Psycho-Oncology
Psycho-Oncology **25**: 217–224 (2016)
DOI: 10.1002/pon.3904

Factors associated with quality of life among family caregivers of terminally ill cancer patients

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Received: 11 March 2015
Revised: 23 May 2015
Accepted: 15 June 2015

Abstract

***Objective*: Limited research has examined the quality of life (QOL) and its correlates among family caregivers (FCs) during the final stage of terminal cancer. The purpose of this study was to investigate the determinants of overall QOL and its subdomains among Korean FCs at the very end of life.**

***Methods*: For this cross-sectional study, we enrolled 299 FCs of terminal cancer patients from seven palliative care units. To assess FCs' QOL and its predictors, we used the Caregiver Quality Of Life Index-Cancer, which contains four domains. Possible determinants of caregiver QOL were categorized into patient, caregiver, and environmental factors. A multiple regression model was used to identify factors associated with FCs' QOL.**

***Results*: Variance in each Caregiver Quality Of Life Index-Cancer domain was explained by different factors. FCs of younger patient felt more burden but were more likely to adapt positively. Emotional distress of FCs was strongly associated with total QOL, burdensomeness, and disruptiveness. Positive adaptation was related to more visits for care, FCs' religiousness, more social support, and satisfactory perceived quality of care. Financial concerns were more likely in married FCs, FCs with less social support, or low incomes.**

***Conclusion*: Emotional distress of FCs was the most important factor determining the overall and negative aspects of FCs' QOL, whereas various environmental factors were associated with positive coping. Appropriate support programs directed at these factors are needed to maintain and improve FCs' QOL.**

Introduction

Cancer has an enormous impact not only on patients but also on their family caregivers (FCs) [1]. A substantial body of research has documented that providing care for cancer patients can influence the emotional, social, and physical well-being of FCs [2,3] and often results in reduced quality of life (QOL), even more so than caring for individuals with other chronic illnesses [4]. It is essential to preserve the QOL of FCs because their negative experiences may compromise their ability to provide care [5].

Caregivers' distress and QOL are significantly affected by the patient's stage of illness [2]. Caring for terminally ill cancer patients may pose particularly substantial burdens on FCs because they must face the impending death of a loved one, as well as the patient's dramatically worsening condition [6]. FCs of palliative care patients have generally reported lower QOL than those caring for curative-phase patients [7]. Many studies have attempted to identify the determinants or factors associated with QOL of FCs of cancer patients, but most have focused on earlier stages of cancer or have not considered any specific phase [3,8,9]. Phase-specific research will help clinicians identify FCs at high risk for untoward consequences, so they can be offered timely support [10].

Few studies have directly addressed the QOL of FCs of patients during the terminal phase of cancer. Limited research has been conducted in Western countries, but it did not include populations from other cultures [11]. The cancer experience is embedded within cultural characteristics [12]. The Confucian culture of 'filial piety' encourages Koreans to feel obliged to care for their terminally ill family members themselves; FCs strive to meet cultural expectations of providing dedicated care [13]. Among studies in Asian cultures, some researchers did not consider strong potential confounders, such as depression or anxiety [14,15]. Additionally, there has been no consideration of individual QOL domains, despite evidence suggesting that different aspects of QOL have different determinants [16].

As some interventions exist for improving FCs' QOL [17], it is necessary to fully identify the factors associated with their QOL. Using a validated measure of QOL with a relatively large sample size, we comprehensively evaluated variables suggested as predictors in previous studies [2,18,19]. We categorized these variables into patient, caregiver, and environmental factors (Figure 1) and examined the associations between these factors and FCs' QOL, both overall and for each domain.

Methods

Study design and subjects

A cross-sectional survey was conducted at seven medical centers in Korea during 2014. Study approval was obtained from the institutional review board at each center. We identified consecutive terminally ill cancer patients hospitalized in each palliative care unit. Eligible patients were chosen by palliative care physicians and given information regarding the study. All patients signed written informed consent and were required to identify their primary FC, defined as the person who provided the most informal care and who was ≥20 years old, able to complete the questionnaire and communicate with the interviewer, and willing to participate.

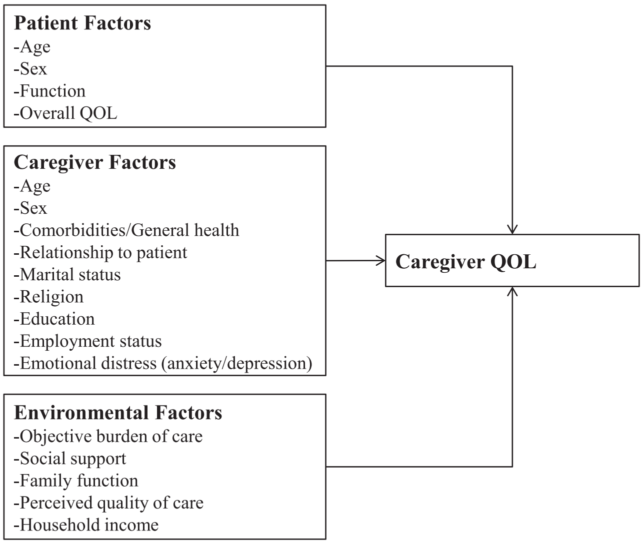

Figure 1. Conceptual framework for studying quality of life of family caregivers of terminal cancer patients. The model is based on the hypothesis that environmental factors, plus caregiver factors and patient factors, are associated with quality of life (QOL) of family caregivers of terminal cancer patients

A trained research assistant explained the study to eligible participants and was responsible for collecting data. We identified 332 eligible FCs. Of those, 29 FCs were excluded because they declined to participate; the most common reason was an 'uncomfortable' feeling or lack of interest. The FCs completed the self-administered questionnaire with the assistance of an interviewer, if necessary (e.g., they had low visual acuity or another disability). The interviewer reviewed the responses and asked the respondents to complete the missing items, if present. The final percentage of missing items was <2%. Data from 299 pairs of patients and FCs were included in the final analysis.

Measures

Outcome variable

To assess FCs' QOL, we used the Korean version of the Caregiver QOL Index-Cancer (CQOLC) [20]. CQOLC consists of 35 items, each rated on a five-point Likert scale (0 = *not at all* to 4 = *very much*). Ten items pertain to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns, and eight to additional factors (sleep disruption, satisfaction with sexual functioning, day-to-day focus, mental strain, information about the illness, patient protection, management of patient's pain, and family interest in caregiving) [8]. A total score was obtained by adding all item scores, and domain scores were calculated by adding the item scores for each domain. The maximal total score was 140, with higher scores reflecting a better QOL. In this study, its Cronbach's alpha coefficient was 0.892.

Independent variables

Patient information was collected, such as age, sex, and functional status (assessed using the European Cooperative Oncology Group Performance Status, an observer-rated scale of physical ability ranging from 0 to 4). The overall patient QOL was measured using the global item from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 for Palliative Care [21], which is a validated instrument for hospice patients. This item has seven response options.

The FC survey contained questions about variables selected from previous QOL models: demographic characteristics (age, sex, marital status, employment status, religiousness, and educational level), relationship to the patient, general health status (five-point Likert response from *excellent* to *poor*), comorbidities (e.g., cancer or endocrine, vascular, pulmonary, musculoskeletal, or dental disease), and emotional distress. Questionnaires also queried environmental factors, such as household income, perceived social support, family function, perceived quality of care, and objective burden of care (hours per day and days per week).

Emotional distress was assessed using the Hospital Anxiety and Depression Scale (HADS), which has been extensively validated in Korean populations [22]. HADS is composed of two subscales to assess depression and anxiety in the prior week: seven items for depression and seven for anxiety. Each subscale is scored from 0 to 21, with higher scores indicating more severe depression or anxiety. Scores were categorized as normal (0–7), mild (8–10), moderate (11–14), and severe (15–21). In this study, the Cronbach's alphas for depression and anxiety were 0.835 and 0.853, respectively.

The Korean version of the Medical Outcome Study Social Support Survey (MOS-SSS) was used to assess social support systems [23]. MOS-SSS consists of 19 items rated on a five-point Likert from 1 to 5. After transforming the total score into a 0–100 scale, subjects were classified into two groups according to the median value of the current sample: 'high support' or 'low support'. In this study, its Cronbach's alpha was 0.973.

Family function was assessed using the Korean version of the family Adaptation, Partnership, Growth, Affection, and Resolve [24]. This instrument has five items relating to adaptation, partnership, growth, affection, and resolve. Each item is scored on a three-point scale (0 = *hardly ever*, 1 = *sometimes*, and 2 = *almost always*). The total score, ranging from 0 to 10, was obtained by totaling the each item scores. It was graded as 0–3 (severely dysfunctional), 4–6 (moderately dysfunctional), and 7–10 (highly functional). In this study, its Cronbach's alpha was 0.880.

Quality of care was measured using the Korean version of the Quality Care Questionnaire-End of Life [25], which is a brief, validated, self-reported, and cancer-specific measure of quality of care. The Quality Care Questionnaire-End of Life contains 16 items and is scored on a four-point Likert-type scale, with a higher score indicating a higher perceived quality of care. Using the median total score in the current sample, we formed two categories: 'satisfied' or 'unsatisfied'. In this study, its Cronbach's alpha was 0.874.

Other variables were classified into two groups, as appropriate, based on their distribution in the current FC sample (Table 1). 'Other' marital status included single, divorced, separated, and widowed options; the question regarding religion included non-Catholic Christian, Buddhist, Catholic, and 'others' option; and the relationship to patient option included spouse, child, parent, or daughter-in-law.

Statistical analysis

Comparisons of CQOLC scores by characteristics were assessed using a linear regression analysis. Univariate analyses were performed to test differences in the CQOLC total and each domain score across categorical variables. Variables significantly associated with CQOLC scores during univariate analysis were included in the final multivariate regression model. The data were analyzed using STATA SE 9 (STATA Corp., TX, USA). All levels of significance were set at $p < 0.05$ and two-sided.

Results

Characteristics of participants

Table 1 lists patient and FC characteristics. The performance of most patients (73.3%) was poor (European Cooperative Oncology Group Performance Status ≥3), and their overall QOL was 36.8 (0–100 scale). Most caregivers were female (74.6%) and the patient's spouse (41.1%). The mean HADS score was 11.0 for anxiety and 8.0 for depression. According to Adaptation, Partnership, Growth, Affection, and Resolve scores, 153 families (51.7%) were highly functional, 107 (36.2%) were moderately dysfunctional, and 36 (12.2%) were severely dysfunctional. On average, FCs provided care 15.9 h per day and 5.6 days per week.

Univariate analysis

Table 2 presents hospital-adjusted CQOLC total and domain scores across variables. Among patient factors, patient age was the only factor associated with the FCs' QOL. Emotional distress was the caregiver factor most strongly associated with the overall and domain CQOLC scores, except for the positive adaptation domain. Associations were also noted between overall and/or domain CQOLC scores and other caregiver factors, including age, marital status, religiousness, and relationship to the patient. Several environmental factors, including objective burden of care, social support level, family function, satisfaction with care, and monthly household income, were also associated with the total or various CQOLC domain scores.

Factors associated with FC QOL in multivariate analysis

Factors related to caregiver QOL were identified using multivariate regression analysis (Table 3). FCs of younger patients felt more burdensomeness but were more likely to adapt positively, compared with FCs of elderly patients. Emotionally distressed caregivers exhibited poorer overall QOL, felt more burden, and experienced more disruption: these results were related to the degree of emotional distress. Positive adaptation was associated with various environmental factors: more frequent visits, religiousness, more social support, or being satisfied with the current care. Married FCs and FCs with less social support or low income were more likely to report financial problems.

Table 1. Characteristics of 299 patient–caregiver pairs

		Range	
Variables	**Mean ± SD or *N* (%)**	**Interquartile**	**Possible**
Patient factors			
Age (years)	62.9 ± 12.3	55–72	
Sex (male)	171 (57.2)		
Performance status (ECOG)			0–4
1	10 (3.3)		
2	70 (23.4)		
3	162 (54.2)		
4	57 (19.1)		
Overall QOL (EORTC QLQ-C15-PAL)	36.8 ± 23.4	17–50	0–100
Caregiver factors			
Age (years)	49.1 ± 13.7	40–60	
Sex (male)	74 (25.4)		
Marital status (married)	244 (82.2)		
Current job (yes)	110 (37.3)		
Religious (yes)	175 (60.8)		
Education (≥college)	135 (45.6)		
General health status (good)	97 (32.7)		
Number of comorbidities			
0	130 (43.5)		
1	84 (28.1)		
≥2	85 (28.4)		
Relationship to patient[a] (spouse)	118 (41.1)		
Emotional distress (HADS score)			
Anxiety	11.0 ± 4.4	8–14	0–21
Depression	8.0 ± 4.2	5–10	0–21
Quality of life (CQOLC score)			
Total	68.6 ± 17.2	57–80	0–140
Burdensomeness	17.8 ± 8.1	12–24	0–40
Disruptiveness	14.2 ± 5.4	10–18	0–28
Positive adaptation	14.1 ± 4.8	11–17	0–28
Financial concerns	7.3 ± 3.1	5–10	0–12
Environmental factors			
Monthly household income (KW ≤ 2 000 000)	149 (53.0)		
Social support (MOS-SSS total)	73.8 ± 16.1	60–85	0–100
Family function (APGAR score)	6.7 ± 2.7	5–10	0–10
Quality of care (QCQ-EOL total)	23.1 ± 7.7	18–28	0–48
Hours spent caregiving (per day)	15.9 ± 8.7	7–24	0–24
Days visiting for caregiving (per week)	5.6 ± 1.8	5–7	0–7

ECOG, Eastern Cooperative Oncology Group; QOL, quality of life; EORTC QLQ-C15-PAL, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 for Palliative Care; KW, Korean Won; HADS, Hospital Anxiety and Depression Scale; CQOLC, Caregiver Quality of Life Index-Cancer; MOS-SSS, Medical Outcome Study Social Support Survey; APGAR, Adaptation, Partnership, Growth, Affection, and Resolve; QCQ-EOL, Quality Care Questionnaire-End of Life; SD standard deviation.

[a] Non-spousal caregivers were children, parents, and daughters-in-law of the patients.

Discussion

Considering QOL in a culture- and phase-specific manner, we performed a detailed analysis to identify factors associated with Korean FCs' QOL. At the very end of life, different factors may contribute to different domains of FCs' QOL. We found that emotional distress of the FC was the strongest determinant of overall and negative aspects of QOL, whereas positive coping was related to various environmental factors. To our knowledge, no previous multi-dimensional studies have evaluated the QOL of FCs of terminally ill cancer patients, especially in Asian cultures. A longitudinal study by Tang and colleagues [18] focused on the fluctuation of FCs' QOL and highlighted the coherence among various predictors. However, that study was performed in a general medical unit setting and did not evaluate potential confounders such as FCs' emotional distress. A comprehensive understanding of factors that influence FCs' QOL allows palliative care providers to target interventions toward vulnerable caregivers, potentially reducing the risk of poor outcomes.

Korean FCs are under the double torture of natural duty and financial burden. Strong blood relationship makes them take care of ill family members by themselves, and there is a substantial pressure from relatives who are not primary caregivers [26]. Sharing of caregiving within family is also getting more difficult because of decreased family size in Korea. In addition, caregiving in Korea is not

Table 2. Quality of life scores of family caregivers according to patient, caregiver, and environmental characteristics

Characteristics	Total	Burdensomeness	Disruptiveness	Positive adaptation	Financial concerns
Patient factors					
Age[a]					
≥65 years	69.5 ± 1.5	**19.1 ± 0.7**	14.1 ± 0.5	**13.4 ± 0.4**	7.5 ± 0.3
<65 years	67.7 ± 1.4	**16.6 ± 0.6**	14.3 ± 0.4	**14.7 ± 0.4**	7.1 ± 0.2
Sex					
Male	68.2 ± 1.4	17.8 ± 0.6	14.1 ± 0.4	14.2 ± 0.4	7.2 ± 0.2
Female	68.9 ± 1.6	17.7 ± 0.7	14.5 ± 0.5	14.0 ± 0.4	7.3 ± 0.3
ECOG PS					
0–2	70.6 ± 2.0	18.0 ± 0.9	15.0 ± 0.6	13.9 ± 0.5	7.4 ± 0.4
3–4	67.8 ± 1.2	17.7 ± 0.5	14.0 ± 0.4	14.2 ± 0.3	7.2 ± 0.2
Overall QOL[b]					
Non-problematic	68.6 ± 1.3	17.9 ± 0.6	14.4 ± 0.4	13.9 ± 0.3	7.2 ± 0.2
Problematic	68.4 ± 1.8	17.4 ± 0.8	13.9 ± 0.6	14.5 ± 0.5	7.4 ± 0.3
Caregiver factors					
Age[a]					
<50 years	**70.9 ± 1.5**	18.1 ± 0.7	**14.9 ± 0.5**	14.3 ± 0.4	7.2 ± 0.3
≥50 years	**66.6 ± 1.4**	17.5 ± 0.6	**13.7 ± 0.4**	14.0 ± 0.4	7.3 ± 0.2
Sex					
Male	69.7 ± 2.0	18.9 ± 0.9	14.5 ± 0.6	13.5 ± 0.6	6.9 ± 0.4
Female	68.3 ± 1.2	17.4 ± 0.6	14.2 ± 0.4	14.3 ± 0.3	7.4 ± 0.2
Marital status					
Married	68.4 ± 1.1	17.5 ± 0.5	14.2 ± 0.3	**14.4 ± 0.3**	**7.5 ± 0.2**
Other	69.2 ± 2.4	19.0 ± 1.1	14.5 ± 0.8	**12.7 ± 0.7**	**6.3 ± 0.4**
Employment status					
Unemployed	67.3 ± 1.3	17.3 ± 0.6	14.0 ± 0.4	14.3 ± 0.4	7.4 ± 0.2
Employed	70.6 ± 1.7	18.6 ± 0.8	14.8 ± 0.5	13.6 ± 0.5	7.1 ± 0.3
Religious					
Non-professing	68.2 ± 1.7	18.1 ± 0.7	14.7 ± 0.5	**13.1 ± 0.4**	7.3 ± 0.3
Professing	68.9 ± 1.3	17.5 ± 0.6	14.0 ± 0.4	**14.8 ± 0.4**	7.3 ± 0.2
Education					
≤High school	66.4 ± 1.4	17.2 ± 0.6	13.8 ± 0.4	14.1 ± 0.4	7.1 ± 0.2
≥College	70.6 ± 1.5	18.4 ± 0.7	14.7 ± 0.5	14.0 ± 0.4	7.4 ± 0.3
General health status					
Good	71.9 ± 1.8	18.8 ± 0.8	15.1 ± 0.5	14.6 ± 0.5	7.5 ± 0.3
Not good	66.9 ± 1.3	17.2 ± 0.6	13.8 ± 0.4	13.9 ± 0.3	7.2 ± 0.2
Presence of comorbidity					
Yes	67.4 ± 1.4	17.1 ± 0.6	14.0 ± 0.4	14.3 ± 0.4	7.2 ± 0.2
No	69.9 ± 1.5	18.7 ± 0.7	14.6 ± 0.5	13.9 ± 0.4	7.3 ± 0.3
Relationship to patient					
Spouse	**65.7 ± 1.7**	**16.5 ± 0.7**	14.1 ± 0.5	13.8 ± 0.5	7.2 ± 0.3
Other	**70.7 ± 1.4**	**18.7 ± 0.6**	14.4 ± 0.4	14.3 ± 0.4	7.3 ± 0.2
Anxiety level (HADS score)					
Normal (0–7)	**82.6 ± 1.5**	**23.9 ± 0.7**	**17.1 ± 0.5**	14.5 ± 0.5	**8.3 ± 0.3**
Mild (8–10)	**73.4 ± 0.9**	**19.9 ± 0.5**	**15.3 ± 0.3**	14.2 ± 0.3	**7.6 ± 0.2**
Moderate (11–14)	**64.2 ± 0.9**	**16.0 ± 0.4**	**13.4 ± 0.3**	13.8 ± 0.3	**7.0 ± 0.2**
Severe (15–21)	**54.9 ± 1.4**	**12.0 ± 0.7**	**11.6 ± 0.5**	13.5 ± 0.4	**6.3 ± 0.3**
Depression level (HADS score)					
Normal (0–7)	**76.3 ± 1.2**	**21.0 ± 0.5**	**15.8 ± 0.4**	14.2 ± 0.4	**7.9 ± 0.2**
Mild (8–10)	**67.5 ± 0.9**	**17.3 ± 0.4**	**14.0 ± 0.3**	14.1 ± 0.3	**7.2 ± 0.2**
Moderate (11–14)	**58.7 ± 1.3**	**13.5 ± 0.6**	**12.1 ± 0.5**	14.0 ± 0.4	**6.5 ± 0.3**
Severe (15–21)	**49.9 ± 2.1**	**9.8 ± 1.0**	**10.3 ± 0.7**	13.9 ± 0.7	**5.7 ± 0.4**
Environmental factors					
Visits for caregiving per week[c]					
≤5 days	**71.3 ± 1.7**	**20.0 ± 0.8**	**15.2 ± 0.5**	**13.0 ± 0.5**	7.4 ± 0.3
>5 days	**66.8 ± 1.3**	**16.5 ± 0.6**	**13.7 ± 0.4**	**14.8 ± 0.4**	7.2 ± 0.2
Time spent caregiving per day[c]					
≤8 h	**73.6 ± 1.9**	**20.1 ± 0.9**	**15.8 ± 0.6**	13.5 ± 0.5	7.6 ± 0.3
>8 h	**66.4 ± 1.2**	**16.8 ± 0.5**	**13.6 ± 0.4**	14.3 ± 0.3	7.1 ± 0.2
Level of social support[a]					
High	**72.5 ± 1.4**	18.3 ± 0.6	**15.0 ± 0.4**	**15.0 ± 0.4**	**8.0 ± 0.2**
Low	**63.9 ± 1.5**	17.1 ± 0.7	**13.3 ± 0.5**	**13.1 ± 0.4**	**6.3 ± 0.3**

(Continues)

Table 2. *(Continued)*

Characteristics	Total	Burdensomeness	Disruptiveness	Positive adaptation	Financial concerns
Family function					
Highly functional	**72.1 ± 1.3**	18.5 ± 0.6	**14.9 ± 0.4**	**14.9 ± 0.4**	**8.0 ± 0.2**
Moderate dysfunctional	**66.3 ± 1.2**	17.3 ± 0.5	**13.8 ± 0.4**	**13.6 ± 0.3**	**6.8 ± 0.2**
Severely dysfunctional	**60.4 ± 2.3**	16.2 ± 1.1	**12.8 ± 0.7**	**12.2 ± 0.6**	**5.5 ± 0.4**
Satisfaction with quality of care[a]					
High	**71.3 ± 1.5**	17.3 ± 0.7	14.8 ± 0.5	**15.5 ± 0.4**	**7.7 ± 0.3**
Low	**66.3 ± 1.4**	18.2 ± 0.6	13.8 ± 0.4	**12.9 ± 0.4**	**6.9 ± 0.2**
Monthly income					
<2 million KW	67.6 ± 1.4	17.6 ± 0.7	13.6 ± 0.4	14.4 ± 0.4	**6.7 ± 0.3**
≥2 million KW	69.8 ± 1.5	18.2 ± 0.7	14.8 ± 0.5	13.5 ± 0.4	**7.8 ± 0.3**

Data are mean ± standard error.

ECOG PS, Eastern Cooperative Oncology Group Performance Status; KW, Korean Won; HADS, Hospital Anxiety and Depression Scale.

$p < 0.05$ values are in bold; p values were obtained using a hospital-adjusted regression model.

[a] Classified according to median value in current sample.

[b] Classified according to cutoff score for adequate functioning in European Organization for Research and Treatment of Cancer manual (≥33 on a 0–100 scale).

[c] Classified according to first quartile in current sample.

Table 3. Factors associated with caregivers' quality of life

	Regression coefficient (standard error)[a]				
Variables	**Total**	**Burdensomeness**	**Disruptiveness**	**Positive adaptation**	**Financial concerns**
Younger patient (*vs.* ≥65 years)		−1.76 (0.84)		1.10 (0.54)	
Depressed caregiver (*vs.* normal)					
Mild	−4.71 (2.29)				
Moderate	−9.08 (3.16)	−3.39 (1.54)			
Severe	−10.03 (3.87)	−4.79 (1.90)	−3.19 (1.42)		
Anxious caregiver (*versus* normal)					
Mild	−7.35 (2.55)				
Moderate	−13.74 (2.73)	−5.86 (1.30)	−2.62 (0.96)		
Severe	−19.51 (3.52)	−7.64 (1.72)	−2.85 (1.27)		
Caregiver's religiousness (*versus* no professed religion)				1.17 (0.56)	
More visits for caregiving (*vs.* <5 days/week)				1.38 (0.57)	
More social support	3.75 (1.86)			1.28 (0.55)	1.14 (0.39)
Satisfactory care				2.24 (0.55)	
Low household income					−0.79 (0.36)
Married caregiver					−1.00 (0.48)
R^2	0.42	0.32	0.17	0.17	0.21

[a] Using a multivariate regression model with adjustment for significant ($p < 0.05$) variables during univariate analyses.

reimbursed by the National Health Insurance [27]; hospitals require to keeping at least one FC or paid informal caregiver. Quitting a job to care for the patient increases financial problem, which has been reported to influence QOL in Korean FCs [8].

Compared with previously reported scores for FCs of terminally ill cancer patients, which ranged from 54.8 to 77.1 on a 0–100 scale [18,28,29], our mean score of 49.0 is clearly lower. This discrepancy is likely primarily explained by the much shorter survival time (18 days) in palliative care units in Korea [30], as all institutions were subsidized by the Korean government. Investigations have consistently shown significant deterioration of FCs' QOL as a patient's death approaches [18], and Korean FCs often remain with their family members in the hospital for a long time, without proper resting areas or other facilities. Although Korean FCs seem to have lower QOL than their non-Korean counterparts [31], it is unclear whether this is due to characteristics of Koreans *per se* or other factors, such as limited services in Korea.

Various factors found to be predictors of negative aspects of FC QOL in previous studies (FC's age, relationship to patient, objective burden of care, and family function) did not remain significant predictors during multivariate analysis in the current study. This may be because taking care of patients had a different meaning to FCs in our study. At the very end of life, providing care is no longer perceived as a never-ending job, and FCs may realize that this is their last chance to be helpful, thus encouraging them to be more willing to provide time and energy to their loved ones. However, emotional distress of FCs remained a firm predictor of the overall and negative aspects of QOL [32]. Mental health can be easily assessed using a brief self-rating instrument such as HADS, and information should be provided to FCs regarding services for emotional support.

In contrast to other domains, positive adaptation was affected by several factors but was not influenced by emotional distress. This might be because FCs were less likely to suffer psychological distress when they adapted positively [3]. Targeting positive aspects of QOL may be integral in helping FCs maintain their QOL. Some intervention studies have noted encouraging results reporting more positive appraisal of caregiving [33] and improved FCs' QOL [34]. Identifying FCs with lower positive coping can help professionals determine who may benefit most from such interventions.

Besides religiousness of FCs, we identified other potentially modifiable factors associated with positive adaptation during the last phase of cancer care. Accumulating evidence supports the supposition that positive coping is more likely in FCs with greater social support [14] and satisfaction with the provided care [35]. Our findings illustrate that, even at the very end of life, adequate social support is important to help FCs maintain positivity and well-being.

We were surprised that more frequent visits, not more time spent, for caregiving was correlated with positive adaptation. Generally, FCs in Asian culture value sharing time with their dying family members and feel satisfaction with completing their filial duty [13]. Being with the patient also allows FCs more opportunity to interact with the patient or physician, which allows them to become more aware of the patient's prognosis. Our findings are consistent with those of recent research demonstrating that Korean FCs who felt a higher 'disrupted schedule' reported higher positivity [36]. Thus, when introducing respite care that might reduce caregiver burden, a proxy caregiver should not replace the number of FC visits.

Paradoxically, we found that FCs of younger patients felt more burden but were more likely to cope positively. As younger cancer patients have better physical function than older patients, previous studies reported that their caregivers demonstrated a better QOL and fewer mood disturbances [37]. However, this is not necessarily true, at least in the terminal phase of cancer. When we analyzed further, we found that FCs of younger patients visited patients more frequently ($p = 0.001$) (not shown in Table): these might lead to more burdensomeness. On the other hand, non-disclosure of disease information or prognosis is common in East Asia [38], at least partly because of the intention of preventing patients from becoming upset. Pressure about revealing and facing a younger patient's impending death can be particularly stressful for family members; however, it is often easier to conduct an open dialog with younger patients, even more if they share much time. Continuous and clear communications are needed to enhance the psychological well-being of FCs and to help patients adjust.

This study has limitations. For example, its cross-sectional design only allows the identification of associations between variables and does not permit definitive statements about causality. Other variables (i.e., family impact [8] or coping strategies [39]) previously proposed to be associated with caregivers' QOL were not included. To confirm the associations identified in the present study, further research with a longitudinal design and consideration of additional factors should be performed. Furthermore, our participants might not represent the general population of FCs of Korean terminal cancer patients. We evaluated FCs of inpatients in palliative care units within tertiary medical centers, but many more Korean patients do not receive any hospice services [40]. Furthermore, because we included pairs in which the patient was able to consent to the study and the FC was able to complete the survey, our FCs may have had less psychological deterioration than other FCs of terminal cancer patients. This may have underestimated the impact of various factors on QOL.

As the suffering of FCs does not necessarily end with the patient's death and can extend into the bereavement stage, maintaining FCs' QOL at the very end of life is important. We identified relevant factors, which are potential targets of intervention strategies, related to FCs' QOL at the end of life in the context of various dimensions. To improve the QOL of FCs providing end-of-life cancer care, palliative care providers should screen for emotional distress within FCs and focus on environmental factors that may enhance positive adaptation.

Acknowledgements

This study was supported by a Mundipharma Korea Grant of the Korean Society for Hospice and Palliative Care.

Conflict of interest

No financial or other conflict of interest was involved in this study. None of the funding sources had any role in designing and conducting the study.

References

1. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology* 2010;**19**(10):1013–1025.
2. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 2008;**112**(11 Suppl):2556–2568.
3. Rhee YS, Yun YH, Park S *et al.* Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. *J Clin Oncol* 2008;**26**(36):5890–5895.
4. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health* 2008;**20**(5):483–503.

DOI: 10.1002/pon

5. Northouse L, Williams AL, Given B, McCorkle R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncol* 2012;**30**(11):1227–1234.
6. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: “they don’t know what they don’t know”. *JAMA* 2004;**291**(4):483–491.
7. Grunfeld E, Coyle D, Whelan T *et al.* Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 2004;**170**(12):1795–1801.
8. Yun YH, Rhee YS, Kang IO *et al.* Economic burdens and quality of life of family caregivers of cancer patients. *Oncology* 2005;**68**(2-3):107–114.
9. Northouse LL, Mood D, Kershaw T *et al.* Quality of life of women with recurrent breast cancer and their family members. *J Clin Oncol* 2002;**20**(19):4050–4064.
10. DuBenske LL, Wen KY, Gustafson DH *et al.* Caregivers’ differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care* 2008;**6**(3):265–272.
11. Tang WR. Hospice family caregivers’ quality of life. *J Clin Nurs* 2009;**18**(18):2563–2572.
12. Surbone A, Baider L, Weitzman TS *et al.* Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Support Care Cancer* 2010;**18**(2):255–263.
13. Kong EH. The influence of culture on the experiences of Korean, Korean American, and Caucasian-American family caregivers of frail older adults: a literature review. *Taehan Kanho Hakhoe Chi* 2007;**37**(2):213–220.
14. Leow MQ, Chan MF, Chan SW. Predictors of change in quality of life of family caregivers of patients near the end of life with advanced cancer. *Cancer Nurs* 2014;**37**(5):391–400.
15. Jung JG, Kim JS, Kim SS *et al.* Quality of life among family caregivers of terminal cancer patient. *Korean J Hosp Palliat Care* 2005;**9**(1):1–10.
16. Carver CS, Smith RG, Petronis VM, Antoni MH. Quality of life among long-term survivors of breast cancer: different types of antecedents predict different classes of outcomes. *Psycho-Oncology* 2006;**15**(9):749–758.
17. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010;**60**(5):317–339.
18. Tang ST, Li CY, Chen CC. Trajectory and determinants of the quality of life of family caregivers of terminally ill cancer patients in Taiwan. *Qual Life Res* 2008;**17**(3):387–395.
19. Son KY, Lee CH, Park SM *et al.* The factors associated with the quality of life of the spouse caregivers of patients with cancer: a cross-sectional study. *J Palliat Med* 2012;**15**(2):216–224.
20. Rhee YS, Shin DO, Lee KM *et al.* Korean version of the caregiver quality of life index-cancer (CQOLC-K). *Qual Life Res* 2005;**14**(3):899–904.
21. Lee YJ, Suh SY, Choi YS *et al.* EORTC QLQ-C15-PAL quality of life score as a prognostic indicator of survival in patients with far advanced cancer. *Support Care Cancer* 2014;**22**(7):1941–1948.
22. Oh SM, Min KJ, Park DB. A study on the standardization of the Hospital Anxiety and Depression Scale for Koreans: a comparison of normal, depressed and anxious groups. *J Korean Neuropsychiatr Assoc* 1999;**38**:289–296.
23. Lim MK, Kim MH, Shin YJ, Yoo WW, Yang BM. Social support and self-rated health status in a low income neighborhood of Seoul. *Korea Korean J Prev Med* 2003;**36**(1):54–62.
24. Yun BB, Kwak KW. The study of family APGAR score as the evaluation method of the family function. *J Korean Acad Fam Med* 1985;**6**(12):13–17.
25. Yun YH, Kim SH, Lee KM *et al.* Patient-reported assessment of quality care at end of life: development and validation of Quality Care Questionnaire-End of Life (QCQ-EOL). *Eur J Cancer* 2006;**42**(14):2310–2317.
26. Lee EE, Farran CJ. Depression among Korean, Korean American, and Caucasian American family caregivers. *J Transcult Nurs* 2004;**15**(1):18–25.
27. Moon TJ. Light and shadows of the Korean healthcare system. *J Korean Med Sci* 2012;**27**(Suppl):S3–S6.
28. McMillan SC. Quality of life of primary caregivers of hospice patients with cancer. *Cancer Pract* 1996;**4**(4):191–198.
29. Grov EK, Dahl AA, Fossa SD, Wahl AK, Moum T. Global quality of life in primary caregivers of patients with cancer in palliative phase staying at home. *Support Care Cancer* 2006;**14**(9):943–951.
30. Baek YJ, Shin DW, Choi JY *et al.* Late referral to palliative care services in Korea. *J Pain Symptom Manage* 2011;**41**(4):692–699.
31. Weitzner MA, Jacobsen PB, Wagner H Jr, Friedland J, Cox C. The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Qual Life Res* 1999;**8**(1-2):55–63.
32. Grov EK, Dahl AA, Moum T, Fossa SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005;**16**(7):1185–1191.
33. Northouse L, Kershaw T, Mood D, Schafenacker A. Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psycho-Oncology* 2005;**14**(6):478–491.
34. McMillan SC, Small BJ, Weitzner M *et al.* Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 2006;**106**(1):214–222.
35. Morishita M, Kamibeppu K. Quality of life and satisfaction with care among family caregivers of patients with recurrent or metastasized digestive cancer requiring palliative care. *Support Care Cancer* 2014;**22**(10):2687–2696.
36. Park CH, Shin DW, Choi JY *et al.* Determinants of the burden and positivity of family caregivers of terminally ill cancer patients in Korea. *Psycho-Oncology* 2012;**21**(3):282–290.
37. Shahi V, Lapid MI, Kung S, *et al.* Do age and quality of life of patients with cancer influence quality of life of the caregiver? *J Geriatr Oncol* 2014;**5**(3):331–336.
38. Yun YH, Kwon YC, Lee MK *et al.* Experiences and attitudes of patients with terminal cancer and their family caregivers toward the disclosure of terminal illness. *J Clin Oncol* 2010;**28**(11):1950–1957.
39. Benzein EG, Berg AC. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. *Palliat Med* 2005;**19**(3):234–240.
40. Jang SI, Cho KH, Kim SJ, Lee KS, Park EC. Setting a health policy research agenda for controlling cancer burden in Korea. *Cancer Res Treat* 2015;**47**(2):149–157.