Factors Predicting Bereaved Caregiver Perception of Quality of Care in the Final Week of Life: Implications for Health Care Providers

Philip C. Higgins, PhD, LICSW,¹ Melissa M. Garrido, PhD,^{2,3} and Holly G. Prigerson, PhD⁴

Abstract

Background: Cancer caregivers are key stakeholders in the final weeks of life and in bereavement. Research has highlighted end-of-life (EOL) factors important to caregivers, as well as factors contributing to caregiver mental health and bereavement outcomes. There has been limited data on factors predicting caregiver perceptions of quality of EOL care.

Objective: This study's purpose was to identify modifiable predictors of caregivers' Caregiver Evaluation of Quality of End of Life Care (CEQUEL) scores, with the broader aim of informing clinical interventions to improve caregiver impressions of care and subsequent bereavement adjustment.

Methods: Study data came from Coping with Cancer I (CwC1). CwC1 investigators interviewed advanced cancer patients and caregivers prior to the patient's death (Wave 1) and reinterviewed caregivers following the death (Wave 2) ($N=275$ dyads). The authors identified potential Wave 1 predictors of CEQUEL scores and performed a series of linear regression analyses to identify a parsimonious predictive model using corrected Akaike's Information Criterion (AICc) values.

Results: In adjusted analyses, caregivers rated quality of care as poorer when patients died in a hospital ($B = -1.40$, $SE=0.40$, $p=0.001$) (B , unstandardized regression coefficient; SE , standard error) or had less than one week of inpatient hospice care ($B = -1.98$, $SE = -0.70$, $p=0.006$). Whole-person physician care and caregiver religiosity were associated with perceived higher quality of care in unadjusted, but not adjusted, analyses.

Conclusions: Findings suggest that place of death and hospice length of stay best predict bereaved caregiver evaluations of quality of EOL care. These findings equip health care providers with modifiable targets to improve caregivers' experience of EOL care and subsequent bereavement.

Introduction

WITH THE EVOLUTION of patient-focused, family-centered care at the end of life, caregivers—defined here as those family members or other loved ones providing the majority of a patient's unpaid, informal care—are recognized as playing a central role in the experience of dying patients.¹ Caregivers impact the health care team's ability to care for dying patients, and their mental health is also impacted by their perception of that care.^{2–6} Many meet criteria for anxiety, depression, and other psychiatric disorders, but forego mental health support.^{7–11} Caregivers in acute and critical care

settings, particularly those opting for more aggressive end-of-life (EOL) measures, may be at particular risk for poor bereavement outcomes.^{6,12–14}

In order to improve caregiver well-being, it is critical to identify modifiable predictors of how they perceive quality of EOL care. Caregiver priorities for high-quality EOL care typically include shared decision making, communication about patient wishes, awareness of prognosis, preparation for death, and avoiding prolonged death or suffering.^{1,15–18} The few existing instruments that measure quality of EOL care typically elicit the patient's experience rather than that of the caregiver.^{19–23} Those that do assess caregivers, including the

¹Brigham & Women's Hospital and the Dana-Farber/Brigham & Women's Cancer Center, Boston, Massachusetts.

²James J Peters Veterans Affairs Medical Center, Bronx, New York.

³Icahn School of Medicine at Mount Sinai, New York, New York.

⁴Center for Research on End-of-Life Care, Weill Cornell Medical College, New York, New York.

Accepted May 22, 2015.

After-Death Bereaved Family Member Interview from the Toolkit of Instruments to Measure End-of-Life Care (TIME),²⁴ have omitted key factors of patient suffering and prolongation of death.^{1,25} This omission is important, as memories of prolonged death or suffering may foster post-loss symptoms of depression and regret and impede successful grief resolution.^{2,26,27}

The present study expands on two of the authors' previously published reports in which they used Coping with Cancer I (CwC1) data from 275 patient/caregiver dyads to develop and validate the 13-item Caregiver Evaluation of Quality of End of Life Care (CEQUEL) scale. CEQUEL is a more comprehensive measure of caregiver-perceived quality of care in the final week of life that builds on the TIME instrument by including perceived suffering and prolonged dying.²⁸ The purpose of the present study was to identify modifiable predictors of caregiver CEQUEL scores, with the goal of developing clinical interventions to improve caregiver experiences at the end of life and in bereavement. Figure 1 illustrates the authors' conceptual model hypothesizing that caregiver-perceived quality of care (indicated by CEQUEL scores and including perceived suffering, prolonged dying, preparation, and shared decision making) is predicted by a combination of patient-, caregiver-, and 'procedurally' derived aspects of EOL care, while also acknowledging that unavoidable circumstances (e.g., refractory pain) may also contribute to perceptions of care.

Methods

The present study employed frequency and descriptive statistics, means-difference testing, correlational analyses, and uni- and multivariate regression analyses, all performed

using SPSS 19.0 (IBM, Armonk, NY). Data were derived from CwC1, a federally funded, longitudinal, multisite study of psychosocial adjustment and EOL care preferences in advanced cancer patients and their caregivers. CwC1 recruited patients between 2002 and 2008 from eight participating sites in the Northeast United States (US) and Texas. Patients and caregivers were interviewed at baseline (Wave 1), and caregivers were interviewed again following patients' death (Wave 2). Caregivers completed interview questionnaires on their own (mean time = 45 minutes). Completion rate for Wave 2 interviews was over 94%, with few reports of interview burden. Additional information was obtained via postmortem interviews with caregivers or providers caring for patients at the time of death. Of the 726 patients completing Wave 1 interviews, 414 had died at the time of data analysis, and 315 of their caregivers completed Wave 2 interviews. The present study used data for the 275 patient/caregiver dyads with complete caregiver CEQUEL data. Mean time from Wave 1 to death was 3.7 months, from death to Wave 2 was 6.3 months, and from death to postmortem was 1.5 months.

Outcome variable

The study's outcome variable was caregiver CEQUEL scores. Methods used for initial construction and validation of CEQUEL are detailed elsewhere.²⁹ Thirteen dichotomous items measuring caregiver evaluations of four factors (Prolongation of Death, Perceived Suffering, Shared Decision Making, and Preparation for the Death) were summed as a total CEQUEL score, with a possible range of 13 to 26 and with higher scores indicating perceived better quality of care (see Fig. 2). Internal consistency and reliability analyses were

FIG. 1. Conceptual model of caregiver-perceived quality of care at the end of life (EOL, end of life; CG, caregiver).

	YES (1 POINT)	NO (2 POINTS)
1. Was the life of [PATIENT] prolonged by medical interventions longer than you would have wished?		
2. Was the life of [PATIENT] prolonged by medical interventions when _____ was, to the best of your knowledge, dying?		
3. Was the life of [PATIENT] prolonged by medical interventions that resulted in an increase of his/her suffering?		
4. Was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?		
5. Was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?		
6. Did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?	NO (1 PT)	YES (2 PT)
7. To the best of your knowledge, did [PATIENT'S] doctor or the medical staff who cared for (him/her) speak to (him/her) or you about (his/her) wishes about medical treatment?	NO (1 PT)	YES (2 PT)
8. Did you or your family receive any information about what to expect while (he/she) was dying?	NO (1 PT)	YES (2 PT)
9. At any time did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?	SOMETIMES/NEVER (1 PT)	USUALLY/ALWAYS (2 PT)
10. How often were you or other family members kept informed about [PATIENT'S] condition?	EXTREMELY (1 PT)	MINIMALLY (2 PT)
11. To what extent do you think _____ suffered in dying?	VIOLENT (1 PT)	PEACEFUL (2 PT)
12. How peaceful or violent did _____'s death seem to you?	MUCH MORE (1 PT)	MUCH LESS (2 PT)
13. How much did _____ suffer compared to what you expected?		

FIG. 2. Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL) scale (PT, point).

evaluated using Cronbach's α ($\alpha=0.69$). CEQUEL demonstrated strong convergent validity, with higher CEQUEL scores correlating positively with hospice enrollment ($z=-2.09$; $p\leq 0.05$) and patient-physician therapeutic alliance ($\rho=0.13$; $p\leq 0.05$) and negatively with bereaved caregiver regret ($\rho=-0.36$, $p\leq .001$) and trauma symptoms ($z=-2.06$; $p\leq 0.05$).

Predictor variables

The authors followed a theory-based analytical protocol established by Garrido and Prigerson²⁹ to identify the most parsimonious model of factors predicting CEQUEL scores. Potential predictors included items from Wave 1 patient and caregiver interviews and from postmortem interviews. Research specific to factors impacting perceived quality of care is scarce; the authors selected predictor variables based on the existing literature and/or their own clinical experience regarding factors impacting caregiver quality of life, mental health, bereavement, and experience of EOL care.^{18,30,31} Because CEQUEL is derived from Wave 2 interviews, other

Wave 2 variables were not considered in order to make a stronger statement of predictive value. The authors selected for regression analyses only those items potentially modifiable in the clinical context, dividing them into conceptual categories detailed in Figure 3.

Patient predictor variables

Quality of life. Caregivers answered questions about their perception of patient QOL via the McGill Quality of Life questionnaire, a measure of physical, psychological, and existential factors widely used and validated within cancer populations (scale 0–10; 0=desirable and 10=undesirable).^{32–34}

Mental health. Patients completed a Structured Clinical Interview for DSM Disorders (SCID) Axis I modules for Major Depressive Disorder (MDD), Generalized Anxiety Disorder (GAD), Panic Disorder (PD), and Posttraumatic Stress Disorder (PTSD),³⁵ which were summed to indicate the presence of any mental health diagnosis. Patients also reported how often they felt deep inner peace or harmony.³⁶

FIG. 3. Conceptual categories of potentially modifiable factors predicting CEQUEL scores. (Regression analyses were performed using variables first within and then across conceptual categories to identify the most parsimonious explanatory set of predictors fitting the authors' conceptual model.)

Mental health service use. Patients answered whether or not they had discussed mental health concerns with a health care professional or accessed any mental health intervention since cancer diagnosis (both yes/no).

Acknowledgment of terminal illness. Patients described their health status as terminally ill or not terminally ill. Caregivers of patients acknowledging terminal illness are less likely to experience post-loss PTSD.^{6,14,37}

Religiosity, religious support, and religious coping. Patients reported frequency of religious service attendance (scale 1–6; 1 = never, 6 = more than once a week); time spent in private religious activities (scale 1–6; 1 = never, 6 = more than once a day); importance of religion (scale 1–3; 1 = very important, 3 = not important); use of religious coping (scale 1–5; 1 = not at all, 5 = most important); and whether religious views affected recent medical decisions; and these were summed as a measure of religiosity. Patients reported support of their religious beliefs by their religious community and the medical system (scale 1–5; 1 = not at all, 5 = completely); receipt of pastoral care in the hospital/clinic; and visits with outside clergy (both yes/no), which were summed as a measure of religious support. These measures have been associated with better patient QOL, increased hospice enrollment, and lower likelihood of ICU death.^{38–39} Patient use of positive and/or negative religious coping was also assessed via the Brief RCOPE.^{40,41}

Therapeutic alliance. Therapeutic alliance between patients and their oncologists has been associated with dying patients' greater acceptance of terminal illness and decreased ICU time.⁴² Patient responses regarding how much they trusted and respected their physicians, felt respected and seen as a whole person by their physicians, and felt comfortable asking their physicians questions (scale 1–4; 1 = not at all, 4 = a great deal) were summed as a measure of therapeutic alliance. Comfort and whole-person care were also analyzed as individual predictors.

Advance care planning. Patients reported if they had completed a health care proxy and/or living will, if they had discussed EOL wishes with their doctor, and if they had completed a DNR order.

Caregiver predictor variables

Physical and emotional well-being. Caregivers completed the Medical Outcomes Study Short Form 36 Health Survey.⁴³

Health-promoting behavior. Caregiver concerns about staying in shape (yes/no); nutrition (scale 1–4; 1 = not concerned, 4 = very concerned) and calorie intake (scale 1–3; 1 = very little, 3 = very careful); and reports on exercise, taking vitamins, annual checkups, and getting enough rest (all yes/no) were summed as a measure of health-promoting behavior.

Physical health service use. Caregivers reported if they had overnight treatment in a hospital, treatment in an emergency room, or if they had visited a medical office or dentist in the last three months.

Mental health. Caregiver responses to SCID Axis I modules for MDD, GAD, PD, and PTSD were summed to capture any mental health diagnosis.

Mental health service use. Caregivers reported if they had discussed mental health concerns with a health care professional or accessed any mental health intervention since the patient's diagnosis (both yes/no).

Religiosity, religious support, and religious coping. Summary measures of caregiver religiosity and religious support were constructed parallel to those of patients. Caregiver religious coping was assessed via the Brief RCOPE. Negative religious coping has been associated with greater caregiver burden, poorer QOL, decreased satisfaction, and increased depression and anxiety.⁴⁴

Support system and family relationships. Caregivers completed the Interpersonal Support Evaluation List, a validated 16-item measure of perceived social support (e.g., “When I feel lonely, there are several people I can talk to”) (scale 1–4; 1 = definitely true, 4 = definitely false),⁴⁵ and the 12-item Family Relationships Index (e.g., “Family members really help and support one another”) (scale 1–4; 1 = definitely true, 4 = definitely false).⁴⁶

Caregiver burden. Caregivers completed the Caregiver Burden Scale, in which they were asked about time spent (“demand”) on six tasks (e.g., assistance with activities of daily living, medications, household tasks) as well as difficulty associated with each task (scale 1–4; 1 = little or no, 4 = a great deal). Task scores were summed to create separate measures of caregiver demand and difficulty. Caregivers also answered binary questions about whether caregiving felt positive and/or enriching and how well they were performing as caregivers.⁴⁷

Tobacco and alcohol use. Caregivers reported amount and frequency of cigarette and alcohol use.

End-of-life care predictor variables

Aggressive care in the final week of life. Caregiver or provider yes/no reports of ventilator use, resuscitation attempts, ICU stays, feeding tubes, chemotherapy, and antibiotics in the final week of life were summed as a measure of any aggressive care received.

Place of death. Place of death was recorded as acute care hospital (including ICU), home, nursing home, or inpatient hospice. Caregivers or providers reported if patients died where they wanted to die.

Hospice involvement. Inpatient and outpatient hospice involvement were analyzed both individually and together as a measure of any hospice involvement. Length of inpatient or outpatient hospice was also reported.

Consciousness in final week. Patient level of consciousness in the final week of life was reported.

Sociodemographic variables

Caregivers answered questions about their gender, age, race/ethnicity, marital status, income, education, religion, relationship to the patient, and length of time in the caregiving role. Caregiver recruitment site was also recorded.

While previous studies have set out, a priori, to test the predictive validity of specific variables while controlling for confounds (e.g., EOL discussions, hospice use), this study’s analytical protocol allowed the authors to analyze a range of variables in order to derive the most parsimonious explanatory set fitting their conceptual model. In order to do so, the authors first constructed a correlation matrix within each conceptual category to identify highly correlated variables (i.e., correlations >0.40), then conducted a series of linear regression analyses first within and then across conceptual categories, using individual items and combinations of items with low correlations.

Models with the lowest corrected Akaike’s Information Criterion (AICc) values were retained. Items were dropped

from analysis based on high AICc values and not because of high inter-item correlations (e.g., caregiver religiosity and use of positive religious coping), though high correlations prohibited models combining these items.

After identifying a semifinal model, the authors reentered into analysis all variables that had been statistically significant but dropped from preliminary models, in order to maximize the chances of capturing the best predictive model. These included Wave 1 patient QOL, inner peace, religiosity, religious support, and DNR status; Wave 1 caregiver emotional well-being, religious support, social support, physical and mental health service use, and alcohol use; and post-mortem reports of patient consciousness in the final week of life and whether patients died where they wanted to. The authors selected a final unadjusted model with the lowest AICc value and least number of predictors, and then adjusted this model for caregiver sociodemographics.

Results

Seventy-six percent of caregivers in this sample were female, 70% were white, 53% were the patient’s spouse or partner, and 39% were Catholic. Caregivers ranged in age from 20 to 83 years (mean = 51.9) (see Table 1). In bivariate analyses of sociodemographic characteristics, CEQUEL scores varied only by religious affiliation, with Catholic caregivers scoring lower than non-Catholics, and those without religious affiliation scoring lower than those with an affiliation (data not shown).

Regression analyses resulted in a final unadjusted model containing four predictor variables (see Table 2). CEQUEL scores were significantly higher when caregivers had greater religiosity ($B = 0.06$, $SE = 0.02$, $p = 0.004$) and when the patient felt seen as a whole person by their physician ($B = 0.99$, $SE = 0.48$, $p = 0.04$), and significantly lower when patients died in a hospital (versus all other locations) ($B = -0.87$, $SE = 0.33$, $p = 0.01$) or had an inpatient hospice length of stay (LOS) <1 week (versus one or more weeks, and not including patients with no inpatient hospice stay) ($B = -2.12$, $SE = 0.58$, $p < 0.001$). After adjusting for caregiver sociodemographics and recruitment site, hospital death ($B = -1.40$, $SE = 0.40$, $p = 0.001$) and inpatient hospice LOS <1 week ($B = -1.98$, $SE = -0.70$, $p = 0.006$) remained statistically significant (see Table 3).

Discussion

This study’s finding of hospital death as a predictor of perceived poor quality of care (which, in turn, is associated with poor bereavement outcomes) is consistent with previous research suggesting that hospital death, compared to home death, is associated with increased physical and emotional distress and worse QOL for patients, increased risk of prolonged grief disorder in caregivers, and worse caregiver-rated quality of death and dying.^{14,48} A number of studies have further highlighted the detrimental impact of EOL decision making in the hospital on caregiver mental health.^{5,49–52} Our findings related to hospice LOS are also consistent with existing research suggesting that shorter hospice LOS is associated with worse bereaved caregiver outcomes, and that ‘late-stage’ hospice admissions often feel chaotic, emotional, and like a crisis for cancer caregivers.^{6,53–55}

These findings are particularly relevant to health care professionals working in acute care settings. Recent U.S.

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF SAMPLE CAREGIVERS (N=275^a)

Characteristic	Caregivers (N)	Years	Percentage
Sex			
Male	64		24.0
Female	201		76.0
Age			
Mean		51.9	
SD		13.6	
Race/ethnicity			
White	185		70.0
Black	37		14.0
Asian-American, Pacific Islander, Indian	5		2.0
Hispanic	33		12.5
Other	4		1.5
Marital status			
Married	172		68.0
Income			
< \$31,000	62		25.0
≥ \$31,000	123		50.0
Don't know	45		18.0
Declined	14		6.0
Education			
Mean		13.5	
SD		3.6	
Religion			
Catholic	102		39.0
Protestant	47		18.0
Baptist	36		14.0
Pentecostal	11		4.0
Jewish	13		5.0
Other	37		14.0
None	18		7.0
Relationship to patient			
Spouse/partner	120		53.0
Son/daughter	57		25.0
Sibling	15		7.0
Other relative	17		7.0
Friend	6		2.0
Parent	11		5.0
Other	2		1.0
Recruitment site			
Yale University Cancer Center	65		24.0
Veterans' Affairs Connecticut Comprehensive Cancer Clinics	13		5.0
Memorial Sloan-Kettering Cancer Center	18		6.5
Simmons Comprehensive Cancer Center	21		7.5
Parkland Hospital	89		33.0
Dana-Farber Cancer Institute	8		3.0
Massachusetts General Hospital	1		0.5
New Hampshire Oncology Hematology	56		20.5

SD, standard deviation.

^aAvailable *N*s for each characteristic (due to missing data) were as follows: sex, age: *N*=265; race/ethnicity, education, religion: *N*=264; marital status: *N*=253; income: *N*=244; relationship to patient: *N*=228; recruitment site: *N*=27.

data highlight a decrease in overall hospital deaths and an increase in hospice enrollment in the last month of life, tempered by an increase in ICU admission in the final month of life and hospice admission in the final three days of life.^{56–57} The likelihood that more cancer patients are dying or at least spending time in ICUs is cause for concern, given that ICU care typically entails the most aggressive and costly medical interventions including prolonged life-sustaining treatments—care that has been shown to have a negative impact on caregivers at the end of life and in bereavement.⁶

Health care providers should think proactively about the best plan of care for dying patients and their caregivers, including measures to prevent unnecessary or unwanted hospital deaths and to foster earlier hospice enrollment for patients who desire it. Such measures might include standardized team-family meetings to clarify goals of care, development of triggers for palliative care consultation, adherence to established professional EOL care guidelines, proactive consultation of clinical social workers and chaplains, and promotion of generalist palliative care competencies across all disciplines.^{58–62} For patients who cannot leave the hospital, teams should be identifying ways to make in-hospital care feel more peaceful and dignified (e.g., 24-hour family access, private hospital rooms) and developing policies to ensure high-quality EOL care in the acute care setting (e.g., protocols for ventilator withdrawal and palliative sedation).

Caregiver religiosity and patients feeling seen as a whole person, though excluded from the final adjusted model, merit further exploration for clinical intervention. Religion and spirituality are important to most advanced cancer patients.⁶³ A recurrent theme in our findings, religion may provide caregivers with a moral and theological framework, as well as a sense of community with God and fellow church members, from which to approach a loved one's death. Nurses, social workers, and physicians should not only continue to collaborate with chaplain colleagues, but also enhance their own ability to assess religious and spiritual needs. Patient-physician therapeutic alliance, including the feeling of being seen as a whole person, appears to play an important role for caregivers as well. Many caregivers will have been present for clinic visits, hospitalizations, and treatment discussions over the course of illness, and their observations of patient-physician dynamics during these moments will likely influence their perception of care. Social workers, chaplains, and bedside nurses may have a unique vantage point in identifying deficits in patient- or caregiver-physician relationships, and can coach patients and caregivers in communicating their needs to physicians.

This study's findings highlight several limitations as well as directions for future research. While CwC1 included a Veterans Affairs hospital and two community-based institutions in its recruitment sites, the study also included several academic medical centers that may have more inclination or resources to pursue aggressive interventions with advanced cancer patients, including trial participation.

Generalizability of findings may be further limited by culture variations between one U.S. region and the next, and between the United States and countries with different resources or health care policies. CwC1 data come from patients and caregivers active in the medical system and may

TABLE 2. FINAL UNADJUSTED MODEL ($N=193$)

Variable	<i>B</i>	<i>SE B</i>	β	<i>p</i>
Pt feels physician sees him/her as a whole person	0.99	0.48	0.14	0.040
Hospital (non-ICU) death	-0.87	0.33	-0.18	0.010
Inpatient hospice LOS < 1 week	-2.12	0.58	-0.25	<0.001
Caregiver religiosity	0.06	0.02	0.20	0.004

B, unstandardized regression coefficient; β , standardized regression coefficient; ICU, intensive care unit; LOS, length of stay; *p*, significance level; pt, patient; R^2 , coefficient of determination (proportion of variation explained by regression; SE, standard error.

Adjusted $R^2=0.12$.

miss factors unique to those who choose to forego or are otherwise unable to access traditional medical care.

CEQUEL's reliability and validity need to be confirmed in noncancer patient and caregiver samples. While the six-month period between CwC1 patient deaths and Wave 2 interviews was respectful of caregivers' immediate grieving period, future research will need to compare the reliability of bereaved caregiver reports taken closer to the time of death. While caregiver reporting of whether a patient died where they wanted to die was not a significant predictor of CEQUEL scores, it is important to note that these reports may not reflect patients' true wishes. Asking patients directly about their preferences would enhance future studies, both to assess for patient-caregiver agreement and to identify predictive influence on CEQUEL scores.

It is also important to acknowledge the conceptual overlap between patient and/or caregiver religiosity, religious support, and religious coping, as well as the potential for con-

flation between religiosity and spirituality.⁶⁴ Our measure of religious support does not capture broader spiritual support that patients may have received in the community or in the hospital, which also may influence CEQUEL scores. Finally, while the adjusted model explains almost a quarter of the variance in CEQUEL scores, a large proportion remains unexplained. Future studies should explore additional factors that may help to predict caregiver perceptions of EOL care.

Conclusion

The results of this study suggest that place of death, including dying in a hospital and short hospice LOS, best predicts bereaved caregiver evaluation of quality of EOL care. These factors, as well as whole-person care and caregiver religiosity, provide health care providers with key, modifiable targets to improve the caregiver's experience of care at the end of life and in bereavement.

TABLE 3. FINAL ADJUSTED MODEL INCLUDING CAREGIVER SOCIODEMOGRAPHIC CHARACTERISTICS ($N=135$)

Variable	<i>B</i>	<i>SE B</i>	β	<i>p</i>
Pt feels physician sees him/her as a whole person	0.84	0.67	0.11	0.213
Hospital (non-ICU) death	-1.40	0.40	-0.29	0.001
Inpatient hospice LOS < 1 week	-1.98	0.70	-0.23	0.006
Caregiver religiosity	0.05	0.03	0.15	0.114
Northeast recruitment site	-0.46	0.51	-0.11	0.374
Male	0.82	0.42	0.17	0.055
Income <\$31,000 (compared to $\geq$ \$31,000)	0.52	0.43	0.12	0.234
Married	0.45	0.45	0.10	0.321
Patient has health care insurance	-0.18	0.55	-0.04	0.744
Race (reference = White)				
Black	-0.42	0.58	-0.07	0.469
Asian or other	-1.18	1.22	-0.08	0.333
Hispanic	-0.92	0.69	-0.14	0.180
Religious affiliation (reference = Catholic)				
Protestant	0.64	0.55	0.10	0.252
Jewish	-0.65	2.02	-0.03	0.747
Other religion	0.54	0.58	0.09	0.354
No religion	-1.70	0.78	-0.22	0.030
Pentecostal	1.86	0.92	0.18	0.047
Baptist	0.70	0.62	0.12	0.262
Length of time as primary caregiver	0.001	0.003	0.020	0.823
Relationship to patient: spouse (1 = spouse, 0 = all others)	-0.25	0.46	-0.06	0.584
Relationship to patient: child (1 = child, 0 = all others)	-0.66	0.56	-0.13	0.240
Age	0.01	0.02	-0.04	0.711
Education (years)	-0.001	0.060	-0.001	0.991

B, unstandardized regression coefficient; β , standardized regression coefficient; ICU, intensive care unit; LOS, length of stay; *p*, significance level; pt, patient; R^2 , coefficient of determination (proportion of variation explained by regression; SE, standard error.

Adjusted $R^2=0.23$

Acknowledgments

Dr. Higgins would like to thank Dr. Kathleen McInnis-Dittrich, PhD; Dr. Barbara Berkman, PhD; and Dr. Melissa Kelley, PhD, for their contributions in conceptualization and analysis of this study.

Author Disclosure Statement

This research was supported in part by the following grants and other funding sources: Dr. Higgins is supported by DSW1009403SW from the American Cancer Society. Dr. Garrido is supported by CDA 11-201/CDP 12-255 from the Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Health Services Research and Development Service. Dr. Prigerson was supported by MH63892 from the National Institute of Mental Health and CA106370 and CA156732 from the National Cancer Institute. These grants paid for the Coping with Cancer study on which these analyses are based.

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the U.S. government. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

References

1. Teno JM, Casey VA, Welch LC, et al.: Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001;22:738–751.
2. Barry LC, Kasl SV, Prigerson HG: Psychiatric disorders among bereaved persons: The role of perceived circumstances of death and preparedness for death. *Am J Geriatr Psychiatry* 2002;10:447–457.
3. Hanson LC, Danis M, Garrett J: What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997;45:1339–1344.
4. Koop PM, Strang VR: The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clin Nurs Res* 2003;12:127–144.
5. Wendler D, Rid A: Systematic review: The effect on surrogates of making treatment decisions for others. *Ann Intern Med* 2011;154:336–346.
6. Wright AA, Zhang B, Ray A, et al.: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–1673.
7. Hudson PL, Thomas K, Trauer T, et al.: Psychological and social profile of family caregivers on commencement of palliative care. *J Pain Symptom Manage* 2011;41:522–534.
8. Vanderwerker LC, Laff RE, Kadan-Lottick NS, et al.: Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. *J Clin Oncol* 2005;23:6899–6907.
9. Cherlin EJ, Barry CL, Prigerson HG, et al.: Bereavement services for family caregivers: How often used, why, and why not. *J Palliat Med* 2007;10:148–158.
10. Guildin M, Vedsted P, Zachariae R, et al.: Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: A longitudinal cohort study. *Support Care Cancer* 2012;20:1679–1685.
11. Lichtenthal WG, Nilsson M, Kissane DW, et al.: Underutilization of mental health services among bereaved caregivers with Prolonged Grief Disorder. *Psychiatr Serv* 2011;62:1225–1229.
12. Gries CJ, Engelberg RA, Kross EK, et al.: Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest* 2010;137:280–287.
13. Azoulay E, Pochard F, Kentish-Barnes N, et al.: Risk of post-traumatic stress symptoms in members of intensive care unit patients. *Am J Respir Crit Care Med* 2005;171:987–994.
14. Wright AA, Keating NL, Balboni TA, et al.: Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2010;28:4457–4464.
15. Emanuel LL, Alpert HR, Baldwin DC, et al.: What terminally ill patients care about: Towards a validated construct of patients' perspectives. *J Palliat Med* 2000;3:419–431.
16. Gutierrez KM: Experiences and needs of families regarding prognostic communication in an intensive care unit: Supporting families at the end of life. *Crit Care Nurs Q* 2012;35:299–313.
17. Russ AJ, Kaufman SR: Family perceptions of prognosis, silence, and the 'suddenness' of death. *Cult Med Psychiatry* 2005;29:103–123.
18. Steinhauser KE, Christakis NA, Clipp EC, et al.: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
19. Byock IR, Merriman MP: Measuring quality of life for patients with terminal illness: The Missoula-VITAS quality of life index. *Palliat Med* 1998;12:231–244.
20. Curtis JR, Patrick DL, Engelberg RA, et al.: A measure of the quality of dying and death: Initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;24:17–31.
21. Hales S, Zimmermann C, Rodin G: The quality of dying and death: A systematic review of measures. *Palliat Med* 2010;24:127–144.
22. Steinhauser KE, Bosworth HB, Clipp EC, et al.: Initial assessment of a new instrument to measure quality of life at the end of life. *J Palliat Med* 2002;5:829–841.
23. Teno JM, Clarridge BR, Casey V, et al.: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88–93.
24. Teno JM, Claridge B, Casey V, et al.: Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage* 2001;22:752–758.
25. Engelberg RA, Downey L, Wenrich MD, et al.: Measuring the quality of end-of-life care. *J Pain Symptom Manage* 2010;39:951–971.
26. Cassel EJ: The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306:639–645.
27. Akiyama A, Numata K, Mikami H: Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement. *Arch Gerontol Geriatr* 2010;50:175–178.
28. Higgins PC, Prigerson HG: Caregiver Evaluation of the Quality of End-Of-Life Care (CEQUEL) Scale: The caregiver's perception of patient care near death. *PloS One* 2013;8:e66066.
29. Garrido MM, Prigerson HG: The end-of-life experience: Modifiable predictors of caregivers' bereavement adjustment. *Cancer* 2014;120:918–925.
30. Zhang B, Nilsson ME, Prigerson HG: Factors important to patients' quality of life at the end of life. *JAMA Intern Med* 2012;172:1133–1142.
31. Ersek M, Smith D, Cannuscio C, et al.: A nationwide study comparing end-of-life care for men and women veterans. *J Palliat Med* 2013;16:734–740.

32. Cohen SR, Mount BM, Strobel MG, et al.: The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease: A preliminary study of validity and acceptability. *Palliat Med* 1995;9:207–219.
33. Cohen SR, Mount BM, Bruera E, et al.: Validity of the McGill Quality of Life Questionnaire in the palliative care setting: A multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med* 1997;11:3–20.
34. Cohen SR, Mount BM, Tomas JJ, et al.: Existential well-being is an important determinant of quality of life: Evidence from the McGill Quality of Life Questionnaire. *Cancer* 1996;77:576–586.
35. First MB, Spitzer RL, Gibbon M, et al.: *Structured Clinical Interview for the DSM-IV Axis I Disorders, Research Version, Patient Edition (SCID-I/P)*. New York: Biometrics Research, New York State Psychiatric Institute, 1995.
36. Mack JW, Nilsson M, Balboni T, et al.: Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE). *Cancer* 2008;112:2509–2517.
37. Wright AA, Mack JW, Kritek PA, et al.: Influence of patients' preferences and treatment site on cancer patients' end-of-life care. *Cancer* 2010;116:4656–4663.
38. Balboni TA, Paulk ME, Balboni MJ, et al.: Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. *J Clin Oncol* 2010;28:445–452.
39. Balboni T, Balboni M, Paulk ME, et al.: Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer* 2011;117:5383–5391.
40. Pargament KI, Koenig HG, Perez LM: The many methods of religious coping: Development and initial validation of the RCOPE. *J Clin Psychol* 2000;56:519–543.
41. Pargament K, Feuille M., Burdzy D: The Brief RCOPE: Current psychometric status of a short measure of religious coping. *Religions (Basel)* 2011;2:51–76.
42. Mack JW, Block SD, Nilsson M, et al.: Measuring therapeutic alliance between oncologists and patients with advanced cancer: The Human Connection Scale. *Cancer* 2009;115:3302–3311.
43. RAND Corporation: 36-item short form survey from the RAND Medical Outcomes Study. RAND Corporation, 2013. www.rand.org/health/surveys_tools/mos/mos_core_36item.html. Last accessed July 6, 2015.
44. Pearce MJ, Singer JL, Prigerson HG: Religious coping among caregivers of terminally ill cancer patients: Main effects and psychosocial mediators. *J Health Psychol* 2006;11:743–759.
45. Cohen S, Mermelstein R, Kamarck T, et al.: Measuring the functional components of social support. In: Sarason IG, Sarason BR (eds): *Social Support: Theory, Research, and Applications*. New York: Springer-Verlag, 1997, pp. 73–94.
46. Moos RH, Moos BS: *Family Environment Scale manual*. Washington, DC: Consulting Psychologists Press, 1991.
47. Andren S, Elmstahl S: Family caregivers' subjective experiences of satisfaction in dementia care: Aspects of burden, subjective health and sense of coherence. *Scand J Caring Sci* 2005;19:157–168.
48. Kinoshita H, Maeda I, Morita T, et al.: Place of death and the differences in patient quality of death and dying and caregiver burden. *J Clin Oncol* 2015;33:357–363.
49. Norton SA, Tilden VP, Tolle SW, et al.: Life support withdrawal: Communication and conflict. *Am J Crit Care* 2003;12:548–555.
50. Gries CJ, Curtis JR, Wall RJ, et al.: Family member satisfaction with end-of-life decision making in the ICU. *Chest* 2008;133:704–712.
51. Radwany S, Albanese T, Clough L, et al.: End-of-life decision making and emotional burden: Placing family meetings in context. *Am J Hosp Palliat Care* 2009;26:376–383.
52. Tilden VP, Tolle SW, Nelson CA, et al.: Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res* 2001;50:105–115.
53. Bradley EH, Prigerson H, Carlson MDA, et al.: Depression among surviving caregivers: Does length of hospice enrollment matter? *Am J Psychiatry* 2004;161:2257–2262.
54. Kris AE, Cherlin EJ, Prigerson H, et al.: Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *Am J Geriatr Psychiatry* 2006;14:264–269.
55. Waldrop DP, Rinfrette ES: Can short hospice enrollment be long enough? Comparing the perspectives of hospice professionals and family caregivers. *Palliat Support Care* 2009;7:37–47.
56. Goodman DC, Morden NE, Chang C, et al.: Trends in cancer care near the end of life: A Dartmouth Atlas of Health Care brief. The Dartmouth Atlas of Health Care, 2013. www.dartmouthatlas.org/downloads/reports/Cancer_brief_090413.pdf. Last accessed July 6, 2015.
57. Teno JM, Gozalo PL, Bynum JPW, et al.: Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309:470–477.
58. Bernacki RE, Ko DN, Higgins P, et al.: Improving access to palliative care through an innovative quality improvement initiative: An opportunity for pay-for-performance. *J Palliat Med* 2012;15:192–199.
59. Bookbinder M, Glajchen M, McHugh M, et al.: Nurse practitioner-based models of specialist palliative care at home: Sustainability and evaluation of feasibility. *J Pain Symptom Manage* 2011;41:25–34.
60. O'Mahony S, Blank A, Simpson J, et al.: Preliminary report of a palliative care and case management project in an emergency department for chronically ill elderly patients. *J Urban Health* 2008;85:443–451.
61. Cutler D, Skinner J, Stern AD, et al.: Physician beliefs and patient preferences: A new look at regional variation in health care spending. National Bureau of Economic Research, Cambridge, MA. 2013. www.nber.org/papers/w19320. Last accessed July 6, 2015.
62. Quill TE, Abernethy AP: Generalist plus specialist palliative care: Creating a more sustainable model. *N Engl J Med* 2013;368:1173–1175.
63. Alcorn SR, Balboni MJ, Prigerson HG, et al.: 'If God wanted me yesterday, I wouldn't be here today': Religious and spiritual themes in patients' experiences of advanced cancer. *J Palliat Med* 2010;13:581–588.
64. Morrison RS: 'We haven't got a prayer' (Or much of anything else for that matter). *J Palliat Med* 2015;5:1–2.

Address correspondence to:

Holly G. Prigerson, PhD
 Center for Research on End-of-Life Care
 Weill Cornell Medical College
 525 East 68th Street, Box 39
 1404 Baker Pavilion
 New York, NY 10065

E-mail: hgp2001@med.cornell.edu