

# A psychometric validation study of the Quality of Life and FAMCARE scales in Turkish cancer family caregivers

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## Abstract

**Purpose** The aim of this study was to assess the psychometric validation of the Quality of Life and FAMCARE scales in Turkish family caregivers of cancer patients.

**Methods** This is a descriptive study involving 100 family caregivers of cancer patients. The validity and reliability study of the scales was performed in two phases. Phase I focused on the construction of the Turkish version of the instruments and pilot testing. Phase II was the psychometric assessment of the scales.

**Results** The caregivers stated that the two questionnaires were easy to read and to understand. However, the psychometric validation performed afterwards revealed that both the ordering of the factor loadings and content of the scales were influenced by prevailing characteristics of Turkish society. Caregivers were satisfied with the care their patients received, and family concerns were the most negatively affected quality-of-life (QOL) dimensions.

Factors affecting the QOL and satisfaction with care were age, co-residence, relationship to patient, gender of the patients and caregivers, stage of the disease of the patient and marital status of the caregivers.

**Conclusion** Psychometric validation of the Quality of Life and FAMCARE scales demonstrates that these culturally adapted scales are valid and reliable tools to assess the QOL and satisfaction of Turkish family caregivers of cancer patients.

**Keywords** Cancer · Care · Satisfaction · Caregiver · Quality of life

## Introduction

Longer survival times, increasing incidence of cancer, healthcare cost restraints, fewer inpatient beds and a growing trend toward outpatient treatment have resulted in an increased role of the caregiver in the monitoring and management of symptoms experienced by cancer patients. Consequently, family caregivers have become an important link in providing support and managing the care of their patients [1]. However, the successful transition of the patient from an acute in-patient care setting to home usually requires the involvement of family members or others willing to give the care [2, 3]. Thus, most of caregivers are asked to assume an increasing number of complex caregiving tasks at home, such as providing emotional support, helping with activities of daily life, communicating with healthcare professionals, managing treatment and disease-related symptoms, administering medicines, maintaining social activities, handling the behavioral problems and emotional reactions of the patient, providing a special nutrition plan, as well as assisting with other physical

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aspects of caring. During these complex caregiving tasks, the caregiver's own needs are not usually met, and the perceived burden of caregivers increases their negative reactions to care giving [4].

Providing home care for cancer patients and introducing the issue of disease into the daily life of the family lead to a number of minor and major disruptions [5]. Family members can report problems related to their physical, psychological, occupational, social and economic health [6, 7]. Providing care for long periods at home can cause stress and depression, which can dramatically affect the family caregivers' quality of life (QOL) [1, 8]. The subsequent adjustments that need to be made in the lives of families and caregivers of cancer patients raise important questions concerning the QOL of the caregivers themselves, and there are many factors which may affect this QOL: patient factors (increased symptom distress and physical needs, performance status of patients, patient diagnosis, prognosis), caregiver factors (level of education, gender, personality, level of distress, responsibilities, well-being, financial status, length of caring) and social factors (social support, social network) [6, 9–11].

Since the number of informal caregivers of cancer survivors is growing rapidly, it is important to determine the impact that multiple roles of caring has on the well-being of caregivers, as well as their satisfaction with care received at hospital [12], because when nurses take into account the overall care needs of patients, they face the difficulty of determining how to support the patients' families in their care giving [2, 13].

Several instruments have been used to examine the overall quality, competence, amount of information, physical facilities of caregiver providers' attention and outcomes [14]. Because these instruments are highly culture dependent, it is sometimes not possible or feasible to use translated instruments developed in other languages and for other cultures. In order for such instruments to adequately serve their purpose in Turkey, they need to be culturally adapted to the prevailing characteristics of Turkish society, such as a protective and tolerant attitude toward disease, a fatalistic mentality and a cohesive effect of the disease on all family members.

The purpose of this study was to assess the psychometric validation of the Quality of Life (Family Version) and FAMCARE scales for assessment of the QOL and satisfaction with patient care of Turkish family caregivers of cancer patients.

#### Research questions

1. Are the Turkish versions of the Quality of Life (Family Version) scale and FAMCARE scale valid and reliable measurement tools to assess the QOL and satisfaction

with patient care of Turkish family caregivers of cancer patients?

2. What is the QOL and satisfaction with patient care of the Turkish family caregivers of cancer and the factors affecting it?

#### Methods

After receiving permission from the authors of the FAMCARE scale [15] and Quality of Life (Family Version) scale [16], we tested the validity and reliability of the scales in two phases. Phase I focused on the construction of the Turkish version of the instruments and pilot testing. Phase II was the psychometric assessment of the scales.

#### Phase I: scale construction

##### *Translation*

The 'forward-backward' translation procedure was used to translate the FAMCARE and Quality of Life (Family Version) scales. The double back-translation procedure was performed as follows [17]:

Step (1)—two native Turkish speakers (one English lecturer, one nursing lecturer specialized in oncology) independently made a forward translation of the scales. Step (2)—a second native Turkish speaker not involved in the forward translation process reconsolidated the forward translations.

Step (3)—two native English speakers (one nursing lecturer, one English lecturer) fluent in Turkish performed a back translation of the reconciled version and then reviewed the cross-cultural equivalence of the translated scales.

Step (4)—using a four-point rating scale ranging from 1 (not relevant) to 4 (very relevant), five bilingual experts, including linguists and health professionals, rated the translation relevance of each item in the scales or provided alternative translations to improve items with inadequate pre-existing translations to improve the cultural appropriateness of the tools. The content validity index (CVI) was then calculated based on the experts' ratings. A CVI score of  $\geq 0.80$  indicates good content validity [18]. The CVI of the Turkish version of scales in our study was 0.93 for FAMCARE and 0.89 for the Quality of Life (Family Version) scale.

Step (5)—spelling and grammar of the new forward translation was corrected and verified, and a provisional Turkish version of the scales was provided for pilot testing with native cancer caregivers in Turkey.

### Pilot testing

After obtaining the necessary permission from relevant institutional and ethics review boards, a pilot testing of the provisional Turkish version of the scales was performed at Istanbul University Institute of Oncology with 40 caregivers. The inclusion criteria in the pilot study were being a primary caregiver responsible for the care of a cancer patient, age  $\geq 18$  years, competency in written and spoken Turkish, and the ability to consent to participate in the study. If the caregiver was not the primary person responsible for the care of the cancer patient, was in a social or psychological state that would interfere with their participation in the study, or did not want to participate in the study after it was explained to them, they were not included in the study.

The purpose of the pilot testing was to estimate the initial content validity of the scales from a relevant population of interest. Respondents were asked to comment on items and offer suggestions for improvement of the instruments. The questionnaires could be completed in 15–20 min, and caregivers stated that these questionnaires were easy to read and to understand. Some phrases were changed according to caregivers' proposals.

### Phase II: psychometric assessment of the scales

#### Research setting, study design and sample

There are two main methods for determining the size of a sample in a factor analysis: (1) suggesting a minimum total sample size or (2) examining the ratio of subjects to variables [19, 20]. In this study a minimum of 100 subjects "rule" was used for psychometric evaluation of the scales [20]. We invited 112 caregivers who met the inclusion criteria of the pilot study to participate in the study; of these, six declined to participate; four were unable to participate owing to lack of time and two returned blank questionnaires. Thus, the study cohort comprised 100 caregivers.

#### Data collection

Several evaluation forms were used for data collection: Caregiver Questionnaire, Patient Questionnaire, FAMCARE Scale and Quality of Life (Family Version) Scales.

#### Instruments

*The Caregiver Questionnaire*, developed by the researchers of this study, contains items that address the socio-demographic characteristics of the caregivers (age, gender, marital status, education level, occupation, perceived level of income, current employment status), the usual characteristics of caregiving (duration of care, total time spent with

patient per day/week, living or not living in the same household with the patient, relationship with patient) and the caregiver's state of health (having a chronic disease or not).

*The Patient Questionnaire*, also developed by the researchers of this study, contains items that address the usual demographic data (e.g., age, income level, employment status) and disease and treatment characteristics (e.g., the reason for current hospitalization, type of cancer, stage of disease, type of treatment, ECOG performance status) of the patients.

*The FAMCARE Scale* measures the degree to which family members are content with the healthcare received by both the patient and the family. Kristjanson's [15] conceptual structure for the FAMCARE consist of four subscales and includes 20 items: information-giving (items 2, 3, 4, 16, 17), availability of care (items 6, 11, 12, 20), physical care (items 1, 5, 8, 10, 14, 18, 20) and psychosocial care (items 7, 9, 13, 15). The FAMCARE Scale is answered using a 5-point Likert format (1 = very satisfied; 2 = satisfied; 3 = undecided; 4 = dissatisfied; 5 = very dissatisfied). The scale's internal consistency in the original study was 0.93, the test–retest correlation was 0.91 and the criterion validity using the MsCusker Scale was 0.80 and 0.77 [15]. In another study, Ringdal et al. found that a strong, one-dimensional scale may be formed from 19 of the 20 items (item 14 was excluded) in terms of scalability ( $H_{\text{wt}} = 0.59$ ) and the reliability of the scale (Cronbach's  $\alpha = 0.96$ ) [21].

Low scores on the FAMCARE Scale indicate high levels of satisfaction with care, and high scores indicate low levels of satisfaction [15]. To make the FAMCARE Scale easier to interpret, the scores of the items were rescaled to vary between 0 and 100, so that low values on the scale and subscales indicate low satisfaction with care and high values indicate high satisfaction with care.

*The Quality of Life Scale (Family Version)* [16] was selected because of its reliability and validity in measuring the QOL of family members caring for cancer patients. As a 37-item instrument, the Quality of Life (Family Version) Scale addresses physical well-being (five items), psychological well-being (16 items), social concerns (nine items) and spiritual well-being (seven items). Participants were asked to indicate their agreement with each statement on a Likert-type scale ranging from 0 to 10. Several items have reverse anchors (range 0 = the most positive response to 10 = indicating the most negative response). The items to be reversed are 1–4, 6, 13–20, 22, 24–29 and 33. The score of these items was reversed in this study so that higher scores represent a greater QOL. The family version of the QOL tool is an adaptation of the patient version QOL tool. The instrument was revised and tested from 1994 to 1998 in a study of 219 family caregivers of cancer patients. The test–retest reliability was 0.89, and the internal consistency alpha was 0.69 [16]. However, in the study performed by Lu et al., the confirmatory factor analysis

and internal consistency of this scale confirmed the construct validity of the questionnaire [22].

### *Ethical considerations*

The study was approved by the administration of the Istanbul University Oncology Institute. The caregivers were informed of the nature of the study and verbal consent was obtained.

### *Statistical analysis*

The SPSS ver. 7.5 (SPSS, Chicago, Ill) program was used for data analysis. Descriptive statistics, means, median, frequencies and percentage were used to show the distribution of the socio-demographic characteristics of patient and caregiver, economical status of family, usual characteristics of caregiving, illness or treatment-related characteristics, QOL and satisfaction with care. To explore the dimensionality of the scales, we performed the factor analysis using a principal component analysis with varimax rotation; the acceptable level for scale items was set to be  $>0.40$ . The internal reliability was examined with Cronbach's  $\alpha$ , and validity was determined by the Spearman's correlation test. Nonparametric tests, such as the Mann–Whitney  $U$  and Kruskal–Wallis tests, were used to compare the median value of the QOL and satisfaction with care in subgroups of: (1) socio-demographic characteristics of patient and caregiver (age, gender, marital status, level of education, occupation); (2) economic status of family (perceived level of income, current employment status); (3) usual characteristics of caregiving (living or not living in the same household with the patient, relationship with patient); (4) caregiver's health status (having a chronic disease or not); (5) disease/treatment related characteristics (e.g. type of cancer, stage of disease, the reason for current hospitalization, type of treatment, ECOG performance status). The relationship between QOL/satisfaction with care and duration of care or total time spent with patient per day/week was evaluated by means of Spearman's rho correlation. For all statistical analyses, a two-sided  $P$  value  $<0.05$  was considered to be statistically significant.

## **Results**

### Caregivers' characteristics

The mean age of caregivers was  $40.48 \pm 12.79$  (range 18–76) years, and all were relatives of the patients. The majority were women and married. About half of the caregivers had a secondary school education, and a level of income that they perceived to be moderate; some of them had to give up working due to their care-giving

responsibilities. Most caregivers lived in the same house with the patient, and 20% suffered from a chronic disease (hypertension, diabetes etc.) (Table 1). The mean duration of caregiving was  $11.96 \pm 17.02$  (range 0–120) months.

### Patients' characteristics and findings related to patient's current hospitalization

Most of the patients had a primary or high school educational level and had been hospitalized for chemotherapy. Nearly 30% were young, with disease stage IV and an EGO performance score of "1" (Table 2). Mean duration of time since diagnosis of the cancer was  $10.36 \pm 19.97$  (range 1–144) months. The mean number of hospitalizations (including the current hospitalization) was  $3.97 \pm 4.31$  (range 1–25), and the mean duration of hospitalization during the current stay was  $10.99 \pm 14.88$  (range 2–90) nights.

### Factor analysis and reliability analysis of the scales

#### *FAMCARE scale*

The factor extraction was limited to three factors based on the original study [15]. There were no items with a factor loading of  $<0.40$  at the first iteration, but the content of the items in the three-factor structure of the scale was different from the results of Kristjanson's [15] study (Table 3). Depending on the items, the first factor was labeled as *Availability of the doctor* (items 9, 11, 16, 17, 18, 19, 20), the second as *Information Giving* (items 2, 3, 4, 5, 7, 15), and the third as *Availability of Care* (items 1, 6, 8, 10, 12, 13, 14); the eigen values were 10.21, 1.36 and 1.30, respectively. The Kaiser–Meyer–Olkin measure of sampling adequacy was 0.91, and the Cronbach alpha correlation coefficient for total satisfaction was 0.95. The coefficients for the subscales were 0.91 for *Availability of the doctor*, 0.90 for *Information Giving*, and 0.86 for *Availability of Care*. Inter-item correlations ( $r_s$ ) ranged from 0.54 to 0.78 for the total scale and from 0.63 to 0.85 for the subscales (Table 4).

#### *Quality of Life (Family Version) Scale*

The factor extraction was limited to four factors based on the original study [16]. There were several items with a factor loading of  $<0.40$ . At the first iteration, items with a factor loading of  $<0.40$  were excluded (item 31 "Is the amount of support you receive from religious activities sufficient to meet your needs?" and item 34 "Has your family member's illness made positive changes in your life?"). Based on this algorithm, the factor analysis was run three times before it met the election criteria. Item 5 "Rate your overall physical health", item 23 "Is the amount of

**Table 1** Characteristics of caregivers ( $n = 100$ ) responsible for providing care to cancer patients

Characteristics	<i>n</i>	Percentage of caregiver cohort
<b>Gender</b>		
Female	74	74
Male	26	26
<b>Marital status</b>		
Married	72	72
Unmarried	28	28
<b>Level of education</b>		
Secondary school graduate	46	46
High school graduate	31	31
University graduate	23	23
<b>Occupation</b>		
Housewife	40	40
Self-employed	22	22
Worker	16	16
Civil servant	12	12
Retired	10	10
<b>Perceived income level</b>		
Low	34	34
Moderate	46	46
Good	20	20
<b>Employment status</b>		
Working	26	26
Not working, because of providing care	23	23
Not working because of other reasons (retirement, housewife, etc.)	51	51
<b>Relation to patient</b>		
Child	31	31
Parent	23	23
Spouse	22	22
Relative	24	24
<b>Living in the same house as the patient</b>		
Yes	72	72
No	28	28
<b>History of chronic illness</b>		
Yes (hypertension, diabetes, etc.)	20	20
No	80	80

support you receive from others sufficient to meet your needs?” and item 32 “Is the amount of support you receive from your personal spiritual activities such as prayer or meditation sufficient to meet your needs?” were eliminated on second iteration. Item 6 “How difficult is it for you to cope as a result of your family member’s disease and treatment?” and item 30 “Rate your overall social well being?” were eliminated on the third iteration. The factor analysis of the Quality of Life (Family Version) Scale yielded a four-factor structure with an eigenvalue of 25.13,

**Table 2** The characteristics related to the illness of the patient ( $n = 100$ )

Characteristics related to the illness of the patient	<i>n</i>	Percentage of patient cohort
<b>Patient’s cancer diagnosis</b>		
Rhabdomyosarcoma	16	16
Head and Neck Cancer	16	16
Lymphoma	12	12
Breast cancer	9	9
Ewing’s sarcoma	8	8
Lung cancer	8	8
Osteosarcoma	8	8
Testicular cancer	6	6
Gastrointestinal cancers	4	4
Others (cervical cancer, leukemia etc.)	13	13
<b>Stages of cancer</b>		
Stage I	9	9
Stage II	14	14
Stage III	8	8
Stage IV	35	35
Not applicable (missing data)	34	34
<b>Reason for current hospitalization</b>		
Chemotherapy	55	55
Radiotherapy	20	20
Supportive therapy	25	25
<b>ECOG performance score</b>		
0. Fully active, able to carry on all pre-disease performance without restriction	12	12
1. Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature; e.g., light housework, office work	35	35
2. Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	25	25
3. Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours	14	14
4. Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair	11	11
Missing data	3	3

11.89, 7.38 and 6.01. Compared to results in the original study [16], both the order of the factor loading and the content of the subscales were affected (Table 5). The rotated solution showed four factor loadings, which were labeled as the subscales of psychological well-being (items 7, 8, 9, 10, 11, 12, 17, 21, 35, 36 and 37), family concerns (items 13, 14, 15, 16, 18, 19, 20, 22 and 33), physical well-being (items 1, 2, 3 and 4) and social well-being (items 24, 25, 26, 27, 28 and 29).



**Table 3** Factor analysis of the FAMCARE scale ( $n = 100$ )

Factors in the three-factor analysis	F1''	F1	F2	F3	$h^2$
Availability of the doctor					
9. Doctor's attention to patient's description of symptoms	<b>0.78</b>	<b>0.65</b>	0.37	0.31	0.66
11. Availability of doctors to the family	<b>0.77</b>	<b>0.63</b>		0.40	0.64
16. Information given about how to manage the patient's pain	<b>0.70</b>	<b>0.60</b>		0.38	0.56
17. Information given about the patient's tests	<b>0.77</b>	<b>0.65</b>	0.38		0.66
18. How thoroughly the doctor assesses the patient's symptoms	<b>0.70</b>	<b>0.84</b>			0.76
19. The way in which tests and treatments are followed up by the doctor	<b>0.72</b>	<b>0.77</b>	0.31		0.72
20. Availability of the doctor to the patients	<b>0.76</b>	<b>0.75</b>		0.38	0.74
Information giving					
2. Information provided about the patient's prognosis	<b>0.74</b>	0.40	<b>0.74</b>		0.73
3. Answers from health professionals	<b>0.74</b>		<b>0.80</b>		0.76
4. Information given about side effects	<b>0.69</b>		<b>0.77</b>		0.70
5. Referrals to specialists	<b>0.74</b>		<b>0.71</b>	0.37	0.69
7. Family conferences held to discuss the patient's illness	<b>0.74</b>		<b>0.71</b>		0.68
15. The way in which the family is included in treatment and care decisions	<b>0.70</b>		0.55	0.45	0.56
Availability of care					
1. The patient's pain relief	0.52			<b>0.60</b>	0.41
6. Availability of a hospital bed	0.54			<b>0.66</b>	0.48
8. Speed with which symptoms are treated	<b>0.74</b>	0.40	0.31	0.57	0.59
10. The way in which tests and treatments are performed	<b>0.69</b>		0.39	<b>0.63</b>	0.59
12. Availability of nurses to the family	<b>0.64</b>	0.35		0.55	0.47
13. Coordination of care	<b>0.76</b>	0.37		<b>0.69</b>	0.69
14. Time required to make a diagnosis	<b>0.70</b>	0.30		<b>0.76</b>	0.70
Eigenvalues, initial		10.21	1.36	1.30	
Eigenvalues, rotation		4.56	4.20	4.11	
Variance explained					64.46%

Values given in bold are high factor loadings ( $>0.60$ )

Extraction method: principal component factoring with Kaiser's criterion; rotation: Varimax with Kaiser normalization

F1'' Factor loadings for the first factor in the initial (unrotated) solution; F1, F2 and F3, factor loadings for rotated solution,  $h^2$  communalities—the proportion of the variance in each item which is explained by the factors

The Kaiser–Meyer–Olkin measure of sampling adequacy was 0.76. The Cronbach alpha correlation coefficient for the total QOL score was 0.88. The coefficients for the subscales were 0.86 for the psychological well-being subscale, 0.84 for the family concerns subscale, 0.82 for the physical well-being subscale and 0.70 for the social well-being subscale. The inter-item correlation ( $r_s$ ) ranged from 0.23 to 0.78 for the total scale and from 0.46 to 0.82 for the subscales (Table 6).

#### Caregivers QOL and satisfaction with care and factors affecting them

The overall QOL score for caregivers was moderate, and the greatest disruption in the QOL of the caregivers was revealed in the family concerns subscale with a mean and standard deviation of  $1.79 \pm 1.73$  (Table 6). Psychological well-being was lower in caregivers who cared for male

patients ( $z_{mww} = -1.98$ ,  $P = 0.04$ ) and who were living in the same house as the patients ( $z_{mww} = -2.26$ ,  $P = 0.02$ ). Physical well-being was lower in caregivers of the patient who had stage I disease than in those who cared for stage II or III patients ( $\chi_{kw} = 9.02$ ,  $P = 0.02$ ). However, the QOL caregivers who were parents of the patient was lower in all domains except for social well-being than that in those who were spouse or relatives of the patients ( $P < 0.05$ ).

The satisfaction with care was high, with mean scores were  $\geq 60$ , indicating that most of the family member respondents were satisfied with the care given to the patient (Table 4). A significant positive correlation was found among caregivers' age and satisfaction with care subgroups. Satisfaction with *Information Giving* ( $r = 0.30$ ,  $P = 0.003$ ) and *Availability of Care* ( $r = 0.27$ ,  $P = 0.006$ ) and total satisfaction with care ( $r = 0.28$ ,  $P = 0.004$ ) increased as the age of the caregiver increased. While the caregivers of the metastatic cancer patients reported significantly lower

**Table 4** Description, inter-item correlations ( $r_s$ ) and Cronbach  $\alpha$  values of the FAMCARE scale ( $n = 100$ )

FAMCARE <sup>a</sup>	$\bar{x}$	Median	$\pm$ Standard deviation	Subscale score		Total scale score	
				$r_s$	$P$	$r_s$	$P$
Availability of the doctor	<b>74.04</b>	<b>75.00</b>	<b>17.79</b>			0.88	0.0001
9. Doctor's attention to patient's description of symptoms	75.50	75.00	21.02	0.79	0.0001	0.78	0.0001
11. Availability of doctors to the family	72.25	75.00	23.27	0.82	0.0001	0.75	0.0001
16. Information given about how to manage the patient's pain	69.25	75.00	24.06	0.78	0.0001	0.67	0.0001
17. Information given about the patient's tests	70.50	75.00	24.46	0.82	0.0001	0.77	0.0001
18. How thoroughly the doctor assesses the patient's symptoms	79.75	75.00	17.66	0.82	0.0001	0.70	0.0001
19. The way in which tests and treatments are followed up by the doctor	78.00	75.00	18.56	0.85	0.0001	0.75	0.0001
20. Availability of the doctor to the patients	73.00	75.00	23.75	0.80	0.0001	0.73	0.0001
$\alpha$				<b>0.91</b>			
Information giving	<b>70.67</b>	<b>75.00</b>	<b>21.36</b>			0.92	0.0001
2. Information provided about the patient's prognosis	68.50	75.00	27.89	0.83	0.0001	0.78	0.0001
3. Answers from health professionals	73.00	75.00	26.75	0.81	0.0001	0.75	0.0001
4. Information given about side effects	65.00	75.00	28.43	0.82	0.0001	0.71	0.0001
5. Referrals to specialists	76.00	75.00	21.59	0.75	0.0001	0.72	0.0001
7. Family conferences held to discuss the patient's illness	67.75	75.00	26.18	0.79	0.0001	0.76	0.0001
15. The way in which the family is included in treatment and care decisions	73.75	75.00	24.71	0.72	0.0001	0.71	0.0001
$\alpha$				<b>0.90</b>			
Availability of care	<b>73.18</b>	<b>75.00</b>	<b>16.57</b>			0.89	0.0001
1. The patient's pain relief	78.75	75.00	19.58	0.63	0.0001	0.54	0.0001
6. Availability of a hospital bed	68.25	75.00	28.62	0.71	0.0001	0.62	0.0001
8. Speed with which symptoms are treated	71.50	75.00	22.20	0.81	0.0001	0.78	0.0001
10. The way in which tests and treatments are performed	73.50	75.00	21.27	0.80	0.0001	0.73	0.0001
12. Availability of nurses to the family	79.25	75.00	18.14	0.69	0.0001	0.63	0.0001
13. Coordination of care	72.75	75.00	21.64	0.79	0.0001	0.77	0.0001
14. Time required to make a diagnosis	68.25	75.00	24.58	0.81	0.0001	0.72	0.0001
$\alpha$				<b>0.86</b>			
FAMCARE total score	<b>72.63</b>	<b>73.41</b>	<b>16.68</b>				<b>0.95</b>
$\alpha$							

Values given in bold are high factor loadings ( $>0.60$ )

$r_s$  Spearman's rank correlation coefficient

<sup>a</sup> Average scores of the FAMCARE scale were rescaled to vary between 0 and 100 so that low values on the scale indicate low satisfaction with care and high values indicate high satisfaction with care

<sup>b</sup> Subscales include the items outlined by Kristjanson [15]: information giving (items 2, 3, 4, 16, and 17); availability of care (items 6, 11, 12, and 20); physical care (items 1, 5, 8, 10, 14, 18, and 19); psychosocial care (items 7, 9, 13, and 15)

satisfaction with *Availability of the doctor* ( $\chi_{kw} = 8.76$ ,  $P = 0.03$ ), satisfaction with *Information Giving* was low in male ( $z_{mwu} = -2.13$ ,  $P = 0.03$ ) and unmarried caregivers ( $z_{mwu} = -2.26$ ,  $P = 0.02$ ) of the cancer patients.

## Discussion

The process of care-giving affects the daily life of family members who care for cancer patients, is associated with physiological, social and economic changes in the caregivers and has a negative effect on their QOL [23].

Therefore, assessment of the QOL and satisfaction with patient care of family members caring for a cancer patient has considerable importance [23]. Several instruments have been used to assess the QOL and satisfaction with care of the cancer family caregivers [14, 21–25]. However, cultural adaptation is necessary for translated instruments that are dependent on the cultural characteristics of the caregivers. The purpose of this study was to assess the psychometric validation of the Quality of Life (Family Version) and FAMCARE scales for assessing the QOL and satisfaction with care of the Turkish family caregivers of cancer patients. Compared to results in the original studies

**Table 5** Factor analysis of Quality of Life (Family Version) Scale ( $n = 100$ )

Factors in the four-way analysis	F1''	F1	F2	F3	F4	$h^2$
Psychological well-being subscale						
7. How good is your overall quality of life?	0.40	0.54				0.32
8. How much happiness do you feel?	<b>0.68</b>	<b>0.74</b>				0.65
9. Do you feel like you are in control of things in your life?	0.40	0.51				0.31
10. How satisfying is your life?	<b>0.57</b>	<b>0.74</b>				0.58
11. How is your present ability to concentrate or to remember things?	0.41	<b>0.67</b>				0.52
12. How useful do you feel?		0.50				0.33
17. How much depression do you have?	0.57	0.41				0.35
21. Rate your overall psychological well being?	0.56	<b>0.74</b>				0.59
35. Do you have a purpose/mission for your life or a reason for being alive?	0.33	<b>0.65</b>				0.47
36. How hopeful do you feel?	0.59	<b>0.68</b>				0.53
37. Rate your overall spiritual well being?	<b>0.62</b>	<b>0.72</b>				0.59
Family concerns subscale						
13. How distressing was your family member's initial diagnosis for you?	0.41		<b>0.60</b>			0.46
14. How distressing was your family member's cancer treatment for you?	0.42		<b>0.72</b>			0.55
15. How distressing has the time been since your family member's treatment ended?	0.59	0.33	0.45			0.38
16. How much anxiety do you have?	<b>0.66</b>		<b>0.62</b>			0.54
18. Are you fearful of a second cancer of your family member?	0.59		<b>0.75</b>			0.61
19. Are you fearful of recurrence of your family member's cancer?	<b>0.61</b>		<b>0.81</b>			0.71
20. Are you fearful of the spreading (metastasis) of your family member's cancer?	0.50		<b>0.75</b>			0.58
22. How distressing has your family member's illness been for your family?	0.45		0.50			0.29
33. How much uncertainty do you feel about your family member's future?	0.59		0.52			0.41
Physical well-being subscale						
1. Fatigue	<b>0.65</b>	0.37		<b>0.67</b>		0.66
2. Appetite changes	0.39			<b>0.79</b>		0.65
3. Pain or aches	0.39			<b>0.83</b>		0.71
4. Sleep changes	0.46			<b>0.74</b>		0.61
Social well-being subscale						
24. To what degree has your family member's illness or treatment interfered with your personal relationships?					<b>0.61</b>	0.43
25. To what degree has your family member's illness or treatment interfered with your sexuality?					0.51	0.26
26. To what degree has your family member's illness or treatment interfered with your employment?	0.37				0.53	0.32
27. To what degree has your family member's illness or treatment interfered with your activities at home?	0.49				<b>0.77</b>	0.66
28. How much isolation is caused by your family member's illness or treatment?	0.47				<b>0.63</b>	0.47
29. How much financial burden is caused by your family member's illness or treatment?	0.50			0.40	0.43	0.46
Eigenvalues, initial		25.13	11.89	7.38	6.01	
Eigenvalues, rotation		16.57	14.71	10.09	9.04	
Variance explained						50.43%

Values given in bold are high factor loadings ( $>0.60$ )

Extraction method: principal component factoring with Kaiser's criterion; rotation: Varimax with Kaiser normalization

$F1''$  Factor loadings for the first factor in the initial (unrotated) solution; F1, F2, F3, F4, factor loadings for rotated solution,  $h^2$ , communalities—the proportion of the variance in each item which is explained by the factors

[15, 16], this study revealed that both the order of the factor loading and content of the subscales in the two scales were affected by the cultural characteristics of the caregivers.

The rotated solution for the FAMCARE Scale, which was performed as in the Kristjanson study [15], did not support the results of the original study. The names of the



**Table 6** Description, inter-item correlations ( $r_s$ ) and Cronbach  $\alpha$  values of the Quality of Life (Family Version) Scale ( $n = 100$ )

Quality of Life (Family Version) Scale	$\bar{x}$	Median	$\pm$ Standard deviation	Subscale score		Total scale score	
				$r_s$	$P$	$r_s$	$P$
Psychological well-being subscale	<b>5.89</b>	<b>6.09</b>	<b>1.95</b>				
7. How good is your overall quality of life?	5.36	5.00	2.46	0.48	0.0001	0.27	0.008
8. How much happiness do you feel?	4.81	5.00	2.96	0.78	0.0001	0.57	0.0001
9. Do you feel like you are in control of things in your life?	4.90	5.00	3.56	0.55	0.0001	0.32	0.001
10. How satisfying is your life?	5.50	6.00	3.26	0.73	0.0001	0.47	0.0001
11. How is your present ability to concentrate or to remember things?	5.73	6.00	3.08	0.62	0.0001	0.32	0.001
12. How useful do you feel?	7.42	8.00	2.50	0.47	0.0001	0.23	0.02
17. How much depression do you have?	5.81	6.00	3.50	0.53	0.0001	0.53	0.0001
21. Rate your overall psychological well being?	5.20	5.00	3.04	0.75	0.0001	0.45	0.0001
35. Do you have a purpose/mission for your life or a reason for being alive?	8.28	10.00	2.64	0.46	0.0001	0.23	0.02
36. How hopeful do you feel?	5.99	6.00	3.15	0.68	0.0001	0.44	0.0001
37. Rate your overall spiritual well being?	5.88	6.50	2.90	0.74	0.0001	0.50	0.0001
$\alpha$				<b>0.86</b>			
Family concerns subscale	<b>1.79</b>	<b>1.33</b>	<b>1.73</b>				
13. How distressing was your family member's initial diagnosis for you?	1.03	0.00	2.22	0.57	0.0001	0.29	0.004
14. How distressing was your family member's cancer treatment for you?	1.29	0.00	2.14	0.58	0.0001	0.37	0.0001
15. How distressing has the time been since your family member's treatment ended?	2.78	2.00	2.48	0.62	0.0001	0.52	0.0001
16. How much anxiety do you have?	2.32	1.00	2.80	0.74	0.0001	0.60	0.0001
18. Are you fearful of a second cancer of your family member?	2.04	0.50	2.91	0.68	0.0001	0.46	0.0001
19. Are you fearful of recurrence of your family member's cancer?	1.64	0.00	2.65	0.74	0.0001	0.54	0.0001
20. Are you fearful of the spreading (metastasis) of your family member's cancer?	1.41	0.00	2.53	0.65	0.0001	0.36	0.0001
22. How distressing has your family member's illness been for your family?	1.15	0.00	2.06	0.65	0.0001	0.38	0.0001
33. How much uncertainty do you feel about your family member's future?	2.48	2.00	2.80	0.74	0.0001	0.49	0.0001
$\alpha$				<b>0.84</b>			
Physical well-being subscale	<b>5.11</b>	<b>5.00</b>	<b>3.04</b>				
1. Fatigue	5.10	5.00	3.65	0.78	0.0001	0.78	0.0001
2. Appetite changes	5.44	5.50	3.84	0.81	0.0001	0.55	0.0001
3. Pain or aches	5.25	6.00	3.91	0.82	0.0001	0.56	0.0001
4. Sleep changes	4.67	5.00	3.68	0.79	0.0001	0.61	0.0001
$\alpha$				<b>0.82</b>			
Social well-being subscale	<b>4.27</b>	<b>4.16</b>	<b>2.17</b>				
24. To what degree has your family member's illness or treatment interfered with your personal relationships?	4.06	3.00	3.25	0.61	0.0001	0.32	0.001
25. To what degree has your family member's illness or treatment interfered with your sexuality?	4.59	5.00	3.47	0.49	0.0001	0.29	0.004
26. To what degree has your family member's illness or treatment interfered with your employment?	4.51	5.00	3.46	0.57	0.0001	0.41	0.0001
27. To what degree has your family member's illness or treatment interfered with your activities at home?	4.14	4.00	3.25	0.82	0.0001	0.54	0.0001
28. How much isolation is caused by your family member's illness or treatment?	4.85	4.00	3.78	0.71	0.0001	0.47	0.0001
29. How much financial burden is caused by your family member's illness or treatment?	3.49	3.00	4.85	0.58	0.0001	0.57	0.0001
$\alpha$				<b>0.70</b>			
Total quality of life	<b>4.27</b>	<b>4.17</b>	<b>1.59</b>				
$\alpha$						<b>0.88</b>	

Values given in bold are high factor loadings (>0.60)

$r_s$  Spearman's rank correlation coefficient

subgroups of the FAMCARE scale were changed depending on the items placed in each subgroup. The Cronbach alpha correlation coefficient for scale and subscales in the culturally adapted FAMCARE scale was high, but in light of the eigen values of this scale, it was decided that a one-dimensional scale might be formed from the 20 items with satisfactory reliability, which support the conclusion drawn by other researchers [21, 24].

The construct validity of the Quality of Life Scale (Family Version) was confirmed in the study performed by Lu et al. [22], but both the order of the factor loading and the content of the subscales were affected in our study. Low factor loading was found for items 5, 6, 23, 30, 31, 32 and 34, suggesting that these seven items are not really measuring the QOL of the caregivers because of the protective and tolerant attitude of the caregivers toward the disease. Therefore, these items were removed from the scale and the name of the subscales was changed. On the other hand, this result explains a fatalistic mentality and the cohesive effect of the disease on family members, which are all prevailing characteristics of Turkish society.

Earlier studies involving Turkish caregivers [23, 26] and the results of this study reveal that most caregivers are women, although on occasion the care of patients may require the involvement of both men and women to meet the wide range needs of the cancer patient. While the number male caregivers is increasing, it is still traditionally women who fulfill the traditional role of providing care for patients. In developed and developing countries, as well as in Turkey, with the effect of cultural factors, the role of caregiving is assumed predominantly by women.

In accordance with findings from earlier research [2, 5, 10, 25], the caregivers were “satisfied” with hospital care, and family concerns were the most negatively affected dimensions of the QOL in our study. However, other factors affecting the quality of life and satisfaction with care in this study were age, co-residence, relationship to patient, gender of the patients and caregivers, stage of the disease of the patient and marital status of the caregivers.

Psychological well-being was lower in caregivers who were caring for male patients and who were living in the same house with his/her patient. Several studies have shown that, over time, providing care has a pronounced effect on caregiver’s psychological well-being [27]. Caring for an ill or disabled family member can cause substantial stress and often results in psychosocial difficulties for the caregiver [2, 28].

Physical well-being was lower in caregivers of the patient who had stage I disease. Providing care for cancer patients affects a caregiver’s physical well-being. Many caregivers experience disrupted sleep or a lack of sleep, severe fatigue, lack of rest time and physical problems [27, 29–31].

The QOL of the parents’ caregivers was lower in all domains except for social well-being. Family members often assume the role of primary caregivers of cancer patients following their discharge from hospital. Providing cancer care brings a unique and specific type of stress, which can be markedly different from that associated with caring for persons with other types of illnesses. This is due in part to the perceived threat of mortality associated with a cancer diagnosis and its treatment [32].

A significant positive correlation was found among caregivers’ age and satisfaction with care for *Information Giving, Availability of Care* and total satisfaction with care. While the caregivers of the metastatic cancer patients reported significantly lower satisfaction with *Availability of the doctor*, satisfaction with *Information Giving* was low in male and unmarried caregivers. Family caregivers often become active members of the healthcare team, with little or no preparation, sometimes under sudden and extreme circumstances. These family members frequently lack the requisite resources or skills to undertake their new and complex role, which may include assistance with activities of daily living, wound care, administration of medicine and financial and psychological support [28]. Services that provide care that promotes family or caregiver satisfaction can minimize this potential burden.

#### Implications for nursing

The results of this study confirmed the validity and reliability of Turkish version of the Quality of Life (Family Version) and the FAMCARE scales for the assessment of QOL of family caregivers and their satisfaction with care. These scales will facilitate the support of family caregivers in Turkey with the aim of improving the QOL of caregivers and their satisfaction with care.

#### Limitations and recommendations

Although the study recruited caregivers from a single oncology hospital, the Istanbul University Institute of Oncology receives patients from all areas of Turkey, and the participants in the study were representative of Turkish cultural characteristics. However, our study has several limitations. One of the most obvious limitations of this study is that a minimum of 100 subjects “rule” was used for psychometric evaluation of the scales depending on the number of items in each scale and the number of patients each year who received chemotherapy in our hospital. Another limitation may be the “mixing” of caregivers who care for patients with a different cancer diagnosis or treatment. In future studies, the cancer diagnosis of the patient and type of the treatment need to be specified to be able to obtain more information on the relationship of the

factors affecting caregivers QOL and their satisfaction with care.

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