Brief Report

The Influence of Patients’ Quality of Life at the End of Life on Bereaved Caregivers’ Suicidal Ideation

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Abstract

Context. Recent studies have shown that patients’ quality of life at the end of life (QOL@EOL) affects the psychosocial adjustment of bereaved family caregivers.

Objectives. To examine the relationship between patients’ QOL@EOL and the suicidal ideation of their surviving bereaved caregivers.

Methods. Data were derived from the Coping with Cancer (CwC1) Study, a U.S. National Cancer Institute-funded multicenter prospective cohort investigation of patients with advanced cancer and their caregivers, in which patients were enrolled September 2002 to February 2008. CwC1 data were used to examine changes in suicidal ideation in family caregivers before and after the patient’s death (N = 127). Caregiver baseline suicidal ideation was assessed using the Yale Evaluation of Suicidality (YES) Scale a median of 4.1 months pre-loss; caregivers’ perception of patients’ QOL@EOL was assessed a median of 1.9 months postloss; and caregiver suicidal ideation in bereavement was assessed using the YES a median of 6.5 months postloss. Suicidal ideation was defined as a positive screen on the YES. We used multiple logistic regression analysis to examine the effect of caregivers’ perceptions of patients’ QOL@EOL on the suicidal ideation of bereaved caregiver’s, adjusting for the caregiver’s baseline suicidal ideation and confounding influences.

Results. Caregivers’ perception of patients’ QOL@EOL was significantly inversely related to caregivers’ suicidal ideation postloss (adjusted odds ratio = 0.79, P = 0.023), after we adjusted for caregivers’ baseline suicidal ideation, relationship to patient, and years of education.

Conclusion. The more caregivers perceive their loved ones’ QOL@EOL to be poor, the greater their risk for suicidal ideation in bereavement over and above prior levels of suicidal ideation. Caregivers of patients who have poor QOL@EOL appear to be a group of caregivers to target for reduction of suicidal risk. J Pain

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Introduction

Recent research has shown that the aggressiveness of medical care that patients with cancer receive at the end of life (EOL) adversely affects their quality of life at the end of life (QOL@EOL).[^1] Much less is known about how patients’ QOL@EOL affects the psychosocial adjustment of their surviving family caregivers. Family caregivers of patients who experience more suffering at the EOL are at an increased risk for psychological distress while the patient is dying[^2] as well as after the patient has died.[^3][^4][^5][^6][^7] Prolonged, intense grief of bereaved caregivers has been shown to be associated with much psychosocial distress, including suicidal ideation.[^8][^9] It is especially important to identify and ultimately reduce risk factors associated with suicide because it is preventable.[^10] At present, no study has examined the effects of patients’ QOL@EOL on the suicidal ideation of bereaved caregivers.

Studies have shown that distress and disability experienced by patients with advanced cancer influence the emotional well-being of their informal family caregivers. Patient pain in home palliative care settings has been found to be inversely related to the psychological well-being of family caregivers.[^11] Caregivers of patients with cancer who experienced physical pain had more anxiety and depression than caregivers of patients without pain.[^12] Given et al.[^13] report an association between the number of patient’s physical symptoms at the EOL and the severity of caregiver depressive symptomatology at that time. Bambauer et al.[^14] found that patients with advanced cancer who met criteria for an anxiety disorder were significantly more likely to have family caregivers who also met criteria for an anxiety disorder. Caregivers of cognitively impaired patients with advanced cancer also have been shown to be at heightened risk for depression.[^15] These findings demonstrate that the psychological state of a family member during the period of active caregiving depends, at least to some extent, upon the psychological and physical state of the patient.

Research suggests further that patients’ QOL@EOL affects the psychological well-being of bereaved caregivers. The nature and location of the death and circumstances surrounding the loss can influence prolonged grief disorder (PGD), post-traumatic stress disorder, and major depressive disorder (MDD).[^16][^17][^18][^19] Bereaved caregivers of patients with advanced cancer who die in the intensive care unit (ICU) are at an increased risk for mental disorders (e.g., post-traumatic stress disorder).[^20] Patients who die in the ICU and receive other forms of aggressive life-prolonging care have worse QOL.[^21] Patients whose QOL was perceived to be poor by their caregivers have bereaved family survivors who report more regrets and greater rates of MDD.[^22] Elsewhere, it has been shown that bereaved caregivers who perceive the death as prolonged or violent are at risk for MDD and those who report feeling unprepared for the death are at greater risk for PGD.[^23] These findings suggest that the patient’s QOL near death will influence the psychological state of bereaved family survivors.

Bereavement in general can be a risk factor for suicidality,[^24] especially when grief is severe and enduring.[^25][^26][^27] Bereaved caregivers of patients with advanced cancer are also at risk for PGD, which itself heightens risk for suicidality.[^28][^29] Despite this increased risk for suicidality among bereaved individuals, little is known about the effect of patient QOL@EOL on caregiver suicidality in bereavement.

Identifying factors that could help to prevent suicidal ideation in bereaved caregivers of patients with cancer is a first step toward developing interventions to reduce the risk of suicide in bereaved survivors—a group at heightened risk for suicide. Here, we investigated the relationship between patient QOL@EOL and caregiver suicidality in bereavement. Specifically, we hypothesized that caregivers who perceived their loved ones’ QOL@EOL...
Methods

Sample

Study participants were informal caregivers recruited as part of the Coping with Cancer (CwC) study, a prospective, multi-institutional cohort study of patients with advanced cancer and their caregivers funded by the National Cancer Institute (CA106370) and the National Institute of Mental Health (MH63892). Participants were recruited between September 2002 and February 2008 at seven comprehensive cancer centers across the United States: Yale Cancer Center (New Haven, CT, USA), Veterans Affairs Connecticut Healthcare System Comprehensive Cancer Clinics (West Haven, CT, USA), Memorial Sloan-Kettering Cancer Center (New York, NY, USA), Parkland Hospital (Dallas, TX, USA), Simmons Comprehensive Cancer Center (Dallas, TX, USA), Dana-Farber Cancer Institute (Boston, MA, USA), and New Hampshire Oncology-Hematology (Hookset, NH, USA). Criteria for patient eligibility included diagnosis of advanced cancer (presence of distant metastases and disease refractory to first-line chemotherapy); age 20 years or older; availability of an informal caregiver willing to participate in the study; adequate stamina to complete the interview; and fluency in English or Spanish. Review boards of all participating institutions approved the study procedures; all participants provided written informed consent.

The sample for this study is a subsample of the CwC study sample, comprising informal caregivers of CwC patient participants who died by the close of the study and who completed baseline (pre-loss) and follow-up (postloss) assessments of suicidal ideation and postmortem assessments of perceived patient QOL@EOL. Caregivers in the current study (N = 127) were more likely to be non-Latino white (78.7% vs. 69.5%; Chi-square = 4.28, df = 1, P = 0.039) and better educated (mean [SD] = 14.4 [3.3] years vs. mean [SD] = 13.5[3.5] years; t = 2.62, df = 685, P = 0.009) than other caregivers enrolled in the CwC study (N = 561) but did not differ from them with respect to age, gender, or relationship to the patient. Among the 127 caregivers included in the study sample, those with missing data for caregiver relationship to patient (n = 13) did not significantly differ from those with complete data (n = 114) with respect to caregiver age, gender, race/ethnicity, education, baseline suicidal ideation, aggressive EOL patient care, and perception of patient QOD.

Measures

Sociodemographic Characteristics. Informal caregivers provided information to a trained interviewer regarding their age (years), gender (male or female), race/ethnicity (white, black, Asian or Pacific Islander, Hispanic, or other), education (years), and relationship to the patient (spouse or partner, child, sibling, parent, other relative, friend, or other).

Suicidal Ideation. Suicidal ideation was assessed at a median of 4.1 months pre-loss and again at a median of 6.5 months postloss using the Yale Evaluation of Suicidality (YES) scale. The YES is a 17-item instrument that measures current suicidal thoughts and actions, and past and planned attempts; it includes four screening items. These four screening items include “In light of your circumstances, how strong has your wish to die been?” and “In light of your current circumstances, have you ever had thoughts of killing yourself?” Response options were: “no,” “possibly,” and “yes.” Because of the rarity with which any suicidality was endorsed, we divided the suicidality screening items as follows: answers “yes” and “possibly” were regrouped to create a binary variable where 1 = “yes” and 0 = “no.” The YES scale has been found to be a valid and reliable measure of suicidality.

Aggressive EOL Care. Aggressive patient care at the EOL was defined as care in an ICU or use of mechanical ventilation, tube feeding, chemotherapy, or cardiopulmonary resuscitation in the last week of life as documented in postmortem chart reviews and interviews conducted with the formal or informal caregiver most knowledgeable about the health care the patient received in his/her final week.

Perceived QOL@EOL. Perceived QOL@EOL was measured at a median of 1.9 months
postloss using three items from the postmortem assessment. These items asked the caregiver to rate the patient’s psychological distress, physical distress, and the overall QOL in the last week of the patient’s life on a scale of 0 to 10. These three scores were averaged (after reverse coding the psychological and physical distress items) such that greater scores represent better QOL@EOL as perceived by the caregiver. Validating caregivers’ perceptions of QOL@EOL, there was a significant inverse association between perceptions of QOL@EOL and aggressive patient care at the EOL. Caregivers of patients who received aggressive EOL care had significantly lower perceptions of patient QOL@EOL ($n = 30$, mean [SD] = 4.3 [2.7]) than caregivers of patients who did not receive aggressive EOL care ($n = 97$, mean [SD] = 6.5[2.7]) ($t = -5.87$, df = 125, $P < 0.001$). Patients’ reports of their own QOL were highly significantly correlated with the caregivers’ baseline reports of the patients’ QOL, suggesting the accuracy of caregiver perception of QOL. These items have been used reliably in past research.2,4,21

Statistical Analysis

Means, SDs, and frequencies were used to describe caregiver study variables, including pre-loss caregiver suicidal ideation, aggressive EOL patient care and caregiver perception of patient QOL@EOL. Associations between caregiver variables and suicidal ideation in bereavement were assessed in terms of odds ratios (ORs) estimated using logistic regression. Caregiver variables significantly associated with suicidal ideation in bereavement were included in a final multiple logistic regression model. All analyses were performed using the SAS statistical package, version 9.2 (SAS Institute Inc., Cary, NC, USA).

Results

Of the 127 caregivers in this study, 33 (26%) were men, 100 (79%) were non-Latino white, and 58 of 114 (51%) were the patient’s spouse. The average age of the caregivers was 53 years (SD = 13) and the average total years of formal education was 14 (SD = 3). Suicidal ideation was reported in 15 (12%) of the caregivers at pre-loss, and in 21 (17%) of the caregivers postloss. Thirty (24%) cared for patients who received aggressive EOL care. Average perceived patient QOL@EOL was 6 (SD = 2.8) on a scale from 0 to 10.

Four caregiver variables were significantly bi variately associated with caregiver suicidal ideation in bereavement: spousal relationship to patient (OR = 4.53, $P = 0.012$), baseline suicidal ideation (OR = 6.13, $P = 0.002$), education (OR = 0.81, $P = 0.012$), and perceived patient QOL@EOL (OR = 0.82, $P = 0.020$). A multiple logistic regression model for caregiver suicidal ideation in bereavement including these four caregiver variables as predictors ($n = 114$) found that caregivers’ perception of patients’ QOL@EOL remained significantly inversely related to caregivers’ suicidal ideation postloss (adjusted odds ratio = 0.79, $P = 0.023$; Table 1).

Discussion

This study found that the more caregivers perceive their loved ones’ QOL@EOL to be poor, the greater their risk for suicidal ideation in bereavement. Other risk factors for suicidal ideation in bereavement were a spousal relationship to the patient and baseline suicidal ideation. Spouses with lower levels of perceived patient QOL@EOL who endorsed baseline suicidal ideation were at the greatest risk for suicidal ideation after the patient died.

Aggressive patient care at the EOL, although not directly related to caregiver suicidal ideation, was significantly related to caregivers’ perceptions of patient QOL@EOL, with aggressive EOL patient care being associated with lower caregiver perceived patient QOL@EOL. Caregivers have been found to accurately report their loved ones’ QOL.4 Thus, aggressive EOL care appears to indirectly affect bereaved individual’s suicidality through its influence on patient QOL. Regardless of the factors contributing to poor QOL@EOL, however, to the extent caregivers perceive the QOL@EOL to be better, their risk of suicidal ideation in bereavement would be expected to be reduced. Interventions to reduce suicidality of bereaved caregivers—a group at much elevated risk for suicide—might target caregivers who evaluate the patient’s QOL@EOL to be poor.

This study has several limitations as well as some strengths. Limitations include its modest overall sample size ($N = 127$) and the small
absolute number of caregivers with suicidal ideation in bereavement \((n = 21)\). Nevertheless, this sample was sufficient to find statistically significant effects of caregivers’ perception of patient QOL@EOL on caregiver’s severity of suicidal ideation in bereavement, adjusting for pre-loss levels. Another limitation of the study is that items used to measure suicidal thoughts and ideations do not reflect actual suicide attempts or completions. However, suicidal ideations are significant predictors of completed suicide.\(^{22}\)

Strengths of the study include its longitudinal design, with caregiver assessments of suicidal ideation both pre- and postloss, and its use of both aggressiveness of actual EOL patient care and caregivers’ perceptions of patients’ QOL@EOL.

Suicidal ideation is the result of serious psychological distress. Because it is modifiable, it is important to identify risk factors to inform interventions to reduce suicidal risk. Caregivers of patients with cancer at the EOL should be screened for suicidal ideations. Those found to screen positive should be referred for support or intervention to reduce suicidal risk in this vulnerable group. This study has identified risk factors for suicidal ideation in bereaved caregivers, and one of those risk factors, perception of poorer patient QOL@EOL, relates to the intensity of EOL care the patient receives. The American Medical Association’s Choose Wisely\(^{23}\) campaign targets reduction in futile overtreatment. To the extent that unbeneficial, burdensome intensive care in dying patients is averted, reducing overtreatment might improve caregiver perception of QOL@EOL and thus indirectly reduce suicidal ideation among bereaved caregivers.

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References


Table 1

<table>
<thead>
<tr>
<th>Caregiver Variable</th>
<th>Descriptive Statistics</th>
<th>Association With Suicidal Ideation in Bereavement (21/127 = 16.5%)</th>
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<td>n (%)</td>
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<td>Categorical variables</td>
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<td>Baseline suicidal ideation</td>
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<td>Aggressive EOL patient care</td>
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<td>Continuous variables, mean ± SD</td>
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<td>Education, yrs</td>
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<tr>
<td>Perceived patient QOL@EOL</td>
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</table>

QOL@EOL = quality of life at the end of life.
The multiple logistic regression model to estimate adjusted odds ratios \((N = 114)\) included caregiver relationship to patient, baseline suicidal ideation, education, and perception of patient QOL@EOL (average of three items—mental distress [inverse coded], physical distress [inverse coded], and overall quality of death).


