

Association between Family Caregivers' Satisfaction with Care for Terminal Cancer Patients and Quality of Life of the Bereaved Family: A Prospective Pre- and Postloss Study

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Abstract

Background: The quality of life (QOL) of family caregivers often deteriorates after the death of patients with terminal cancer. Although previous retrospective cross-sectional studies of the bereaved family caregivers of cancer patients have suggested that lower satisfaction with care given to terminal cancer patients was related to lower QOL of the bereaved family caregivers, the retrospective cross-sectional study design has limitations.

Objectives: To clarify family caregivers' satisfaction with the care of terminal cancer patients and bereaved family caregivers' QOL.

Design: A prospective pre- and postloss study.

Setting/Subjects: Family caregivers of terminal cancer patients were recruited from three inpatient hospice/palliative care units in Japan.

Measurements: Family caregivers completed questionnaires, including the Family Satisfaction with Advanced Cancer Care (FAMCARE) scale before loss and the 36-item Short-Form Health Survey (SF-36) questionnaire before loss and six months after the patient's death.

Results: A total of 114 family caregivers were included in each analysis. After the patient's death, bereaved family caregivers' mental component summary score of SF-36 significantly differed between low- and high-satisfaction caregiver groups ($n=47$ in both groups, mean difference = 3.50, $p=0.048$). The proportion of family caregivers with depressive symptoms (moderate or worse) at preloss was 41% (25/61) in the low-satisfaction group and 22% (11/51) in the high-satisfaction group.

Conclusions: Family caregivers' satisfaction with the care provided to terminal cancer patients at the end of their lives was associated with the bereaved family caregivers' QOL six months postloss. Enhancing family caregivers' satisfaction with care has the potential to improve their postloss QOL.

Keywords: cancer and oncology; family caregiver; quality of life; satisfaction with care; terminal cancer

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Introduction

LOSING A FAMILY MEMBER owing to cancer causes tremendous psychological distress for the bereaved families. Factors such as emotional distress and many external adjustments required by the loss may cause lower quality of life (QOL) and poorer mental health than the general population.¹ About 10% of the bereaved family caregivers of cancer patient suffers from complicated grief and depressive symptoms.^{2,3} Psychological distress is associated with lower QOL among family caregivers of cancer patients.^{4,5} Family caregivers are the patients' partners/spouses, children, relatives, and friends who provide care, involving a substantial amount of time and a wide range of tasks.⁶ The deterioration of QOL and the high prevalence of depressive symptoms and complicated grief among bereaved family caregivers of cancer patients are social issues.

A growing body of research suggests that family caregivers' satisfaction with the care given to cancer patients during the terminal stage plays an important role in the caregiver's psychological status. Family caregivers' satisfaction with care has been found to be associated with the psychological distress and QOL of family caregivers before^{7,8} and after^{3,9} the patient's death. Large retrospective cross-sectional studies of the bereaved family caregivers of cancer patients have demonstrated that lower satisfaction with care was associated with increased prevalence of psychiatric disorders of bereaved family caregivers.⁹ However, there are limitations to the retrospective study designs. First, they cannot avoid recall bias. Recall bias has been shown to be negligible when an assessment is carried out within nine months of the death of the patient¹⁰ but the magnitude of recall bias when an assessment is conducted more than a year later is unknown. Second, because of the low response rate in these large retrospective studies (approximately 30%–67%),^{3,9} the study's internal validity is unclear, as the final sample may not be representative of the intended study population.

These limitations may be addressed through a prospective study design with a reasonably high response rate where family caregivers are assessed before and after the loss of the patient with cancer. Besides the psychological distress of bereaved family caregivers assessed in the previous studies,^{3,9} in this study, we focus on bereaved family caregiver's QOL, which can be considered a critical outcome for family caregivers.⁷ The objective of this study was to clarify the association between family caregivers' satisfaction with the care given to patients with terminal cancer and their bereaved family caregivers' QOL.

Methods

Procedure

This study was a prospective pre- and postloss study of family caregivers' bereavement. Family caregivers completed questionnaires at two data collection time points: first, when the patient was hospitalized in an inpatient hospice/palliative care unit (Time 1) and, again, six months postloss (Time 2). Time 2 was set by assuming that accumulated bereavement reaction in the acute phase is related to the substantially deteriorated QOL at six months from the patient's death. At the first data collection point, information on patients' demographic characteristics and previous treatment was recorded.

Family caregivers were recruited from three inpatient hospice/palliative care units in two hospitals: a designated cancer hospital and a general hospital in Japan with the collaboration of the health care staff. The researchers selected the family caregivers using medical records and confirmed with the patients' primary physician whether the family caregivers met the study's inclusion criteria. Each site identified all family caregivers of patients with cancer hospitalized in the palliative care units from February 2017 to March 2018. The questionnaires were confidential, and the questionnaires at Time 1 and Time 2 and the medical records were identified by identification number; however, the family caregivers' contact information was separated from the data and kept confidential. Written informed consent was obtained from each of the family caregivers. Family caregivers who failed to return questionnaires were treated as having dropped out. The ethical committee of Shizuoka Cancer Center (Approval Number: T28-63) and all the participating institutions approved this study.

Participants

The inclusion criteria included (1) being the primary informal family caregivers of a patient with cancer who had been admitted to a participating palliative care unit for at least 72 hours; (2) caring for a patient 20 years or older; (3) being 20 years or older; and (4) speaking and understanding Japanese. We did not define primary informal family caregivers in terms of the relationship with the patient (spouse, children, or friend), whether living together or not, or time spent for caregiving. Family caregivers were ineligible if they were physically or mentally compromised, as determined by the doctor or head nurse. The date of patient death was provided by the staff in the applicable palliative care unit. The Time 2 questionnaires were mailed by the investigators to the bereaved family caregivers. Family caregivers received a JPY 1000 (approximately USD 10) voucher upon receipt of the questionnaire at each data collection point.

Measurements

Outcome variables. To assess family caregivers' QOL, we used the mental component summary score (MCS) of the Japanese version of the 36-Item Short-Form Health Survey (SF-36) of the Medical Outcomes Study,^{11,12} which was the primary outcome of this study. SF-36 is a 36-item self-reported measure consisting of eight domains (i.e., Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health) that comprise the mental and physical summary scores, ranging from 0 to 100. Higher mental (physical) summary component scores indicate higher mental (physical) health status. The reliability and validity of SF-36 has been established.^{11,12} Cronbach's alphas in this study ranged from 0.76 to 0.96.

The secondary outcomes of this study were family caregivers' depressive symptoms and grief. We used Patient Health Questionnaire 9 (PHQ-9),¹³ which is the simplest and most often used in clinical research, to screen depression. PHQ-9 is a nine-item self-reported measure. Hereafter, we use "depressive symptoms" rather than "depression" because the family caregivers in this study have not been medically diagnosed. Each item was rated on a 0–3 scale, with total scores ranging from 0 to 27. A score of 0–4

represents minimal, 5–9 mild, 10–14 moderate, 15–19 moderately severe, and 20–27 severe depressive symptoms. The reliability and validity of the Japanese version of PHQ-9 have been confirmed.¹⁴ Cronbach's alpha in this study ranged from 0.84 to 0.87.

Family caregivers' grief was assessed with the Brief Grief Questionnaire (BGQ).¹⁵ The BGQ is a five-item self-report measure. Each item was rated on a 0–2 scale, with total scores ranging from 0 to 10. A higher score indicated higher levels of grief. A score of 5–7 represented moderate grief, and a score of 8–10 indicated probable complicated grief. The reliability and validity of BGQ have been previously established.¹⁶ Cronbach's alpha in this study was 0.76.

The questionnaire included SF-36 and PHQ-9 at Time 1 and SF-36, PHQ-9, and BGQ at Time 2.

Explanatory variables. We used the Japanese version of the Family Satisfaction with Advanced Cancer Care (FAMCARE) scale to assess the satisfaction family caregivers found in care.^{17,18} The Japanese version of the FAMCARE scale consists of 20 items, each comprising four subscales: an adequate amount of information, attitude of medical personnel, education and support systems for family caregivers, and emergency responses. Each item was rated from 0 (*very dissatisfied*) to 5 (*very satisfied*), with the total score ranging from 0 to 100 and a higher total score indicating higher satisfaction with care. The reliability and validity of the FAMCARE has been established.¹⁸ Cronbach's alpha in this study was 0.95.

Family functioning was assessed using the family relationship index (FRI), a simplified version of the Family Environment Scale.^{19,20} The FRI is a 12-item self-report measure by items on three subscales: family cohesion, family expressiveness, and family conflict. Each item was rated either *yes* (1) or *no* (0); thus, the total score ranged from 0 to 12. A higher score indicates a good family relationship (e.g., greater cohesiveness, greater expressiveness, and less conflict). A total score ≥ 9 indicates a good family relationship. The reliability and validity of the FRI has been established.²¹ Cronbach's alpha in this study ranged from 0.61 to 0.67.

The burden of care was assessed using the Japanese version of the caregiver reaction assessment (CRA).²² The Japanese version of the CRA is an 18-item self-report measure. Each item was rated on a five-point scale with total scores ranging from 0 to 90. A higher score indicates a higher burden of care. The reliability and validity of the CRA has been established.²³ Cronbach's alpha in this study was 0.84.

The characteristics of patients and family caregivers were assessed at Time 1. We searched patients' medical records and collected the following data: age, gender, marital status, time since diagnosis, palliative prognostic index (PPI), comorbidities, and day of hospitalization. PPI was described by the primary doctor and other data were described by the researchers. The family caregivers were asked their age, gender, marital status, economic status, and presence of other informal caregivers.

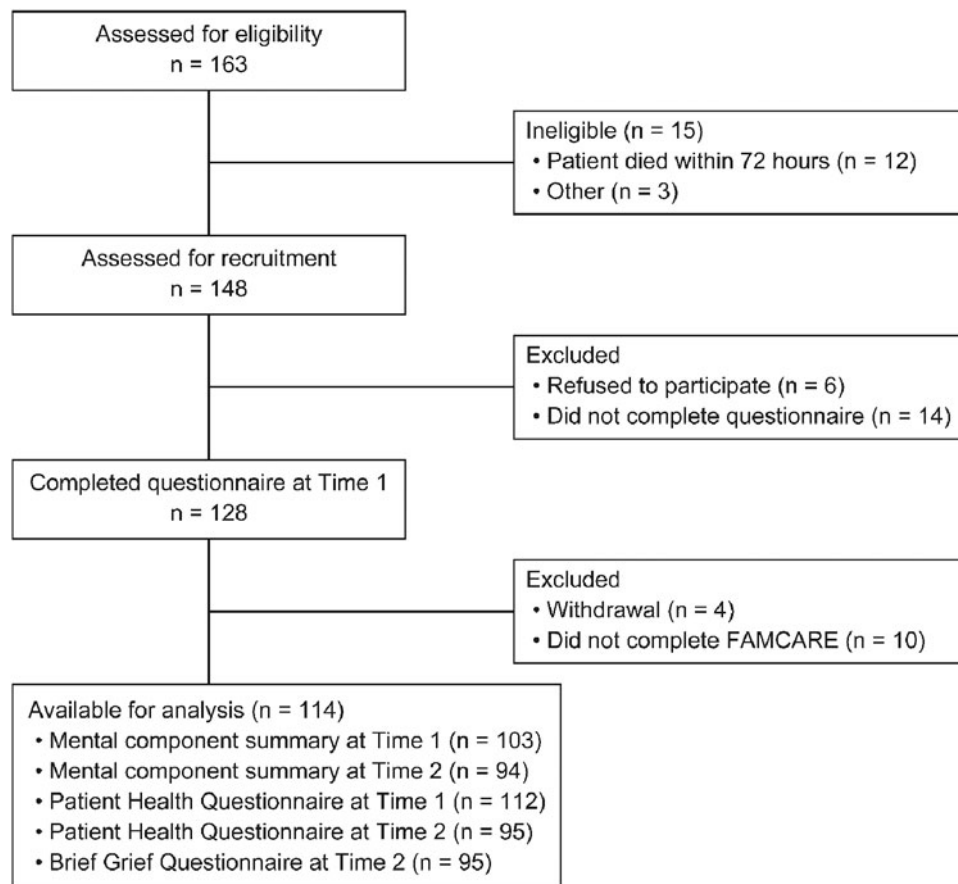


FIG. 1. Participants' flowchart.

Statistical analysis

We calculated summary statistics of the characteristics of patients and family caregivers. We calculated Pearson's correlation coefficients between scores (satisfaction with care, SF-36, BGQ, and PHQ-9). The primary analysis was an independent-sample *t*-test to compare the MCS at Time 2 between two groups defined by a total FAMCARE score. As the total score was 80 when all items were rated 4 (*satisfied*), we used this threshold to define the high- and low-satisfaction groups. We assumed a mean difference of 6 between the two groups with a standard deviation (SD) of 10. To reject the null hypothesis, a sample size of 90 at Time 2 was required to achieve 80% power with a significance level of 5%.

The number of family caregivers with depressive symptoms and probable complicated grief was calculated. We used linear regression models to assess the predictors of the MCS at Time 2. The initial model examined the association between the MCS at Time 2 and the following variables: family caregiver's characteristics (age and relationship with the patient), patient's condition (time since diagnosis, presence of comorbidities, and PPI), burden of care, and family functioning. We used the backward stepwise selection method to obtain a final model using a threshold of $p < 0.20$. Similarly, the predictors of depressive symptoms (mild or worse) and grief (moderate or worse) were assessed using logistic regression models. Missing values were not imputed.

A value of $p < 0.05$ was considered statistically significant. We calculated study sample size and conducted all statistical analyses using Base SAS and SAS/STAT version 9.4 software of the SAS System for Windows (SAS Institute, Cary, NC, USA).

Results

A total of 148 family caregivers and patients met the inclusion criteria and 128 family caregivers completed the questionnaires. After excluding family caregivers whose satisfaction with the care scale was not available, 114 were included in the analysis (Fig. 1). Of the 142 eligible family caregivers who agreed to participate, 128 (90%) responded at Time 1. Four family caregivers withdrew their consent before Time 2, then a second questionnaire was mailed to 124 bereaved family caregivers, and 104 (84%) bereaved family caregivers responded.

Characteristics of family caregivers and patients

The family caregiver and patient characteristics are summarized in Table 1. The mean age of family caregivers was 61.4 years (SD=12.2 years). Correlation coefficients between scores are given in Table 2. The total score of the FAMCARE was significantly correlated with the MCS, but the magnitude of the correlation was not high (between 0.20 and 0.30).

Satisfaction with care and MCS

In both high- and low-satisfaction groups, the MCS increased between the pre- and postloss assessments (top of Fig. 2). The mean MCS in the high-satisfaction group ($n=55$) increased from 47.2 (standard error [SE]=1.6) to 52.4 (SE=1.3). The mean MCS in the low-satisfaction group ($n=48$) increased from 43.2 (SE=1.2) to 48.9 (SE=1.2). The MCS showed significant differences (mean difference=3.5,

TABLE 1. CHARACTERISTICS OF CAREGIVERS AND PATIENTS ($N=114$)

	n	%
Family caregivers		
Gender		
Female	83	72.8
Age (years) ^a	61.4 ± 12.2	27–84
Marital status		
Married	92	80.7
Economic status		
Bad	103	90.4
Good	10	8.8
Relationship to the patient		
Spouse	54	47.4
Child	34	29.8
Brother or sister	12	10.5
Relative	2	1.8
Other	10	8.8
Other informal caregivers		
Present	77	67.5
Absent	35	30.7
Burden of care ^a (A total score of the CRA)	49.7 ± 9.2	30–71
Good family function (A total score of the FRI ≥9)	43	37.8
Satisfaction with care (A total score of the FAMCARE)	77.5 ± 10.3	50–100
Patients		
Gender		
Male	59	51.8
Age (years) ^a	73.4 ± 10.2	36–96
Marital status		
Married	79	69.3
Cancer site		
Digestive	15	13.2
Lung	32	28.1
Hepatobiliary/pancreas	23	20.2
Colorectal	7	6.1
Urinary	6	5.3
Uterus/ovarian	6	5.3
Other	25	21.8
Time since diagnosis (years) ^a	2.7 ± 3.7	0.1–24.9
PPI	7.2 ± 3.4	1–15

Missing responses were included in the denominator.

^aMean ± standard deviation (range).

CRA, caregiver reaction assessment; FAMCARE, the Family Satisfaction with Advanced Cancer Care; FRI, family relationship index; PPI, palliative prognostic index.

$p=0.048$) between the high- and low-satisfaction groups at Time 2 ($n=47$ in both groups). Furthermore, the MCS at Time 1 differed significantly (mean difference=4.0, $p=0.042$). The pre- and postloss slopes were almost parallel between the high- and low-satisfaction groups.

Proportion of family caregivers with depressive symptoms or grief

The proportion of family caregivers and bereaved family caregivers with depressive symptoms or grief is given in Figure 2 (middle and bottom). The proportion of family

TABLE 2. CORRELATION COEFFICIENT BETWEEN SCORES

	Time	FAMCARE				
		Total	Sub 1	Sub 2	Sub 3	Sub 4
FAMCARE						
Total	1	—				
Sub 1	1	0.917	—			
Sub 2	1	0.892	0.769	—		
Sub 3	1	0.949	0.824	0.791	—	
Sub 4	1	0.874	0.742	0.707	0.778	—
MCS	1	0.235	0.169	0.203	0.259	0.196
	2	0.272	0.235	0.281	0.266	0.190
PCS	1	0.019	0.085	-0.038	0.014	0.000
	2	-0.020	0.024	0.040	-0.064	-0.064
BGQ	2	-0.029	-0.034	-0.005	-0.086	0.056
PHQ-9	1	-0.144	-0.166	-0.109	-0.130	-0.093
	2	-0.017	-0.025	-0.034	-0.025	0.034

Subscales of FAMCARE are an adequate amount of information (sub 1), attitudes of medical personnel (sub 2), education and support systems for families (sub 3), and emergency responses (sub 4). Pearson's correlation coefficients are shown, with value of $p < 0.05$ given in bold.

BGQ, Brief Grief Questionnaire; FAMCARE, the Family Satisfaction with Advanced Cancer Care; MCS, mental component summary score; PCS, Physical Component Summary score; PHQ-9, Patient Health Questionnaire 9.

caregivers with depressive symptoms (moderate or worse) at Time 1 was 41% in the low-satisfaction group and 22% in the high-satisfaction group. The proportion of bereaved family caregivers with grief (moderate or worse) at Time 2 was 42% in the low-satisfaction group and 33% in the high-satisfaction group.

Predictors of bereaved family caregiver's QOL and psychological status

The predictors of the bereaved family caregiver's QOL and psychological status are given in Table 3. The final model revealed the following factors as being significantly associated with good MCS: higher age ($p = 0.033$) and higher satisfaction with care ($p = 0.011$). Different factors were clarified as being associated with a higher risk of depressive symptoms and grief for the bereaved family caregivers. Presence of comorbidities in family caregivers ($p = 0.012$) was associated with a higher risk of depressive symptoms, whereas a longer time since diagnosis ($p = 0.023$) and being the patient's spouse ($p = 0.043$) were associated with a higher risk of grief. Satisfaction with care was not correlated with the risk of depressive symptoms or grief.

Discussion

To the best of our knowledge, this was the first prospective study that examined the association between family caregivers' satisfaction with care for terminal cancer patients and the mental health aspects of bereaved family caregivers'

FIG. 2. Mental Component Summary score (top), Patient Health Questionnaire 9 (middle), and Brief Grief Questionnaire (bottom) of family caregivers of terminal cancer patients pre- (Time 1) and postbereavement (Time 2) compared between low- and high-satisfaction care groups. In the top graph, the mean \pm standard error is shown.

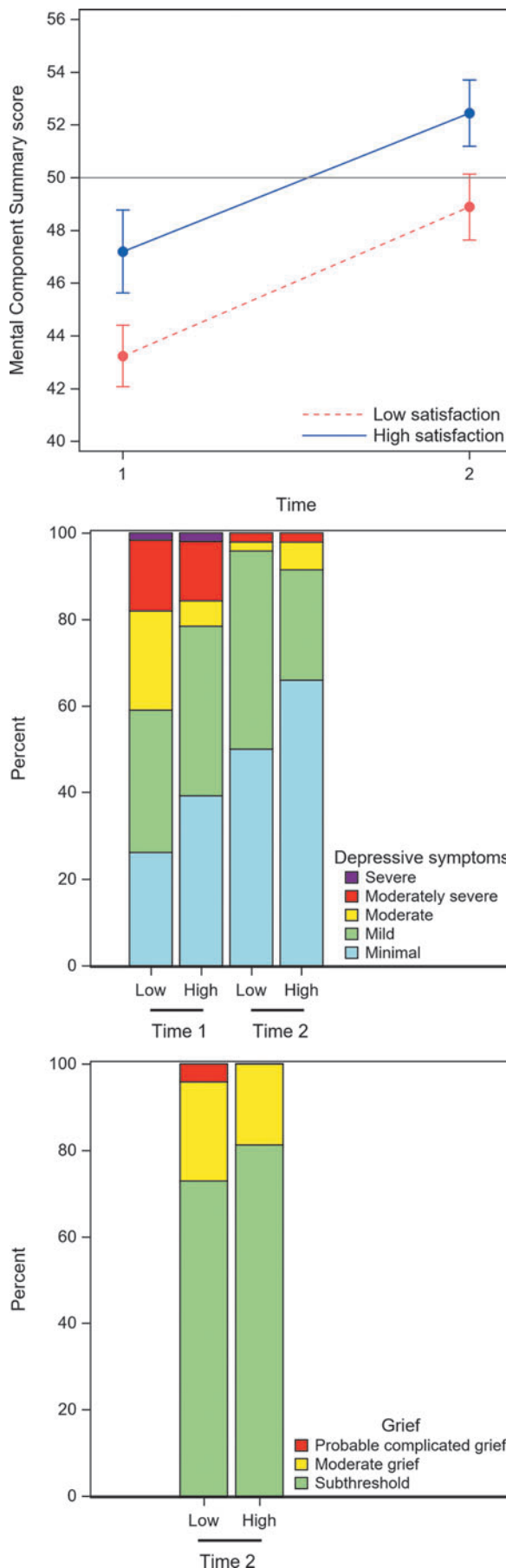


TABLE 3. FACTORS ASSOCIATED WITH MENTAL COMPONENT SUMMARY SCORE, DEPRESSION, AND GRIEF

Outcome variable	Initial model		Final model	
	β	p	β	p
MCS				
Age (high)	4.09	0.081	3.73	0.033*
Family functioning (good)	3.20	0.094	3.22	0.067
Time since diagnosis (longer)	-2.91	0.095	-3.02	0.072
Satisfaction with care	0.21	0.018	0.22	0.011*
Any comorbidity (present)	-0.88	0.676		
Burden of care (high)	-0.20	0.937		
Relationship to the patient (spouse)	0.04	0.987		
PPI (high)	-0.31	0.864		
Depressive symptoms (mild or worse)				
Age (high)	-0.76	0.252		
Family functioning (good)	-0.63	0.200	-0.78	0.111
Time since diagnosis (longer)	-0.12	0.802		
Satisfaction with care	-0.01	0.610		
Any comorbidity (present)	1.64	0.009	1.20	0.012*
Burden of care (high)	0.82	0.252	1.02	0.138
Relationship to the patient (spouse)	0.16	0.785		
PPI (high)	0.34	0.482		
Grief (moderate or worse)				
Age (high)	-0.27	0.666		
Family functioning (good)	-0.07	0.882		
Time since diagnosis (longer)	1.02	0.031	1.03	0.023*
Satisfaction with care	0.01	0.640		
Any comorbidity (present)	0.53	0.334		
Burden of care (high)	-0.14	0.837		
Relationship to the patient (spouse)	1.06	0.073	0.91	0.043*
PPI (high)	0.63	0.193		

β indicates unstandardized regression coefficients.

* $p < 0.05$.

MCS, mental component summary score; PPI, palliative prognostic index.

postloss QOL. We used a prospective pre- and postloss study design and achieved a high response rate from our sample of family caregivers.

This study confirmed our hypothesis that family caregivers' higher satisfaction with the care received by the terminal cancer patients predicted increased postloss MCS. Previous cross-sectional studies using samples of family caregivers of terminal cancer patients showed an association between family caregivers' satisfaction with care and their QOL.^{7,8} Similarly, this study demonstrated that the MCS significantly differed between low- and high-satisfaction groups at the end of life for terminal cancer patients. Consistent with our hypothesis, the findings demonstrated that higher satisfaction with care was associated with a higher MCS in our sample of bereaved family caregivers, indicating that MCS continued to differ between the high- and low-satisfaction groups for at least six months after the patient's death.

Another predictive factor of the MCS of the bereaved family caregivers was age, with older family caregivers reporting better mental health. Furthermore, good family functioning and time since diagnosis showed a marginally significant association with MCS. These associations are

consistent with previous research, which demonstrated that the age of family caregivers²⁴ and family functioning²⁵ were related to family caregivers' QOL.

The second important finding of this study was that although satisfaction with care was associated with depressive symptoms and grief in previous studies,^{3,9} we did not find this association in this study. We have three possible explanations for this difference. First, the characteristics of depressive symptoms and grief are different for those family caregivers who lost the patients before the assessment (i.e., family caregivers in our study) and family caregivers who have lost the patients after a longer period (e.g., a mean time of three years postloss³). An influential grief theory, the dual-process model, may support this explanation. The model describes grief as a process of oscillation between two contrasting modes of functioning: loss orientation and restoration orientation.²⁶ The model suggests that the focus of coping may differ from one moment to another; in other words, time since the patient's death is associated with a change in the construction of grief. Second, recalling satisfaction with care after the loss of a family member does not show complete agreement with satisfaction with care at the end of life for terminal cancer patients. Because the former could be influenced by the family caregiver's mental health at the time of assessment, it might be affected by recall bias when it is used as a surrogate for satisfaction with care before the patient's death. Third, the impact of the family caregivers' satisfaction with care at the end of life for terminal cancer patients could be absorbed into other postloss factors more directly associated with depressive symptoms or grief. Several studies showed that postloss greater social support was associated with bereaved family caregivers' lower probability of severe depressive symptoms⁵ and comorbid probable complicated grief and depressive symptoms.³

The presence of comorbidities, being the patient's spouse, and time since diagnosis were found to predict depressive symptoms or grief experienced by the bereaved family caregivers. Comorbidities^{4,9} and being the spouse^{2,3} have been previously identified as predictive factors. We found that time from diagnosis to admission to the palliative care unit was associated with increased psychological disorders in bereaved family caregivers. Contrary to our expectations, a longer time since diagnosis was associated with a higher prevalence of grief. A previous study demonstrated that time since diagnosis was correlated with mental (positively) and physical (negatively) health status.²⁷ Physical fatigue from caregiving for a long time might contribute to the unfavorable psychological status among bereaved family caregivers.

Satisfaction with care is one of the modifiable factors for family caregivers of patients with terminal cancer. As this was an observational study, we cannot infer a causal relationship between family caregivers' satisfaction with care and bereaved family caregivers' QOL, and therefore cannot conclude that enhancing their satisfaction with care affects their QOL. To assess the effect of an intervention, a randomized controlled trial is necessary. A related study of early palliative care clarified that intervention improves satisfaction with care for family caregivers of patients with advanced cancer but does not affect their QOL.²⁸ Early palliative care interventions might have a delayed effect on the QOL after loss; thus, the impact of the intervention on the bereaved family caregivers' QOL may be worth investigating.

This study's strengths included its prospective study design. In particular, a thorough assessment of family caregivers and patients preloss increased the contributions of this study. Furthermore, the high family caregiver response rate is another strength of this study. There are few concerns of recall bias, owing to the study design. The final response rate was higher than anticipated, reaching the favorable response rate of 80%.²⁹ Despite these strengths, this study had several limitations that should be noted. First, the study was conducted in three hospice/palliative care units in two hospitals in Japan; therefore, the study population is not representative of all family caregivers of terminal cancer patients. Second, the causal relationship is unknown because of the observational study design. Third, this study assessed the family caregivers at only two time points. Several assessment points are necessary to capture changes in mental health status.^{5,30} Finally, grief and depressive symptoms were assessed by self-reported instruments, and the family caregivers were not clinically diagnosed with depression.

Conclusions

The family caregivers' satisfaction with care of terminal cancer patients was associated with their MCS six months after loss. This prospective study revealed no association between their satisfaction with care and postloss depressive symptoms and grief. Enhancing family caregivers' satisfaction with care potentially improves their QOL after loss.

Authors' Contributions

M.M.K.: Conceptualization, methodology, investigation, writing—original draft, project administration, funding acquisition. A.T.: Conceptualization, investigation, data curation, writing—review and editing. S.A.: Resources, writing—review and editing. Y.S.: Resources, writing—review and editing. Y.I.: Resources, writing—review and editing. H.M.: Resources, writing—review and editing. T.K.: Formal analysis, visualization, writing—review and editing.

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Author Disclosure Statement

No competing financial interests exist.

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