Scale	Total items	Range of scores	Cancer Caregivers (Turkish CQOLC)		
			Mean	SD	α
Burden	10	0–35	14·29	7·66	0·83
Distruptiveness	6	0–24	11·79	5·01	0·79
Positive adaptation	6	1–24	14·82	5·13	0·73
Financial concerns	3	0–12	6·83	3·04	0·77
Total CQOLC	25	31–116	71·77	16·08	0·88

Table 3 Mean, standard deviation (SD), internal consistency (Cronbach's α coefficient) of the CQOLC for Turkish cancer caregivers (*n* = 237)

indicating a satisfactory reliability. The coefficient alpha values among cancer caregivers are 0·83 for the burden, 0·79 for the distruptiveness, 0·73 for the positive adaptation and 0·77 for the financial concerns (Table 3). In the calculation of the item-total score reliability, CQOLC's correlation coefficients were found to range between 0·20–0·61, which can be used to do the following: clarification of relationship between every item's variance and the total score variance and determination of whether or not every item on the questionnaire had equal weight. The analysis of inter-item correlations indicated a unidimensional scale.

Construct validity

Confirmatory and exploratory factor analyses were carried out using principal component analysis with varimax rotation and Kaiser Normalization to test its construct validity. The KMO was 0·86, indicating that the sample was large enough to perform a satisfactory factor analysis and that the sample size was sufficient for psychometric testing of a 35-item scale.

Construct validity was provided by factor analysis. Table 4 lists the item-to-factor loadings for the Turkish version of the 25-item CQOLC when the data from all 237 cancer caregivers were analyzed. As a result of the factor analysis, four factors were extracted: burden (Factor 1), distruptiveness (Factor 2), positive adaptation (Factor 3) and financial concerns (Factor 4). In the four factor solution that accepted eigenvalue of at least 1·00, the factors as a result of varimax rotation, explained 40·8% of the variance. Factor one was the major factor and account for 25·4% of the total variance. A more suitable factor extraction was sought. Finally, a four-factor solution was chosen because this appeared to have the best possibilities for interpretation. After selecting a four-factor solution, factor loadings were sorted from largest to smallest values for each factor. Items 4, 10, 12, 16, 22, 23, 27, 28, 34 and 35 were removed from the original 35-item measure of our sample on the basis of predetermined criteria. None of the items were considered as loading on more than one factor, as their factor loadings are not greater than or

equal to 0·40. Finally, the exploratory factor analyses yielded a 25-item measure with a four-factor solution. Each factor was then interpreted by examining item content and pattern of coefficients and four factors were labelled as the same as in the original American study (burden, distruptiveness, positive adaptation and financial concerns).

The individual items retained in the model and factor loadings (≥0·40) are presented in Table 4 for our sample. The orderings of factors in our sample are the same with the original scale and almost the same items were grouped together to form a factor with the exception of factor 3, positive adaptation. One can easily notice the striking similarities of our factor structure with those of the American sample. The classification of items into subscales obtained with our exploratory factor analyses was reflected almost exactly in the factor structure produced by Weitzner *et al.* (1999). However, some of the items were loaded on different factor in our samples, since the eight items that were excluded from the original factor analysis were rather different than the ten items that we excluded from our analysis. The major difference was in the positive adaptation factor. Burden and distruptiveness factors were almost similar with the original ones and the financial concern factor was exactly the same as the original one. One of the differences was that items 17 and 33 in the burden factor of the original factor structure appeared in the positive adaptation factor in our results. Other slight difference was that item 21 was loaded onto the burden factor instead of the distruptiveness factor for our sample and item 15 not appearing in the original factor structure appeared in the burden factor of our sample.

Discussion

As the focus of cancer care, caregiver QoL may have a profound impact upon patient health outcomes in the future. Hence, there is a need for periodic screening to identify those caregivers who are in distress and need intervention. For this purpose a quick assessment tool is needed to give a reliable measure of caregiver QoL in Turkey.

Table 4 Four factors with factor loading for caregivers samples (n = 237)

Items	Caregivers			Item-factor correlation (α)
Burden	Factor 1			0·83
(19) I feel nervous	0·74			0·80
(14) I feel sad	0·68			0·81
(15) I feel under increased mental strain	0·61			0·81
(20) I worry about the impact my loved one's illness has had on my children or other family members	0·57			0·81
(11) My level of stress and worries has increased	0·52			0·81
(25) I fear the adverse effects of treatment on my loved one	0·49			0·82
(9) I fear my loved one will die	0·46			0·82
(31) It upsets me to see my loved one deteriorate	0·45			0·82
(18) I feel frustrated	0·42			0·82
(21) I have difficulty dealing with my loved one's changing eating habits	0·40			0·82
Distruptiveness		Factor 2		0·79
(3) My daily life is imposed upon		0·68		0·72
(1) It bothers me that my daily routine is altered		0·63		0·74
(2) My sleep is less restful		0·55		0·76
(5) It is a challenge to maintain my outside interests		0·47		0·76
(29) It bothers me that my priorities have changed		0·46		0·77
(13) It bothers me, limiting my focus to day-to-day		0·40		0·76
Positive adaptation			Factor 3	0·73
(30) The need to protect my loved one bothers me			0·62	0·67
(26) The responsibility I have for my loved one's care at home is overwhelming			0·58	0·65
(33) I am discouraged about the future			0·53	0·66
(24) It bothers me that I need to be available to chauffeur my loved one to appointments			0·50	0·71
(32) The need to manage my loved one's pain is overwhelming			0·47	0·69
(17) I feel guilty			0·40	0·75
Financial concerns				Factor 4 0·77
(6) I am under a financial strain				0·72 0·68
(7) I am concerned about our insurance coverage				0·70 0·70
(8) My economic future is uncertain				0·69 0·70

Extraction method: principal component analysis.
Rotation method: varimax with Kaiser Normalization.

The aim of this study was to investigate whether the Turkish CQOLC was a relevant, valid and reliable instrument for the assessment of QoL among cancer caregivers. The physical and psychological consequences of cancer and its treatment are likely to affect the QoL of cancer patients and their caregivers. The importance of assessing CQOLC in this population, with the ultimate goal of minimising the negative consequences of cancer and its treatment on caregivers, is now recognised widely. Self-report measures have been developed for cancer patients that are multidimensional and include generic and cancer-specific measures. These instruments are broadly applicable across types and severity of diseases, different medical treatments or health interventions, demographic and cultural subgroups. However, the need continues for a cancer caregiver self report instrument that measures CQOLC among cancer caregivers. Overall, our data provide evidence for the validity and reliability of the CQOLC as a comprehensive, multidimensional self-report questionnaire for that purpose.

In summary, there is stil no gold standard for cross-cultural validation, but the procedures for the first step, the creation of items, are narrowing down. In this study, the Turkish version of the CQOLC was created through the standard procedure reported before and it was demonstrated that detailed efforts were needed in this process. The second step toward demonstrating equivalence, the evaluation of psychometric testing, is challenging. For the cross-cultural validation of Turkish CQOLC, several statistical approaches were undertaken. A factor analysis was considered to be good tools in cross-cultural comparison because these statistics

revealed the conceptual difference of the QoL cancer caregivers in the Turkish CQOLC. Despite the fact that this qustionnaire originally was developed in USA and the sample in this study was from a culturally diverse population, the questionnaire was translated succesfully and it was well accepted by caregivers. These findings indicate that there were cross-culturally common and culture-specific QoL items.

The internal consistency of each scale was estimated by Cronbach's alpha coefficient. Internal consistency reliability for the total CQOLC was measured by Croncbach's alpha and this suggests that the use of the CQOLC subscales is feasible. The reliability coefficient obtained was high ($\alpha = 0.88$) in this study among cancer ceregivers and this would indicate a high degree of reliability for this tool in this study (Table 3). The Cronbach's alpha coefficients of the CQOLC achieved acceptable standards for reliability. The homogeneity of the CQOLC was seen to be at an adequate level in terms of item correlations. The results were very similar to the findings from the original validation study. In the original study, 239 family caregivers of hospice patients with a variety of cancer diagnoses participated and internal consistency for the instrument was found 0·87 (Weitzner & McMillan 1999) and in the other research, 263 family caregivers providing home care for cancer patients participated and internal consistency was found 0·91 (Weitzner *et al.* 1999). The Korean version of the CQOLC was administered to 270 cancer caregivers and the internal consistency of the scale was found 0·90 (Rhee *et al.* 2005).

Yun *et al.* (2005) examined the impact of illness on the caregiver's QoL, they found the mean score ± SD of the Total CQOLC was 61·7 (SD 20·1) and scores of the four subscales were as follows: Burden 14·1 (SD 8·7), distruptiveness 13·7 (SD 6·2), positive adaptattion 14·4 (SD 5·2) and financial concerns 5·3 (SD 3·6). Cancer caregivers had lower QoL scores. These findings were similar with our findings.

Looking specifically at the items in the Turkish scale compared with the original scale, cultural characteristics may have been an influencing factor. This also questions the KMO procedure. This indicated that the sample was large enough to perform a satisfactory factor analysis, but further validation of the original scale clearly showed that factor solutions were associated with sample size. The 'construct validity' of the Turkish version of the CQOLC was evaluated with the principal component method with varimax rotation. In our study, using varimax rotation, the factor analysis indicated four factors, factor analysis yielded factor loadings above 0·40 and factor loadings of the items in the scale ranged 0·43–0·73. Weitzner *et al.* (1999) found that factor loading of the items ranged 0·38–0·82.

The confirmatory factor analysis demonstrated that there are cultural differences which go beyond the extent of agreement to individual statements of the CQOLC instrument. It is evident that the belief structures about caregivers also vary between different cultures. The factor structure derived and confirmed on an American sample at the end of the 1990s was not confirmed on a Turkish sample in the 2007s. Previous researches have used the CQOLC in different cultural setting without any check on the applicability of the factor structure using the confirmatory factor analysis. They all retained the existing factor structure. Of course, retaining the original factor structure allows us for straightforward comparison of factor scores between different cultures. Such comparisons may, however, be rather simple and it can be arguable that the most appropriate way to evaluate the quality of life of the caregiver in different cultural settings is to use quantitative methods.

The results indicate some differences in the factor structures of the CQOLC scale between Turkish and American samples. There are a lot of differences between Turkish and American culture. This, however, could be a reflection of a culturally unique concept of health and QoL as perceived by Turkish cancer caregivers and it exists in the questionnaire items. In other words considering that people with different cultural back-ground may have different perceptions of health and its determinants, the findings of this study indicated that these determinants were perceived different by both Turkish and American cancer caregivers.

In Turkey, caregivers of cancer patients were mostly spouses, some family members and other relatives. This is consistent with Turkish social structure, where the family is the most important source of support for patients. It is well known that cancer diagnosis affects psychosocial adjustment in the family and increasing attention is focused on the caregiver. Patients require varying degrees of assistance with activities of daily living throughout the course of their illness. Assistance may be needed in personal care, meal preparation, housekeeping, shopping, transportation, completion of insurance forms and obtaining financial and legal advice (Weitzner & McMillan 1999). In addition, many other household activities can be managed at the same time while taking care of patients at home.

In Turkish society, family caregivers play a major role in the treatment of cancer patients because of the Turkish cultural expectations and obligations. In Turkey, cancer is one of the leading causes of death. A diagnosis of cancer can have significant unfavorable physical, psychological and economic consequences for both the cancer patients and

caregivers. In Turkey, the care provided to dependent people by families, friends or others who do not receive any economic remuneration for the assistance they provide.

The results indicate differences in some aspects of CQOLCs factor structure between Turkish and American populations. The shorter version of the CQOLC could mitigate the participant burden associated with assessing the QoL of the family caregivers in the future. However, the present findings need to be replicated in independent samples to confirm the factor structure. Qualitative interviews with caregivers may also generate additional dimensions of caregivers' QoL and can be incorporated into existing measures of QoL. Ongoing research programs examining dimensions of caregivers' QoL will create better assessment tools for clinicians and researchers alike. A better version could be prepared with a large enough sample size, comprising people from different regions in Turkey and diverse populations of the world. Once a valid and reliable scale is ready for use, it can be used to measure outcomes in a study. With the Turkish scale now, the study can proceed to further validation of the scale and use in research outcomes.

To our knowledge, the present study is the only one in Turkey that has translate to Turkish attempted to evaluate the QoL of cancer caregivers. In addition, our results have implications for health care policy and research. Thus, the high prevalence of family burden and its impact on caregivers QoL should be considered in planning a national health care system, as should healthcare professionals assessments and intervention programs aimed at assisting caregivers be initiated.

Conclusions

The adapted instrument was seen to correctly measure the QoL of cancer caregivers. As the CQOLC was not available in Turkey, we translated the instrument into Turkish and tested it on a sample of Turkish cancer caregivers. The Turkish version of the CQOLC has shown statistically acceptable levels of reliability and validity. Our findings demonstrated that the instrument had good internal validity, reliability and was sensitive to measure QoL of cancer caregivers, although it needs further testing, particularly as regards the factor structure. We believe that this instrument will become valuable in future cross culture research on cancer caregivers. Further study and development may lead to the identification of variables that would improve this Turkish version of the CQOLC. This scale should be further evaluated with a larger sample size, in different regions in Turkey and with diverse populations.

Relevance of clinical practice

In research and practice, valid measurement instruments are needed to assess QoL in Turkish cancer caregivers. The CQOLC scale is simple to administer and nurses by using this equipment in routine appointments will be able to better identify caregiver at risk for developing cancer related distress and worse QoL. It also provides us with an important instrument to assess the effects of caregiver interventions in clinical trials or related research.

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Contributions

Study design: HAB, ZCO; data collection and analysis: HAB, ZCO and manuscript preparation: HAB, ZCO.

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