RESEARCH ARTICLE

Reliability and Validity of Turkish Version of the Caregiver Quality of Life Index Cancer Scale

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Abstract

Background: Measuring effects of cancer on family caregivers is important to develop methods which can improve their quality of life (QOL) . Nevertheless, up to now, only a few tools have been developed to be used in this group. Among those, the Caregiver Quality of Life Index-Cancer Scale (CQOLC) has met minimum psychometric criteria in different populations in spite of conflicting results. The present study was conducted to evaluate reliability and validity of CQOLC among Turkish cancer family caregivers. Materials and Methods: The CQOLC was administered to 120 caregivers, along with Beck Depression Inventory (BDI), Medical Outcomes Study MOS 36- Item Short Form Health Survey (SF-36), State–Trait Anxiety Inventory (STAI), and Multidimensional Scale of Perceived Social Support (MSPSS). Internal consistency and test-retest stability were used to investigate reliability. Construct validity was examined by using known group method, convergent, and divergent validity. For the known group method, we hypothesized that CQOLC scores would differ between depressed and non-depressed subjects. We investigated convergent validity by correlating scores for CQOLC with scores for other similar measures including SF-36 and STAI. The MSPSS was completed at the same time as CQOLC to provide divergent validity. Results: The values for internal consistency and test-retest correlation were 0.88 and 0.96, respectively. The CQOLC discriminated those who were depressed from those who were not. Convergent validity supported strong correlations between CQOLC scores and two main component scores (PCS, MCS) in SF-36 although there was a weak correlation between CQOLC and STAI scores. Regarding divergent validity, the correlation between CQOLC and MSPSS was in the low range, as expected. Conclusions: The Turkish CQOLC is a reliable and valid tool and it can be utilized to determine QOL of family caregivers.

Keywords: Cancer - care - caring - quality of life - validity

Introduction

Cancer is one of the most frequent causes of death in Turkey. In fact, the most frequent cause of death is diseases of the circulatory diseases followed by cancer in Turkey. According to a study conducted by the Ministry of Health of Turkey between 2000 and 2006, there are 396,000 cancer patients. It is estimated that 150,000 people are diagnosed with cancer and 140,000 people die every year because of cancer (Mollahaliloglu et al., 2011).

Development of medical technology, tendency towards community-based care, changes in health policies and a shift from care delivery in hospital to home settings have increased awareness on complex long-term care needs and large involvement of informal care systems like family members who take care for cancer patients recently. Patients with cancer are often taken care of by their families after discharged from hospital (Yun et al., 2005; Sherwood et al., 2008; Sternberg et al., 2010; Tamayo et al., 2010; Rankin et al., 2011).

The family caregivers' role is often unrecognized and invisible. However, people providing care for their family members with cancer often feel stressed out and have difficulties partly because of the widespread belief that cancer has a high rate of deaths (Kim and Carver, 2007; Lambert et al., 2012).

Caregivers' life is affected by the demanding and overwhelming process they go through while offering care for their family members (Sternberg et al., 2010; Tamayo et al., 2010). It was shown that in the former studies, family caregivers experience increased physical burden (Aoun et al., 2005; Dumont et al., 2006; Palos et al., 2011; Song et al., 2011; Gaugler et al., 2012), anxiety, depression (Grov et al., 2005; Dumont et al., 2006; Chang et al., 2007; Mystakidou et al., 2007; Song et al., 2011; Fridriksdottir et al., 2011; Gorgi et al., 2012), restricted daily activities and social roles, strain in marital relationships (Gaugler et al., 2005; Chen et al., 2007), financial difficulties (Yun et al., 2005; Longo et al., 2006; Miedema et al., 2008; Hassett, 2010; Houtven et al., 2010) and decreased quality of life (QOL) (Yun et al., 2005; Fleming et al., 2006; Tamayo et al., 2010; Song et al., 2011; Fridriksdottir et al., 2011;

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Gorgi et al., 2012).

Caregivers' ability to provide care for cancer patients is adversely affected by the care-giving process as mentioned above (Weitzner et al., 1999a; Given and Sherwood, 2006). Thus, measuring effects of cancer on family caregivers is important to develop new methods to enhance QOL of caregivers of patients with cancer (Tamayo et al., 2010). Effects of cancer on family caregivers have been determined by using general QOL measures. There have been only few measurement tools to be used in this focused group, namely, the Caregiver Quality of Life Index-Cancer Scale, the Caregiver Quality of Life Index, the Quality of Life Tool, and the Quality of Life Index-Cancer Version. The Caregiver Quality of Life Index-Cancer Scale (CQOLC) satisfied minimum psychometric criteria (Edwards and Ung, 2002).

The CQOLC was developed by Weitzner, Jacobsen, Wagner, Friedland and Cox (1999b) to assess QOL of family caregivers of patients with cancer (Weitzner et al., 1999b). The CQOLC was validated in American (Weitzner et al., 1999b), Korean (Rhee et al., 2005), Turkish (Bektas and Ozer, 2009) and Taiwanese populations (Tang et al., 2009). In spite of some conflicting findings related to construct validity of CQOLC, these results were relevant to assess QOL specific to cancer patients' family caregivers. In the Turkish validation study, factor analysis was computed to evaluate construct validity and 10 items were removed from the original CQOLC because of low factor loadings (Bektas and Ozer, 2009).

The aim of the current study was to investigate psychometric properties of the CQOLC among another cancer patients' family caregivers sample in Turkey.

Materials and Methods

Participants

This is a descriptive and methodological study and included 120 family members offering care for cancer patients at the chemotherapy and radiotherapy outpatient clinics and oncology wards at a Medical Center. Eligibility criteria were being the primary family caregiver for cancer patient, being minimum 18 years of age, having minimum a sixth-grade education, not having a history of psychiatric disorders that would prevent the interview, not being diagnosed with cancer of any type, and willingness to take place in the study. In the current study, we defined a caregiver as one of the family members who give most assistance in patient care and daily living activities.

We obtained ethical approval in accordance with the Helsinki Declaration. We also obtained written informed consent from each participant before the study. Data were gathered between October 2007 and June 2008.

Data collection

Data were collected with five instruments. Those were the CQOLC Scale, the Beck Depression Inventory (BDI), the Medical Outcomes Study MOS 36-Item Short Form Health Survey (SF-36), the State-Trait Anxiety Inventory (STAI), and the Multidimensional Scale of Perceived Social Support (MSPSS).

The CQOLC is a scale which can be completed by

participants without assistance and which was developed to determine QOL in family caregivers of cancer patients. It is used to assess important aspects of QOL including physical, emotional, family, and social functioning. They are measured in terms of burden, disruptiveness, positive adaptation, and financial concerns. The CQOLC is a 5 point Likert scale (0=not at all to 4=very much) and consists of 35 items. Out of 35 items, 10 are about burden, 7 are about disruptiveness, 7 are about positive adaptation, 3 are about financial concerns, and 8 are about additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, being informed on disease, protection of patient, pain management, and family interest in caregiving). The maximum total score for the CQOLC is 140 and higher scores show better QOL (Weitzner et al., 1999b).

The BDI was devised by Beck, Ward, Mendelson, Mock and Erbaugh to determine depression severity among individuals aged 15 years and above. Cognitive, motivational and somatic components of depression can be assessed by BDI. Respondents indicate the severity of each symptom on a scale from 0 (no symptom for depression) to 3 (whole symptoms for depression), and the range of total scores is 0-63. Higher scores show more severe symptoms of depression (Beck et al., 1961). Reliability and validity of BDI in Turkey were studied by Tegin (1980) and Hisli (1989). The cut off value was considered as 17 in Tegin's study. In our study, the cut-off value was considered as 17 and scores higher than 17 showed depression. In the current study, we found an internal reliability coefficient of the BDI as 0.89.

Ware and Sherbourne was developed the SF-36 to assess two main health dimensions (physical health and mental health) and different health domains including physical functioning, role limitations due to physical problems, bodily pain, general health perception, vitality, social functioning, role limitations due to emotional problems, and mental health (Ware and Sherbourne, 1992). The physical health and mental health scores are calculated from the subdomain scores and are summarized as the physical component scale (PCS) and mental component scale (MCS). Subdomain scores and total scores of PCS and MCS range between 0 (worst health status or QOL) and 100 (best health status or QOL). The SF-36 can be employed by practitioners, researchers and health policy evaluators. It has been adapted to various languages including Turkish. Reliability and validity of the SF-36 were determined by Pinar (1995). We re-investigated internal reliability of the SF-36 in this study and found Cronbach's alpha value to be 0.90 for PCS and 0.87 for MCS.

The STAI consists of 40 items related to state and trait anxiety. In the current study, items for trait anxiety were used. Respondents indicate their answers to items in Trait Anxiety Scale on a 4 point Likert scale as follows: "almost never", "sometimes", "often", and "almost always". Total scores change between 20 and 80. Scores 0-19 correspond to "no anxiety", 20-39 to "a little anxiety", 40-59 to "moderate anxiety" and 60 to 79 to "higher anxiety", and 80 and over to "panic or crisis". Psychometric properties of the Turkish STAI were studied by Oner and Lecompte

(1998). Cronbach's alpha coefficient was 0.87 in our study.

The MSPSS was designed by Zimet et al. (1988) to evaluate how social support provided by family, friends, and significant others is perceived. Each item in MSPSS requires using a 7-point Likert scale ranging from "very strongly disagree" (1) to "very strongly agree" (7). The scores range from 12 (the lowest score) to 84 (the highest score). Eker and Arkar (1995) tested the validity and reliability of MSPSS in a Turkish sample. In this study, we found Cronbach alpha coefficient for the support by family, friends, and significant others to be 0.92, 0.92, and 0.91 respectively.

Procedures

The reliability and validity were tested following translation of the CQOLC into Turkish. The forward-backward translation method was used. After obtaining written permission from the researcher who developed the CQOLC, the process included forward translations from English into Turkish, back translations from Turkish into English, examination of the original English, Turkish and back translated English forms by a group of experts for clarity, discrepancies, and semantic mistakes and resolution of all differences in the forms, reviewing the back translated English form and original English form by the author, and finally developing Turkish CQOLC. During translation period, we realized that eight items (item 3, 5, 13, 15, 24, 25, 27, and 32) in the back translated English form were inconsistent with the items in the original English form.

After consultation with Weitzner and an expert committee, we reorganized all those items as in the original form except item 32. This item, stated as "The need to manage my loved one's pain is overwhelming" in the original English form has been changed into "I feel devastated by being unable to control my loved one's pain" in the back translated English form and into "Sevdigim insanın agrısını dindiremedigim için kahroluyorum" in the final Turkish form. All translations were made by bilingual translators familiar with both English and Turkish cultures.

After developing the Turkish form, we performed a pilot study on 18 family caregivers of cancer patients to evaluate clarity and comprehensibility of the Turkish form. We found the Turkish CQOLC to be simple and easy to understand. After completing the translation procedure, we started to collect data to assess psychometric properties of the CQOLC.

Internal consistency and test-retest stability were used to investigate reliability of the scale. A minimum Cronbach's alpha of 0.70 was thought to be satisfactory for the internal consistency (Todd and Bradley, 1994). Intraclass correlation coefficient (ICC) was utilized to determine test-retest stability. We conducted retest procedure two weeks after the first test of the CQOLC in a sample consisting of 20 caregivers.

Known group method, convergent, and divergent validity were used to assess construct validity. For the known group method, using BDI, we divided the sample into two groups; namely nondepression and depression groups. We hypothesized that CQOLC scores would be different in depressed subjects from those without

depression. Independent sample t test was employed for comparisons between the two groups. Convergent validity was investigated by examining the correlation between CQOLC scores and scores from other similar measures including SF-36 and STAI. Depending on the relevant literature, we hypothesized that there would be a strong positive relationship between CQOLC and SF-36 main component scores, on the basis of the fact that two tools measure similar constructs.

We also hypothesized that there would be a relatively negative high correlation coefficient between CQOLC and STAI scores in these comparisons, congruent with former studies (Weitzner et al., 1999b; Rhee et al., 2005).

The MSPSS, which is a dissimilar measure, was completed at the same time as CQOLC to provide divergent validity. A low correlation was expected in this comparison as shown in the original validation study (Weitzner et al., 1999b).

We performed statistical analyses with Statistical Package for the Social Sciences (SPSS). Pearson's correlation coefficients were calculated to examine associations between two continuous variables. Significance for all statistical tests was defined as p value lower than 0.05.

Results

Characteristics of patients and family caregivers

We used descriptive statistics including frequencies, means and standard deviations to reveal demographic features of the subjects. The patients with a mean age 53.6 included 46 females and 74 males. Forty-two percent of them had cancer lasting for less than 6 months, 35.8% of them had metastasis, and 43.3% of them were on chemotherapy.

The majority of the caregivers were female (72.5%) and married (75.8%) with a mean age of 44.7. Seventy-four point two percent of them had children and 95% were living with their family.

Reliability

Internal consistency coefficient and ICC were 0.88 and 0.96 respectively.

Validity

Findings on validity are presented in Table 1. According to BDI scores, 42.5% of the caregivers were depressed. The CQOLC discriminated depressed from non-depressed subjects. The scores of depressed caregivers indicated that these caregivers had significantly poorer QOL than

Table 1. Validity Findings of CQOLC (N=120)

		CQOLC	
SF-36:	Physical health	r=0.53	p=0.000
	Mental health	r=0.57	p=0.000
BDI:	Depressed (n=51)	67.11±14.96 (SD)	t=8.21
	Non depressed (n=69)	90.62±15.88 (SD)	p=0.000
STAI		r=-0.24	p=0.007
MSPSS:	Family	r=0.23	p=0.012
	Friend	r=0.23	p=0.010
	Significant other	r=0.24	p=0.007

nondepressed caregivers as we hypothesized.

We found significant results in planned comparisons to investigate convergent and divergent validity. The correlation between CQOLC and PCS of SF-36 measuring physical health and MCS of SF-36 measuring mental health were strong, though the correlation of CQOLC with PCS of SF-36 was relatively lower than the correlation of CQOLC with MCS of SF-36. Inconsistent with our hypothesis, there was a weak correlation between CQOLC and STAI. By means of divergent validity, the correlation between CQOLC and MSPSS was in the low range as expected.

Discussion

The findings obtained in this study confirmed the reliability and validity of the Turkish CQOLC.

Internal consistency coefficient of the caregivers fulfilled the recommended minimal Cronbach's alpha coefficient standard (0.70). Our result was comparable with findings from the original validation study in Americans' family caregivers of cancer patients (Weitzner et al., 1999b). Our result was also comparable with the results from previous studies from Korea (Rhee et al., 2005), Turkey (Bektas and Ozer, 2009) and Taiwan (Tang et al., 2009). These results suggest a strong correlation between the individual items of the instrument.

The test-retest correlation coefficient measured by ICC showed the stability of CQOLC in the Turkish sample. Our results were quite similar to those reported by Weitzner, Jacobsen, Wagner, Friedland and Cox (1999b) who found test-retest reliability to be 0.95.

The results of known group method supported our hypothesis that depressed caregivers will have poorer QOL than nondepressed caregivers. Weitzner et al. (1999b) from America and Rhee et al. (2005) from Korea both showed a negative correlation between scores for CQOLC and depression scores measured by BDI (Weitzner et al., 1999b; Rhee et al., 2005). Grov et al. (2006), demonstrated that depression was the most important factor for caregiver burden. These results indicate that the CQOLC has sufficient sensitivity to reveal differences in caregivers' depression, suggesting that depression is a predictor for caregiver's poor QOL.

The CQOLC and physical and mental component scores of SF-36 were strongly correlated, which indicated that poorer QOL correlated with worse physical and mental health. However, the correlation of CQOLC with PCS of SF-36 was relatively lower than the correlation of CQOLC with MCS of SF-36, showing that the CQOLC reflects caregivers' mental health better than their physical health. In the original validation study, there was a high correlation between CQOLC and MCS (r=0.65), but a very low correlation between CQOLC and PCS (r=0.13). Rhee et al. (2005) found very similar results to those from Weitzner et al. (1999b). Differences in these results indicate that some cultural factors may be effective in perceived health and QOL. In other words, cancer patients' caregivers who have different cultural backgrounds may perceive health and its determinants differently. The results of our study showed differences in perceptions of health determinants between Turkish, American and Korean caregivers. This study also confirmed that QOL was consistent with perceived physical and mental health, which is a causal determinant of health related quality of life in Turkish cancer family caregivers. This emphasizes the importance of the ability to recognize the presence of a causal relationship between caregivers' health and QOL, consistent with the results of a study by Fayers and Machin (2000).

Our study showed a low correlation between caregiver QOL and anxiety. In contrast to our results, in the original validation study, the correlation between CQOLC and STAI was moderate (r=-0.52). This difference between Turkish and Americans caregivers can also be attributed to cultural differences. By means of divergent validity, the CQOLC scores were weakly correlated with perceived social support, as we had predicted. Our results were comparable with findings from Weitzner et al. (1999b) who also found a weak correlation (r=0.20). The findings of our study suggest that CQOLC shares certain common themes with STAI and MSPSS, but measures different constructs other than anxiety and social support in Turkish caregivers. Grov et al. (2006) demonstrated that depression was the most important factor for caregiver burden; however, they also reported that anxiety and social support did not directly influence caregiver burden. In fact, both may play a role in depression and have indirect effects. For this reason, health-care staff should take account of caregivers' depression and recommend an evaluation or an intervention to improve caregiver QOL.

This study has several potential limitations. Firstly, the study sample was based on non-random sampling of family caregivers. Furthermore, the inclusion criterion that caregivers have minimum sixth-grade education limits the applicability of the CQOLC among caregivers who are illiterate or who have no formal education. Therefore, further research on randomly selected family caregivers who have different educational background is required. In addition, we did'nt considered the influence of cancer's stages, specifically including later stages and end of life, which may reduce the generalizibility of the findings. This information could have been useful to analyze of construct validity.

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