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Trajectory and determinants of the quality of life of family caregivers of terminally ill cancer patients in Taiwan

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Abstract

Background Family caregiving is common and important in Taiwanese culture. However, the combination of anticipated loss, prolonged psychological distress, and the physical demands of caregiving can seriously compromise the quality of life (QOL) of a family caregiver (FC). The effect of caring for a dying cancer patient on a FC's QOL has been explored in western countries—primarily with small sample sizes or short-term follow-ups—but has not yet been investigated in Taiwan. Therefore, the purposes of this study were to: (1) identify the trajectory of the QOL of FCs of terminally ill cancer patients in Taiwan; and (2) investigate the determinants of the QOL of FCs, in a large sample and with longer follow-ups, until the patient dies.

Methods A prospective, longitudinal study was conducted among 167 FCs. Trajectory and determinants of FCs' QOL were identified by a generalized estimation equation (GEE).

Results Caregiving for a terminally ill cancer patient extracts a toll from a FC's QOL and causes it to deteriorate significantly over time. The results from the multivariate GEE analysis indicated that this deterioration of a FC's QOL reflects the patient's increasing distress from symptoms, the gradual loss of confidence in caregiving and an increased subjective caregiving burden on the FC as the patient's death approaches, and a weaker psychological resource (i.e., sense of coherence) of the FC.

Conclusion Taiwanese FCs' QOL deteriorated significantly as the patient's death approached. This study contributes to the family caregiving literature by using longitudinal data to confirm that the available psychological resource of a FC and the 'appraisals of caregiving' are more salient in determining a FC's QOL than the patient's/FC's characteristics and the caregiving demands.

Keywords End-of-life care · Family caregiving · Quality of life · Sense of coherence · Terminally ill cancer patients

Introduction

A recent national survey [1] in the United States of America indicated that family caregivers (FCs) provide care to approximately three-quarters of the chronically disabled elderly in their last year of life. In Taiwan, due to the Confucian idea of filial piety and the traditional caregiving ideology, family caregiving is an important and integral element; it is commonly practiced because the Taiwanese see it as a repayment to their parents or family members. Cancer has been the leading cause of death in

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Taiwan since 1982 and accounted for 28.1% of total deaths in 2006 [2]. Statistics show that nearly 90% of dependent and chronically ill (including terminally ill cancer) patients in Taiwan receive care from their family members [3]. The statistics for the USA and Taiwan underscore the considerable influence that families exert on end-of-life care in both Western and Eastern cultures. Their involvement also represents an important conceptual dimension of what constitutes a good death [4, 5].

Decades of research on the effects of family caregiving to chronically disabled patients has documented that being a FC is stressful and has deleterious consequences for FCs. Caregiving responsibilities generate competing demands that make FCs vulnerable to physical diseases and psychological distress, which hinder their social engagement [6–8] and extend into the bereavement stage, with difficulties in adjustment and increased morbidity and mortality [9, 10]. Therefore, intense caregiving is subject to a variety of public health concerns [11]. It is in the interest of both public health and fiscal solvency that the caregiving burden experienced by FCs is reduced.

The combination of anticipated loss, prolonged psychological distress, and the physical demands of caregiving can seriously compromise FCs' quality of life (QOL) when they provide end-of-life care to a terminally ill cancer patient [1, 12–14]. Such negative impact on QOL may increase over time [15]. While the QOL of FCs is important in its own right, it is also integral to the dying patient's well-being. If the informal networks become too stressed, homecare arrangements may collapse and may result in institutionalization of patients [16, 17] and death at a hospital or nursing home, which is generally not what the patient wishes [18].

The effects of caring for a dying cancer relative on a FC's QOL has moved to the forefront in recent years [19] and has been explored in western countries [12–15]. However, it has not yet been investigated in Taiwan. Furthermore, Kitrungrote and Cohen [20] have indicated that one of the insufficiencies in research on the QOL of cancer patients' FCs is a lack of longitudinal research. Among the 28 studies reviewed, 18 assessed the QOL of FCs only once. Cross-sectional design may not capture the fluctuations of care tasks, caregiving burden, FCs' psychological distress, and the impact of caregiving on the FC's QOL as the patient's disease progresses and death approaches. Even among the researchers who had aimed at investigating the longitudinal change pattern of the QOL of FCs who provide end-of-life care to cancer patients, they used either a small sample size ($N < 60$) [14, 15, 21, 22] or a short-term (1 month) follow-up design [22–24]. Family caregivers may be physically and psychologically robust initially, but they become exhausted when the patient's death approaches. Caregiving experiences at the very end of a patient's life may be more important in deciding the degree of FCs' QOL than what was measured earlier.

In addition, research which investigates the determinants of the QOL of FCs who provide care to patients at their end of life rarely uses a comprehensive approach to incorporate the four categories of factors suggested by researchers [19, 25, 26]: (1) contextual factors, (2) caregiving demands, (3) available psychological and social resources, and (4) appraisals of the caregiving situation. The literature indicates that psychological resources play a prominent role in deciding the effects of caregiving on a FC's QOL because inner strength can channel the experiences that one encounters [26, 27]. Furthermore, a cognitive appraisal of the stressful situation, which is based on the assessment of balance between demands and resources available and the FC's efficacy of coping with the situation as perceived by the individual, is key to understanding the effects of stressors on an individual's well-being [27]. Antonovsky [28] found that people can experience an inner sense of coherence (SOC) despite extremely pressing circumstances, such as providing care to a loved one at his or her end of life. In this study, SOC is assumed to be an important aspect of FCs' psychological resources that can help them cope with and meet the challenges of caregiving for a loved one at the end of life and determine the outcomes of that caregiving. If FCs can find meaning in caregiving, clearly comprehend the demands imposed by caregiving, and perceive that the necessary resources for fulfilling these demands are adequately at their disposal, then the probability of a positive caregiving outcome will be high (i.e., a better QOL).

Therefore, the purposes of this prospective, longitudinal study were to: (1) identify the trajectory of FCs' QOL of terminally ill cancer patients in Taiwan; and (2) investigate the roles of the four aforementioned categories of factors in determining the QOL of a FC in a large sample and continue following the FCs until the patient dies. If there is a clear understanding of the QOL experienced by FCs' as cancer patients approach death, and a fuller appreciation of the detrimental effects that caregiving challenges are likely to have on FCs' QOL, adequate and appropriate healthcare resources can be allocated and effective interventions may be initiated to improve the QOL of FCs when they provide important services to their loved one and society.

Methods

Study design and sample

From March 2005 to October 2006, a prospective, longitudinal study was conducted at the general medical inpatient units of three medical centers and two regional teaching hospitals in northwestern Taiwan in order to fulfill the aims of this study. A convenience sample of FCs was recruited. The eligibility criteria were that they had to be a family member who: (1) had a relative with terminal stage cancer as judged by the patient's physician; (2) were identified by the patient as the person most involved with their actual care; (3) were 21 years of age or older; (4) were willing to participate and could communicate with the data collectors. The research ethics committees of the study sites approved the research protocol. Written informed consent was obtained from all FCs.

Measurements

Outcome variable

The QOL of FCs was measured with the Caregiver Quality of Life Index-Cancer (CQOLC) [29]. The CQOLC consists of 35 items and uses a five-point scale that ranges from 0 (not at all) to 4 (very much) to measure the effect of the illness of cancer patients and caregiving on FCs' physical, emotional, social, and family functioning. Potential scores of the CQOLC range from 0 to 140, with higher scores indicating a better QOL. The CQOLC had extensive psychometric support in a number of samples for acceptable internal consistency, content validity, convergent and discriminant validity, known groups, and concurrent validity [30]. The Cronbach's alpha for the CQOLC in this study was 0.91.

Independent variables

The rationale for the selection of variables is primarily conceptual [25, 26] and empirical [19–21, 25] in nature.

(1) *Contextual factors: Characteristics of FCs* included gender, age, whether they were the patient's spouse, and whether they had any chronic diseases.
Demographic and disease-related characteristics of patients included age, length of survival since diagnosis, and comorbidities. Family-perceived patient symptom distress was measured by the Symptom Distress Scale (SDS) [31], an instrument that assesses 13 common symptoms of cancer patients. Each symptom is ranked on a scale that ranges from 1 (normal or no distress) to 5 (extensive distress). The total score ranges from 13 to 65, with higher scores indicating a greater level of distress (Cronbach's alpha = 0.85 in this study).

(2) *Caregiving demands* referred to care tasks and level of care. Care tasks and level of care were measured by the amount of assistance provided in personal care, homemaking, transportation, and health care, as determined by Emanuel et al. [32]. Family caregivers were asked to rate the amount of assistance they provided to the patients in each of these four categories on a 4-point scale that ranged from "none at all" to "a lot". A composite score for the intensity of total assistance provided was computed by summing the scores of those four items, with a range from 4 to 16 (Cronbach's alpha = 0.87 in this study).

(3) *Psychological resources:* Antonovsky's SOC scale [28] was used to measure FCs' psychological resources. Respondents were asked to select a response on a seven-point semantic differential scale with two anchoring phrases on 13 items. Sample items of the SOC scale include: "How often do you have the feeling that there's little meaning in the things you do in your daily life?"; "Do you have the feeling that you are in an unfamiliar situation and don't know what to do?"; and "How often do you have feelings that you're not sure you can keep under control?". The total score ranges from 13 to 91, with higher scores indicating a stronger SOC. Internal consistency and its construct validity were well established [33]. Cronbach's alpha was 0.88 in this study.

(4) *Appraisal of the caregiving situation:* the appraisal was measured by the degree of the FC's confidence in caregiving and the extent of subjective caregiving burden they perceived.
Confidence in caregiving was measured by the three items developed by Teno et al. [34]. These three items measure how confident the FC's perception is of what to expect while the patient is dying, what to do at the time of the patient's death, and how to take care of the patient at home. Each item was measured on a 3-point scale (1 = not at all confident, 2 = fairly confident, 3 = very confident). A composite score for confidence in caregiving was computed by summing the scores of those three items (Cronbach's alpha = 0.85).
Perceived subjective caregiving burden was measured by the Caregiver Reaction Assessment (CRA) [35]. The CRA includes both negative and positive dimensions of caregiving reactions. The self-esteem subscale measures the positive aspect derived from caregiving and assesses whether providing care was rewarding (i.e., I will never be able to do enough caregiving to repay my ill family member; I feel privileged to care for my ill family member). The schedule subscale assesses the impact of providing care on the FCs' usual activities, including whether providing care has forced them to eliminate activities and if providing care has interfered with relaxation. The support subscale measures the ability of the family to support the FC and to

work together in the care situation, and it also measures the FC's perception of being abandoned by other family members. The other dimensions of the CRA include how caregiving affects the health and financial situation of the FC. For the scoring of the CRA, the data were transposed prior to data analysis where necessary, so that a score of "1" always indicated the least and "5" the most *negative* impact of caregiving on each item. For each subscale, a total score was computed as the average of the subsequent item scores. In this study, the Cronbach's alphas for the subscales ranged from 0.68 to 0.85.

All instruments used in our study were translated into Chinese through a cyclic process of forward translations, back translations, and expert evaluation of equivalence by bilingual and English speaking experts, and was validated by the principal investigator's previous studies [36, 37].

Data collection

Primary physicians at each study site were given a detailed explanation regarding the purpose of the study and were asked to identify terminally ill cancer patients. After the eligibility criteria of the FCs had been verified, the purposes and procedures of our study were explained to potential subjects by Master's- or Doctoral level oncology nurses who were not involved in the clinical care of the terminally ill cancer patients or their FCs, so that coercion to participate or participation due to social desirability would be avoided. All data collectors were trained in the recruitment of subjects and in conducting interviews through small group sessions and were individually coached by the principal investigator and two senior project managers. Potential subjects were invited to participate in this study with the understanding that participation was voluntary and that declining to participate would not impact on their ill relative's future medical care.

After the FCs had agreed to participate, they were initially interviewed prior to the patients' discharge from the hospital. Since the SOC generally has been recognized as a stable trait of an individual [33], the characteristics of the FCs, the demographic and disease-related characteristics of the patients, and the SOC were measured at the initial interview only. The other variables were re-assessed at a 2-week interval until the death of the patient by personal interviews.

Statistical analysis

Data were first descriptively analyzed so that the distribution of all study variables could be checked. To compare the QOL scores measured by different QOL instruments across the published studies, we constructed a proportional score of 100 for each of the QOL instruments, to represent a perfect QOL, while a score of 0 meant the QOL was abysmal. To explore the trajectory of the FCs' QOL, we determined the proximity in time to the patient's death as the period between the time of the patient's death and the day that the interview was conducted. To illustrate graphically the change of mean scores on the Caregiver Quality of Life Index-Cancer scale, we further categorized the proximity in time to the patient's death into 1–30 days, 31–90 days, 91–180 days, and >181 days as conventionally used in the estimation of survival for terminally ill cancer patients [38, 39].

We analyzed the proximity in time to the patient's death as a continuous variable to assess its association with the QOL scores, using a generalized estimation equation (GEE) [40]. The GEE uses robust standard error estimates to take into account within-subject correlations of the QOL scores during the follow-up period. The unequal numbers of follow-up assessments among study subjects was taken into consideration in the GEE analysis because the GEE model used the information obtained from each assessment as the analytical unit. In addition to using the traditional *P* value to judge statistical significances of differences in QOL scores measured at different time points, we treated a change of approximately 5% to 10% or more of the total score of a QOL scale over time as a perceptible change, or minimal clinical important difference, as suggested by Osoba et al. [41]. *P* values indicate the likelihood that the difference occurred by chance. Clinically important difference goes beyond statistical significance to decide whether the statistically significant difference is large enough to have implications for clinical care [42].

The GEE was also used to assess the significance of the crude association between the QOL scores and the selected independent variables individually. Those variables that were significantly associated with the QOL scores in the bivariate analyses were further included in a multivariate GEE to assess their independent associations with the QOL scores. For each significant predictor of the QOL scores, an interaction term of the proximity in time to the patient's death with that predictor was fitted into the GEE to assess whether the magnitude of the association of the QOL scores with that significant predictor remained constant over time during the observation period.

Results

Sample description

A total of 253 FCs of terminally ill cancer patients was recruited. Of them, 47 (18.5%) did not complete follow-ups due to various reasons, i.e., too busy in providing care or participation in the study was perceived as too demanding. There were 167 FCs whose ill relative died during the study period, and 39 FCs remained active in participation in this study on 31 October 2006. Hereafter, this report is only concentrated on the 167 deceased patients' FCs. In general, no significant differences were found in any of the independent variables, nor in the QOL scores measured at the initial interview between the deceased patients' FCs and those who did not complete the follow-ups. However, the FCs who did not complete the follow-ups perceived that their ill relative suffered from less symptom distress (mean ± SD = 27.80 ± 7.96 vs. 32.16 ± 7.66, respectively, $P = 0.0006$) and that they provided less assistance in personal care (mean ± SD = 2.67 ± 1.03 vs. 3.08 ± 0.92, $P = 0.007$).

The majority of FCs were female (68.3%), married (88.6%), the patient's spouse (41.9%) or an adult child (32.9%), living with the patient (74.9%), and with an educational level equal to or higher than high school (57.8%). The mean age of the FCs was 50.3 years. One-third ($N = 55$, 33.1%) of the FCs had a chronic disease such as hypertension (29.6%), diabetes (7.2%), gastric ulcer (6.0%) or heart disease (4.2%).

Two-thirds of the patients (62.9%) were male. The mean age of the patients was 65.0 years. The most common diagnoses among the patients were lung cancer (30.5%), hepatoma (16.2%), colon–rectal cancer (15.0%), gastric cancer (7.8%), and hematological malignancies (7.2%). Of the patients, 60.5% had additional chronic diseases other than the cancer. On average, the patients had been diagnosed 18.66 ± 18.13 months previously (range 1–69 months, median 13 months). The mean length of patients' survival after the FCs' enrollment into this study was 98.05 ± 92.75 (range 2–409, median 64) days, and, on average, the FCs were interviewed 5.78 ± 3.90 (range 1–25, median 5.0) times.

Trajectory of the QOL of family caregivers of terminally ill cancer patients

The result of the simple GEE analysis indicated that the further away the time was from the death of the patient, the better the Caregiver Quality of Life Index-Cancer scores (Table 1). In other words, the FCs' QOL deteriorated as the patient's death approached. Figure 1 illustrates the change in mean scores of the FCs' QOL over time. The mean

Table 1 Association between the quality of life scores and the selected independent variables in bivariate analyses

Potential predictors	Parameter	SE	*Z*	*P*
Proximity in time to the patient's death	0.03	0.01	2.49	0.0127
Characteristics of the family caregiver				
Gender (female = 1; male = 0)	−6.81	2.71	−2.51	0.0120
Spousal relationship with the patient (yes = 1; no = 0)	−1.86	2.65	−0.70	0.4825
With any chronic diseases (yes = 1; no = 0)	−0.89	3.00	−0.30	0.7662
Age	−0.02	0.10	−0.15	0.8804
Demographic and disease-related characteristics of the patient				
Age	−0.02	0.11	−0.20	0.8447
Length of survival after diagnosis	0.03	0.01	2.18	0.0296
With any additional chronic diseases other than the cancer (yes = 1; no = 0)	−1.43	2.84	−0.51	0.6129
Symptom Distress Scale total score	−1.22	0.13	−9.45	<0.0001
Caregiving demands				
Intensity of total assistance provided	−1.81	0.35	−5.19	<0.0001
Psychological resources				
Sense of Coherence total score	0.54	0.08	7.12	<0.0001
Appraisals of caregiving				
Confidence in caregiving	3.86	0.84	4.58	<0.0001
Subjective caregiving burden (subscale score on the Caregiving Reaction Assessment scale)				
ESTEEM	−1.61	0.31	−5.16	<0.0001
HEALTH	−3.51	0.28	−12.62	<0.0001
SCHEDULE	−2.98	0.23	−12.87	<0.0001
FINANCE	−3.52	0.33	−10.82	<0.0001
SUPPORT	−2.46	0.17	−14.61	<0.0001

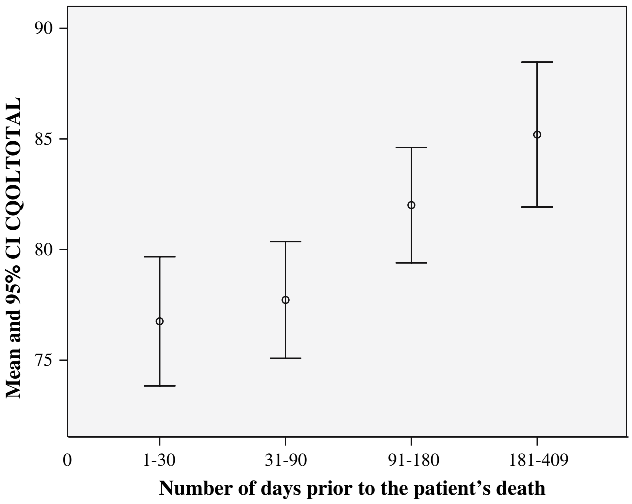

Fig. 1 The pattern of change in quality of life scores during the patient's dying process for family caregivers of Taiwanese terminally ill cancer patients

scores (SD) on the Caregiver Quality of Life Index-Cancer measured 1–30 days, 31–90 days, 91–180 days, and >181 days prior to the patient's death were 76.76 (23.38), 77.72 (23.23), 82.01 (20.99), and 85.19 (20.69), respectively. This result showed a significant linear trend of increase in the mean QOL scores ($Z = 2.49$, $P = 0.01$) away from the time of the patient's death. The constructed proportional scores of the QOL measured at different time points ranged from 54.8 to 60.9. A 6.1% increase in the Caregiver Quality of Life Index-Cancer total scores was found between what was measured 1–30 days prior to the patient's death and that measured >181 days prior to the patient's death.

Determinants of the QOL of family caregivers of terminally ill cancer patients

The results of bivariate analyses of the associations between the QOL scores and the independent variables are presented in Table 1. Only the gender of the FC, the length of survival after diagnosis, the extent of symptom distress of the patient, the intensity of total assistance provided, the strength of the FC's SOC, the confidence in caregiving, and the subjective caregiving burden were identified to be significantly associated with the degree of QOL reported by the FC.

The variables that showed significant associations with the QOL scores in bivariate analyses were fitted into a multivariate GEE model. The results are shown in Table 2. Seven factors remained significant in association with the QOL scores among FCs, but the proximity in time to the patient's death was no longer significant in predicting a FC's QOL. Family caregivers experienced a poorer QOL if they reported that their ill relative experienced a higher degree of symptom distress and indicated that they endured a greater negative impact of caregiving on their own health, daily schedule, finance, and family support. In contrast, FCs enjoyed a better QOL if they expressed more confidence in providing end-of-life care to their ill relative and reported a greater strength of SOC. Assessments of the

Table 2 Multivariate analyses of determinants for quality of life among family caregivers

Potential predictors	Parameter	SE	*Z*	*P*
Proximity in time to the patient's death	−0.0003	0.0065	−0.0400	0.9688
Characteristics of the family caregiver				
Gender (female = 1; male = 0)	0.9314	1.9235	0.4800	0.6282
Demographic and disease-related variables of the patient				
Length of survival after diagnosis	−0.0109	0.0090	−1.2100	0.2261
Symptom Distress Scale total score	−0.7216	0.1175	−6.1400	<0.0001
Caregiving demands				
Intensity of total assistance provided	−0.0679	0.2114	−0.3200	0.748
Psychological resources				
Sense of Coherence total score	0.2016	0.0587	3.4300	0.0006
Appraisals of caregiving				
Confidence in caregiving	2.1493	0.4910	4.3800	<0.0001
Subjective caregiving burden (subscale score on the Caregiving Reaction Assessment scale)				
ESTEEM	0.2425	0.2014	1.2000	0.2284
HEALTH	−1.0545	0.3417	−3.0900	0.002
SCHEDULE	−1.3419	0.2409	−5.5700	<0.0001
FINANCE	−0.8652	0.2963	−2.9200	0.0035
SUPPORT	−1.5551	0.1739	−8.9400	<0.0001

Table 3 Interactions between significant determinants and the proximity in time to the patient's death (DAY)

Significant determinants of quality of life	*P*
Symptom Distress Scale total score × DAY	0.8465
Sense of Coherence total score × DAY	0.6890
Confidence in caregiving × DAY	0.2070
HEALTH × DAY	0.1036
SCHEDULE × DAY	0.0917
FINANCE × DAY	0.1811
SUPPORT × DAY	0.0760

interactions between each of the seven identified determinants of the QOL scores and the proximity in time to the patient's death indicated that none of these factors significantly interacted with the proximity in time to the patient's death (Table 3). In another words, the independent effects of these seven significant determinants did not vary with the proximity in time to the patient's death.

Discussion

This study is the first to reveal that caregiving for terminally ill cancer patients in Taiwan takes a substantial toll on FCs' QOL, especially when the patient's death is imminent. The constructed proportional scores of QOL measured at different time points indicate that providing end-of-life care to an ill relative compromises a FC's QOL to score only at a moderate level (54.8–60.9 on a 0–100 scale). Compared to scores in the documented literature for FCs of terminally ill cancer patients (the constructed proportional QOL scores ranged from 54.8 to 77.1 on a 0–100 scale) [12–14, 21, 23, 43, 44], the scores from the current study are at the lowest end and are only higher than those reported by Sherman et al. [14] and Meyers and Gray [44] (54.8 and 60.0, respectively, on a 0–100 scale). In addition, contrary to the majority of findings from western countries, which reported that the QOL of hospice patients' FCs stays relatively stable, even close to the time of the patient's death [14, 21, 23], the QOL of Taiwanese FCs of terminally ill cancer patients deteriorated significantly over time (6.1% of deterioration). In the west, only Axelsson and Sjödén [15] from Sweden observed deterioration of a FC's QOL as the patient's death approached. These comparisons illustrate the plights of Taiwanese FCs of terminally ill cancer patients. By the criterion of Osoba et al. [41], the deterioration of Taiwanese FCs' QOL in this study was not only statistically but also clinically significant. In our study, the demands in caregiving increased substantially in the last 3 months of the patient's life (data not shown). As FCs provided more assistance to their terminally ill cancer patient, they increased their risk of being negatively affected by the caregiving. In our previous study [37], we found that Taiwanese FCs of terminally ill cancer patients were at an extraordinarily high risk of being afflicted by depressive symptoms (75.9% scored higher than 15 on the Center for Epidemiological Studies-Depression (CES-D) scale). The present study demonstrated that FCs are also vulnerable to a substantial decline in their QOL, especially when their ill relatives approach the very end of their lives. Although filial piety is considered the most important virtue in the Taiwanese culture, a price may need to be paid to uphold these traditional cultural values in today's socioeconomic climate. It is imperative for our society to recognize the negative impact of caregiving on FCs' QOL and to increase support for caregivers to offset the effects of caregiving stress.

The results from the multivariate analysis indicated that the deterioration of the FC's QOL over time is actually a reflection of the patient's increasing symptom distress, the gradual loss of confidence in caregiving and the increased subjective caregiver's burden as the patient's death approaches, as well as a weaker SOC of the FC. These results are generally inline with the findings in other cross-sectional studies. In the existing literature, researchers found a pattern: the lower the patient's symptom level, the higher the QOL of the FC [45, 46]. Researchers also suggested that if FCs know what to expect when they provides end-of-life care at home, their stress levels would decrease, thereby giving them a higher level of confidence in caregiving and, subsequently, a better QOL [46, 47]. In addition, as FCs perceive the degree to which caregiving has changed their various life domains (such as daily schedule, health, family support, and financial sufficiency in meeting the patient's medical care needs) for the worse, their subjective caregiving burden increases and their QOL decreases [12, 20, 48, 49]. In this study, the SOC construct reflects a FC's psychological resource to respond to stressful situations. From the systematic review of factors identified as important in determining a FC's QOL, Kitrungrote and Cohen [20] concluded that a FC's inner strength (such as self-efficacy) was positively related to his/her QOL. Although the impact of SOC on the QOL has not been explored in FCs of terminally ill cancer patients, our study contributes to the family caregiving literature by using longitudinal data to confirm the conclusion drawn from several systematic reviews [8, 25]: that the inner strength of a FC (i.e., the SOC) and the "appraisals of caregiving" are more salient in determining the caregiving outcomes than the patients' or caregivers' characteristics and the objective caregiving loads.

This study has several limitations that should be mentioned before the results can be fully applied: the representation of the targeted population may be compromised by the convenience sample used in this study; generalizability of the findings from this study may not apply to FCs of terminally ill cancer patients who receive care other than at the five study sites or who reside in other geographical areas. Nevertheless, the study sample largely resembled cancer patients who died in Taiwan in 2006 [2] in the distributions of gender, age, and disease categories, although patients with hematological malignancies were over-represented. In our study, the in-depth examination of the roles of the Taiwanese cultural norms for caregiving (such as upholding a sense of filial piety and the extent of commitment to the family), the quality of the patient–FC relationship prior to the cancer episode or the length of caregiving on the FCs' QOL was limited. In addition, concurrent caregiving responsibilities and previous losses or bereavement experiences of the FC were not measured either. This study only investigated the main effects of the SOC in determining the level of FCs' QOL. In future studies, the influence of the SOC and social resources (including the impact of the rapidly changing socio-cultural climate of modern Taiwan) toward caregiving on mediating the relationship between caregiving stressors and caregiving outcomes should also be taken into consideration. However, the determinants of a FC's QOL identified in this study give clues as to where interventions should be targeted. The effects of caregiving to terminally ill cancer patients on a FC's QOL may be tempered substantially through the individual's psychological strength and resilience. Therefore, successful improvement to FCs' QOL may be achieved by developing strategies that can enhance a FC's psychological resources, such as the SOC, to help them find meaning in caregiving, improve the understanding of the demands and challenges of caregiving, and make resources available to manage caregiving tasks. Healthcare providers should assist FCs to manage patients' symptom distress, which, in turn, may increase FCs' confidence in caregiving. Interventions that target the reduction of FCs' negative subjective caregiving burden should be implemented. In fact, recent research yielded exciting results regarding the effectiveness of interventions in successfully facilitating positive appraisals of caregiving [50] and improving the QOL of FCs over time [24, 51]. By enhancing the FCs' psychological resources (i.e., SOC), the burden of caregiving may be lightened, the negative impact of caregiving may be reduced, and an optimal quality of life for the FCs may be obtained.

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References

1. Wolff, J. L., Dy, S. M., Frick, K. D., & Kasper, J. D. (2007). End-of-life care: Findings from a national survey of informal caregivers. *Archives of Internal Medicine, 167*, 40–46.
2. Department of Health. (2007). Statistics of causes of death, volume I. http://www.doh.gov.tw/EN2006/DM/DM2_p01.aspx?class_no=390&now_fod_list_no=9256&level_no=2&doc_no=51991. Accessed 30 December 2007.
3. Ministry of Interior, Executive Yuan, R. O. C. (2003). Report on the Survey of Disabled Citizens' Life Status in Taiwan Area, Republic of China. Taipei, Taiwan. http://www.mor.gov.tw/stat. Accessed 12 April 2007.
4. Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association, 281*, 163–168.
5. Steinhauser, K. E., Christakis, N. A., Clip, E. C., McNealy, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association, 284*, 2476–2482.
6. Covinsky, K. E., Goldman, L., Cook, E. F., Oye, R., Desbiens, N., Reding, D., Fulkerson, W., Connors, A. F., Lynn, J., & Phillips, R. S. (1994). The impact of serious illness on patients' families. *Journal of the American Medical Association, 272*, 1839–1844.
7. Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H., Levine, C., & Gould, D. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affair*, *21*, 222–231.
8. Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer, 39*, 1517–1524.
9. Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a spouse. *New England Journal of Medicine, 354*, 719–730.
10. Schulz, R., Beach, S. R., & Lind, B. (2001). Involvement in caregiving and adjustment to death of a spouse: Findings from the caregiver health effects study. *Journal of the American Medical Association, 285*, 3123–3129.
11. Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*, 224–228.
12. Matthews, B. A., Baker, F., & Spillers, R. L. (2004). Family caregivers' quality of life: Influence of health protective stance and emotional strain. *Psychology and Health, 19*, 625–641.
13. Weitzner, M. A., McMillan, S. C., & Jacobsen, P. B. (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management, 17*, 418–428.
14. Sherman, D. W., Ye, X. Y., & McSherry, C. (2006). Quality of life of patients with advanced cancer and acquired immune deficiency syndrome and their family caregivers. *Journal of Palliative Medicine, 9*, 948–963.
15. Axelsson, B., & Sjödén, P. O. (1998). Quality of life of cancer patients and their spouses in palliative home care. *Palliative Medicine, 12*, 29–39.
16. Argimon, J. E., Limon, E., Vila, J., & Cabezas, C. (2005). Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. *Alzheimer Disease & Associated Disorders, 19*, 41–44.
17. Shyu, Y. I. L., Chen, M. C., & Lee, H. C. (2004). Caregiver's need as predictors of hospital readmission for the elderly in Taiwan. *Social Science and Medicine, 58*, 1395–1403.
18. Higginson, I. J., & Sen-Gupta, G. J. A. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine, 3*, 287–300.
19. Hebert, R. S., & Schulz, R. (2006). Caregiving at the end of life. *Journal of Palliative Medicine*, *9*, 1174–1186.
20. Kitrungrote, L., & Cohen, M. Z. (2006). Quality of life of family caregivers of patients with cancer: A literature review. *Oncology Nursing Forum, 33*, 625–632.

21. Gill, P., Kaur, J. S., Rummans, T., Novotny, P. J., & Sloan, J. A. (2003). The hospice patient's primary caregiver. What is their quality of life? *Journal of Psychosomatic Research, 55*(5), 445–51.
22. Smeenk, F. W., de Witte, L. P., van Haastregt, J. C., Schipper, R. M., Biezemans, H. P., & Crebolder, H. F. (1998). Transmural care of terminal cancer patients: Effects on the quality of life of direct caregivers. *Nursing Research, 47*, 129–136.
23. McMillan, S. C. (1996). Quality of life of primary caregivers of hospice patients with cancer. *Cancer Practice*, *4*, 191–198.
24. McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., & Haley, W. E. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer. *Cancer, 106*, 214–222.
25. Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. J., & van den Bos, G. A. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology, 7*, 3–13.
26. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*, 583–594.
27. Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Co.
28. Antonovsky, A. (1987). *Unraveling the mystery of health*. San Francisco: Jossey-Bass.
29. Weitzner, M. A., Jacobsen, P. B., Wagner, H. Jr., Friedland, J., & Cox, C. (1999). 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. *Quality of Life Research, 8*, 55–63.
30. Edwards, B., & Ung, L. (2002). Quality of life instruments for caregivers of patients with cancer: A review of their psychometric properties. *Cancer Nursing, 25*, 342–349.
31. McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing, 1*, 373–378.
32. Emanuel, E. J., Fairclough, D. L., Slutsman, J., Alpert, H., de Baldwin, W., & Emanuel, L. L. (1999). Assistance from family members, friends, paid care givers and volunteers in the care of terminally ill patients. *New England Journal of Medicine, 341*, 956–963.
33. Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: A systematic review. *Journal of Epidemiology and Community Health, 59*, 460–466.
34. Teno, J. M., Clarridge, B., & Casey, V. (2001). Validation of Toolkit after-death bereaved family member interview. *Journal of Pain and Symptom Management, 22*, 752–758.
35. Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health, 15*, 271–283.
36. Tang, S. T., & Dixon, J. (2002). Instrument translation and evaluation of equivalence and psychometric properties: The Chinese sense of coherence scale. *Journal of Nursing Measurement*, *10*, 59–76.
37. Tang, S. T., Li, C. Y., & Liao, Y. C. (2007). Factors associated with depressive distress among Taiwanese family caregivers of cancer patients at the end of life. *Palliative Medicine, 21*, 249–257.
38. Christakis, N. A., & Escarce, J. J. (1996). Survival of Medicare patients after enrollment in hospice programs. *New England Journal of Medicine, 335*(3), 172–178.
39. Good, P. D., Cavenagh, J., & Ravenscroft, P. J. (2004). Survival after enrollment in an Australian palliative care program. *Journal of Pain and Symptom Management, 27*, 310–315.
40. Burton, P., Gurrin, L., & Sly, P. (1998). Extending the simple linear regression model to account for correlated responses: An introduction to generalized estimating equations and multi-level mixed modeling. *Statistics in Medicine, 17*, 1261–1291.
41. Osoba, D., Bezjak, A., Brundage, M., Zee, B., Tu, D., & Pater, J. (2005). Quality of Life Committee of the NCIC CTG. Analysis and interpretation of health-related quality-of-life data from clinical trials: Basic approach of the National Cancer Institute of Canada Clinical Trials Group. *European Journal of Cancer, 41*, 280–287.
42. Sloan, J. A., Cella, D., Frost, M., Guyatt, G. H., Sprangers, M., & Symonds, T. (2002). Clinical significance consensus meeting group. Assessing clinical significance in measuring oncology patient quality of life: Introduction to the symposium, content overview, and definition of terms. *Mayo Clinic Proceedings, 77*, 367–370.
43. Grov, E. K., Dahl, A. A., Fosså, S. D., Wahl, A. K., & Moum, T. (2006). Global quality of life in primary caregivers of patients with cancer in palliative phase staying at home. *Supportive Care in Cancer, 14*, 943–951.
44. Meyers, J. L., & Gray, L. N. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncology Nursing Forum*, *28*, 73–82.
45. Markowitz, J. S., Gutterman, E. M., Sadik, K., & Papadopoulos, G. (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease & Associated Disorders, 17*(4), 209–214.
46. Northouse, L. L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., & Walker, J. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology, 20*, 4050–4064.
47. Yamamoto-Mitani, N., Ishigaki, K., Kuniyoshi, M., Kawahara-Maekawa, N., Hayashi, K., Hasegawa, K., & Sugishita, C. (2004). Subjective quality of life and positive appraisal of care among Japanese family caregivers of older adults. *Quality of Life Research*, *13*, 207–212.
48. Brouwe, W. B. F., van Exel, N. J. A., van Grop, B., & Redekop, W. K. (2006). The CarerQol instrument: A new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Quality of Life Research, 15*, 1005–1021.
49. McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke, 36*, 2181–2196.
50. Northouse, L., Kershaw, T., Mood, D., & Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psycho-Oncology, 14*, 478–491.
51. Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K. M., Lee, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine, 145*, 727–738.