Health Care Proxy Grief Symptoms Before the Death of Nursing Home Residents With Advanced Dementia

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Abstract

Objectives—The loss experienced by family members of dementia patients before their actual death is known as "predeath grief." This study's objectives were to identify and describe factors associated predeath grief symptoms among health care proxies (HCPs) of nursing home (NH) residents with advanced dementia, and distinguish grief symptoms from those of depression.

Design—Cross-sectional.

Setting—Twenty-one Boston-area NHs.

Participants—Three hundred fifteen NH residents with advanced dementia and their HCPs.

Measurements—Factor analysis was used to distinguish predeath grief and depression symptoms. Multivariate regression analyses identified factors associated with greater predeath grief measured on a 10-item summary scale of grief symptoms. Independent variables included sociodemographic information and health status of HCPs and residents, and depressive symptoms, physician communication, preparedness for death, and satisfaction with care of HCPs.

Results—Predeath grief symptoms were distinct from depressive symptoms. The mean predeath grief scores was 15.0 ± 5.6 (range, 10–49), suggesting relatively low levels of overall grief. Yearning (i.e., separation distress) was the most frequently experienced grief symptom (sometimes, 27%; often, 18%; or always, 15%). Variables associated with greater predeath grief included HCPs whose primary language was not English, HCPs who lived with a resident before institutionalization, more depressive symptoms of HCPs, less satisfaction with care of HCPs, and younger resident age.

Conclusions—Family members of NH residents with advanced dementia experience predeath grief symptoms, particularly separation distress. Predeath grief symptoms are associated with, but distinct from, those of depression. Several factors identified HCPs at higher risk for predeath grief and who may benefit from early interventions to reduce suffering.

Keywords

Grief; depression; advanced dementia; nursing homes; health care proxy

In 2000, an estimated 4.5 million Americans had dementia, and by 2030, this number is expected to exceed 13 million.[1] In 2003, Alzheimer disease was listed as the fifth leading cause

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of death among Americans over 65 years. Surprisingly, little research has focused on the growing number of patients dying with dementia, in part, because of an under-recognition of dementia as a terminal illness.[2] Accordingly, emerging data suggest that the end-of-life experience of these patients is not optimal.[2]

Caring for dying patients has a substantial emotional toll on family members.[3] Almost all mental health research of dementia caregivers has been community based, despite the fact that approximately 70% of persons with dementia die in nursing homes (NHs).[4] Health care proxies (HCPs), who are most often family members, are the decision-makers for these residents, although they do not provide direct care. Thus, the term "HCP," rather than "caregiver," is used in this article. Depression and anxiety among family members do not decline when dementia patients are admitted to NHs, although direct care-giving burdens are relieved.[5] The reasons are not known; however, it is possible that new sources of emotional distress emerge for the family when their loved one is institutionalized (e.g., feelings of guilt, loss of control). Moreover, few NHs offer grief and bereavement support,[6] underscoring the need to better understand and address the sources of burden experienced by the family members in this setting.

Family members of dementia patients experience multiple losses, sometimes referred to as "triple grief."[7] First, they grieve the loss of the patients' personhood before their actual bodily death, which has been called "anticipatory grief" but will be referred to as "predeath grief" in this article. Next, the families experience loss at the time of NH admission. Finally, there is the loss experienced when the patient ultimately dies. Although the concept of dementia-related predeath grief is recognized,[8–13] to our knowledge, its features and characteristics have not been described with empiric data.

Prior work has shown that grief symptoms are distinct from symptoms of depression among bereaved individuals suffering the death of cancer patients.[14] This distinction is important to recognize because the clinical course,[15] outcomes,[16–20] and most notably, the treatment of grief-related symptoms and bereavement-related depression differ.[21–23] This issue has not been studied with regards to pre-death grief and advanced dementia.

Thus, the objectives of this study are 1) to describe the symptoms of predeath grief among HCPs of NH residents with advanced dementia, 2) to distinguish predeath grief symptoms from those of depression, and 3) to identify HCP and resident characteristics associated with greater predeath grief symptoms. This information is a first step toward understanding and reducing the mental health burden experienced by families of loved ones who are dying with advanced dementia in the NH setting.

METHODS

Data Source

Data were obtained from the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study, a prospective cohort study designed to address the major gaps in knowledge needed to improve the care of NH residents with advanced dementia and their families. As described in detail elsewhere,[24] the study followed the clinical course of NH residents with advanced dementia during the end stages of their disease and during the dying process, as well as the experience of their HCPs.

Study Sample

Subjects in the CASCADE study consist of dyads: NH residents with advanced dementia and their HCPs. The residents living in 22 Boston-area facilities were recruited between February 2003 and August 2007. Participant facilities represented a convenience sample of NHs that

met the following criteria: 1) located within a 60-mile radius of Boston, 2) >60 beds, and 3) accessible minimum data set (MDS)[25] assessments to facilitate the screening protocol. The MDS is a standardized assessment tool that is completed on a quarterly basis on residents living in all licensed US NHs. As a first step in identifying the study cohort, all residents living in the facility who met the following screening requirements were identified: 1) >60 years, 2) Cognitive Performance Score (CPS) of 5 or 6 (range = 0–6) on their most recent MDS assessment, indicating severe to very severe cognitive impairment,[26] and 3) length of stay >30 days. Residents meeting these requirements were then evaluated to determine whether they met the following additional eligibility criteria: 1) cognitive impairment was due to dementia, 2) Global Deterioration Scale (GDS) score of 7 as determined by a nurse (range = 1–7, higher scores indicate more advanced dementia),[27] and 3) an appointed HCP who could communicate in English. The diagnosis of dementia was confirmed with the resident's physician if it was ambiguous in the record. At a GDS 7 stage, patients with dementia are characterized by very severe cognitive decline, minimal verbal communication, dependence for eating and toileting, incontinence of urine and stool, and inability to walk.[27]

Health Care Proxy Predeath Grief Symptoms

Baseline HCP measures were obtained during a telephone interview. Predeath grief symptoms were measured using a modified version of the Prolonged Grief Disorder (PGD)-12.[28] The PGD-12 is a validated measure that consists of 12 items; however, only 10 of the 12 items were available for analyses because the CASCADE study design preceded finalization of the PGD-12. The 10-item predeath grief scale asks respondents how often they experienced distressing grief symptoms (Likert scale ranging from 1 [almost never] to 5 [always]) related to yearning, bitterness, interpersonal disengagement, and a sense of meaninglessness (Table 2). A summary score of these 10 items ranged from 10 to 50, with higher scores indicating greater grief symptoms.

Health Care Proxy Depressive Symptoms

The K6 is a validated six-item instrument assessing the frequency with which depressive symptoms are experienced during the prior 30 days[29] (Table 2). Each item is rated on a five-point Likert scale (0 = never, 1 = a little of the time, 2 = sometimes, 3 = most of the time, 4 = all the time), for a total score ranging from 0 to 24, with higher scores indication greater depressive symptoms. The K6 was developed after an extensive content analysis, face validity review, and modern psychometric analysis of 612 questions from 18 dimensional measures, and demonstrated excellent reliability in the National Health Interview Surveys ($\alpha = 0.89$).

Other Health Care Proxy Variables

HCP variables believed to be potentially associated with predeath grief were selected for analysis, a priori, based on the literature and clinical experience.[2,3] These variables included data describing: sociodemographic information, level of engagement with resident, general physical health, communication with care providers, preparedness for death and satisfaction with care.

Sociodemographic variables included age, gender, race (white versus nonwhite), relationship to resident, marital status (married versus other), primary language (English versus other), education level (>high school versus other) and employment status (full-time versus other).

Variables describing level of engagement included: whether the HCP lived with the resident before institutionalization, whether the HCP visited the resident in the NH ≥7 hours per week, and the number of years as HCP. The physical health subscale of the SF-12 measured the HCPs' general health status.[30]

Communication and preparedness variables included whether the HCP spent ≥15 minutes discussing the residents' advance directives with a physician at the time of NH admission, a physician counseled the HCP on the residents' prognosis, the HCP believed life prolongation was the main goal of care, the HCP believed that dementia is a terminal illness, and the HCP felt the resident had <6 months to live (Table 1).

HCP satisfaction with care during the past 90 days was measured using the validated Satisfaction with Care at End-of-Life in Dementia (SWC-EOLD) scale.[31,32] The scale's 10 items address decision-making, communication with health care professionals, understanding the resident's condition, and the resident's medical and nursing care. Each item is measured on a four-point Likert scale ranging from 1 to 4 as follows: strongly disagree, disagree, agree, strongly agree. The summary score ranges from 10–40 (higher scores indicate more satisfaction).

Resident Variables

Resident baseline data were collected from the NH medical records by chart review and nursing interview. Resident variables felt, a priori, to be potentially associated with HCPs' pregrief symptoms were selected for analyses. Resident sociodemographic variables included: age, gender, race, NH length of stay, and whether the resident lived in a special care dementia unit.

Resident health status variables, as determined by a nurse interview, included physical discomfort, functional status and quality of life. Physical discomfort during the prior 90 days was assessed using the validated Symptom Management at End-of-Life in Dementia Scale. [31,32] The scale quantifies the frequency the resident experienced nine symptoms and signs during the previous 90 days including pain, shortness of breath, depression, fear, anxiety, agitation, calm, skin breakdown, and resistance to care. Each item is quantified on a six-point Likert scale (0–5), and a summary score ranges from 0–45 (higher scores indicate better symptom control). The Bedford Alzheimer Nursing Scale—Severity Subscale (BANS-S), a seven-item scale ranging from 7 (no impairment) to 28 (most severe impairment) was used to measure functional disability.[33] The Quality of Life in Late-Stage Dementia measured overall quality of life.[34]

Data Analysis

The summary predeath grief scale was the outcome for all analyses. Descriptive analyses were conducted to characterize the sample and to describe the predeath grief symptom scale.

Cronbach alpha coefficient was calculated for the predeath grief and K6 (depressive symptoms) scales to estimate their internal consistency. The predeath grief symptoms of items, combined with the K6 items, were included in a factor analysis to determine whether the symptoms of these two constructs were distinguishable. The analysis was restricted to the two factors of interest and the scree plot supported this perspective. A varimax rotation was performed on the factor solution to make the solution easier to interpret.

Regression models were used to determine HCP and resident characteristics associated with predeath grief symptoms. The facility effect was controlled for in all regressions (Proc Mixed, SAS). Parameter estimates, 95% confidence intervals (CIs) and p values were produced from all regression analyses. An unadjusted regression model was run for each characteristic listed in Table 1, to guide the selection of variables to be included in the multivariate adjusted regression model (Table 4). Graphical and descriptive information suggested that the predeath grief scale may not be normally distributed, an assumption of regression models. Therefore, we log-transformed the predeath grief scale and included it as the dependent variable in separate, otherwise identical, regression models. An alpha level of 0.05 was used in all analyses

to determine statistical significance. SAS, Version 9.1 for Windows (SAS Institute, Inc., Cary, NC) was used for data management and statistical analyses.

RESULTS

Study Sample

A total of 1,763 NH residents were screened for the study, of which 574 (32.6%) met eligibility criteria. From among those eligible, 325 (56.8%) residents with advanced dementia and their HCPs were recruited. Reasons for nonrecruitment included HCP refusal (N = 247, 82.9%) and physician refusal (N = 1, 0.3%). Nonrecruited eligible residents did not differ significantly from those recruited with respect to mean age or gender. In addition, 10 HCPs (3.1%) who were legal guardians rather than family members were excluded, as their relationship to the resident was not clearly relevant to a study of grief. Thus, a total of 315 HCPs (21 facilities) were included in these analyses.

Table 1 provides characteristics of the NH residents with advanced dementia and their HCPs. HCP were predominately female (63%), white (89%), married (69%), and the majority had greater than a high school education (75%). Their average age was 60 ± 12 years, more than half of the HCPs worked full time (51%), and their primary languages were as follows: English (98%), Russian (1%), French (<1%), and other (1%). The relationship of the HCPs to the resident was: child (70%), spouse (10%), niece or nephew (8%), sibling (5%), grandchild (1%), legal guardian (3%), and other (child-in-law, cousin, friend, or godson) (3%).

Only 36% of HCPs lived with the residents before NH admission, and 21% visited the resident >7 hours per week. The mean number of years as HCP was 7.4 ± 5.8. The mean physical subscale of the SF-12 score was 51.2 ± 9.9, indicating good health. A mean K6 score of 2.2 ± 3.1 suggested that HCPs did not suffer high levels of depressive symptoms. Table 2 displays the K6 items and HCP responses. Cronbach alpha was moderately good for the K6 ($\alpha = 0.76$).

At the time of NH admission, 49% of HCPs spent over 15 minutes discussing advance directives with a physician, and 17% received prognostic counseling. Just 4% of HCPs felt life prolongation was the main goal of care, and 64% believed dementia was a terminal illness, whereas only 13% felt the resident had less than 6 months to live. The mean SWC-EOLD score (30.6 ± 4.2) indicated a moderately good level of satisfaction with care.

The average resident age was 85.2 ± 7.6 years and they were predominately female (85%) and white (89%). The average length of stay in the NH was 1,388 days and 44% lived in a special care unit. The mean BANS-S score was 20.9 ± 2.4, indicating severe functional disability.

Predeath Grief Symptoms

The average predeath grief symptoms score was 15.0 ± 5.6 (range: 10–49). Table 2 presents the pre-death grief scale items and their distributions. Cronbach alpha was good for this scale ($\alpha = 0.81$). The majority of HCPs rarely or never experienced most grief symptoms. However, the notable exception related to yearning or longing, reflective of "separation distress," the most commonly experienced grief symptom.

Distinguishing HCP Predeath Grief and Depressive Symptoms

Table 3 presents the factor loadings from the factor analysis for predeath grief symptoms (factor 1) and depressive symptoms (factor 2). The eigenvalues for factor 1 and factor 2 were 5.1 and 1.9, accounting for 32% and 12% of the common variance, respectively. Two distinct factor clusters were observed. The pre-death grief symptom items consistently had higher factor loadings in factor 1 as compared to factor 2. The only exception to this was in the question

"Your emotional distress about [resident's] illness has significantly impaired your social, occupational or other areas of functioning" where the loadings were similar. We expected this question to be relevant to both factors because it is a generic measure of functional disability. When this item was not included in the analyses, the factor loading results were unchanged.

Factors Associated With Predeath Grief

Table 1 presents the unadjusted regression parameters and corresponding unadjusted 95% CIs and p values for the association between each HCP and resident characteristic with predeath grief symptoms. The following characteristics were significantly associated with pregrief and included in the initial multivariate model: HCP's marital status, HCP's primary language, HCP education level, whether the HCP lived with the resident before institutionalization, whether the HCP visits more than 7 hours per week, depressive symptoms (K6), whether the HCP spent more than 15 minutes discussing advance directive with the physician, satisfaction with resident care (SWC-EOLD), and resident age.

Table 4 presents the final multivariate adjusted regression parameter estimates, 95% CIs and adjusted p values. The following HCP variables were independently associated with greater symptoms of predeath grief: primary language not English, lived with the resident before institutionalization, more depressive symptoms, and less satisfaction with care. Younger age was the only resident factor independently associated with greater predeath grief symptoms. Analyses did not differ when using the log-transformed predeath grief scale; therefore, only results of the untransformed models were presented.

DISCUSSION

To our knowledge, this is the first study describing factors associated with predeath grief symptoms experienced by HCPs before the death of their loved one with advanced dementia in the NH setting. Although the overall mean grief score was relatively low, symptoms of separation distress (i.e., yearning or longing) were common among HCPs. Additionally, we report several factors that may help identify HCPs at higher risk for predeath grief, and who may benefit from interventions designed to reduce suffering. We also demonstrated that predeath grief symptoms are correlated with, but are distinct from, symptoms of depression.

The concept of predeath grief is particularly relevant in advanced dementia compared to other terminal conditions. Unlike cancer, where there may be some hope for recovery, advanced dementia is a progressive disorder that inevitably ends with death. Moreover, during the course of the disease, family members gradually lose the essence of their loved one because of the degenerative nature of dementia. Symptoms of grief, while present, were not extensive among of HCPs. It is possible that grief was more pronounced earlier in the dementia course or before institutionalization.

The decision to institutionalize is typically motivated by the family's inability to continue providing adequate home care, and represents the loss of their role as primary caregiver. To that end, note that HCPs who had lived with the resident before institutionalization had greater predeath grief symptoms compared to those who had not. In addition to relinquishing their care-giving role, HCPs may be emotionally and psychologically closer to their loved ones and accordingly suffer more grief upon their separation. It is not surprising that separation distress was the most common manifestation of grief among HCPs, expressed as a sense of "yearning" for the patients as they used to be. Yearning is also commonly experienced by bereaved family members after the death of a loved one with cancer.[35]

The finding that lower satisfaction with NH care was associated with greater symptoms of grief supports earlier work demonstrating that better end-of-life care for patients is associated with

better outcomes for family members,[36] and offers a modifiable opportunity for improvement. It is not surprising that younger resident age was associated with more predeath grief. Younger age at the onset of dementia is associated with a more rapid rate of decline,[37] and advanced dementia in a relatively younger person may be viewed as a particularly tragic loss. Although only 2% of HCPs spoke a primary language other than English, they experienced more predeath grief symptoms. This finding may reflect a greater sense of loss among cultures that are less accustomed to relinquishing the care of their loved ones to institutions. However, primary language is not an optimal measure of acculturation, and further research is needed to understand cultural differences in the grieving process.

This study, corroborates earlier work showing that grief and depressive symptoms are distinct among bereaved families,[14,16,20,38] but extends this observation for the first time to advanced dementia, and to the concept of predeath grief. Bereavement-related depression and grief differ with respect to risk factors,[39] symptoms,[14,19] clinical course,[15] outcomes,[16–20] and treatment response.[21,22] For example, independent of depression, grief is associated with serious adverse consequences including: increased suicidal behavior, poorer physical health, and reduced quality of life.[16–20] Regarding varying treatment response, Reynolds et al.[21] found that nortriptyline and interpersonal psychotherapy, alone or in combination, ameliorated symptoms of bereavement-related depression (remission rate for combined therapy was 69%), but neither of these treatment modalities proved more effective than placebo in reducing grief symptoms over 16 weeks. In contrast, psychotherapy designed specifically to treat grief-related symptoms has been efficacious in randomized trials.[23] The reason underlying the varying treatment response may relate to the notion that although grief may be associated with sadness, the primary problem is a sense of separation and loss. As such, treatments that aim to prepare family members specifically for those feelings may be more effective that treatments which only target symptoms of depression.[23] Thus, it is important to establish that grief and depression are distinct conditions, so that clinicians do not misdiagnose and mistreat grief-related symptoms.

This study has notable limitations. First, because the CASCADE study was limited to the Boston area and a 89% white sample, our findings may not generalize to other locations and populations. Second, the study is cross-sectional and occurs at a random point in the residents' NH home stay. Third, although the K6 is a validated measure of depressive symptoms, it does not provide a measure of "caseness" of depression. However, the relatively low frequency of depressive symptoms makes it is unlikely that many HCPs would have met the criteria for a major depression. Finally, this study does not explore the impact of predeath grief on HCP outcomes (e.g., bereavement).

Grief is associated with considerable morbidity and societal burden.[18,40] This research is an initial step toward understanding grief among family members of persons with advanced dementia before their death. These family members experience grief symptoms, particularly separation distress, and these grief symptoms are distinct from those of depression. Moreover, health professionals should be particularly alert to family members of relatively younger patients, who are non-English speaking, and who lived with their loved ones before institutionalization, as they may be more susceptible to suffering predeath grief. Finally, improving the overall quality of NH care for residents dying with dementia may reduce symptoms of grief suffered by their families.

Acknowledgements

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TABLE 1

Unadjusted Analyses: Characteristics of Residents With Advanced Dementia and Their Health Care Proxies, and Their Association With Health Care Proxy Predeath Grief Symptoms (n = 315)

Characteristic	Mean (SD) or Frequency (%)	Parameter Estimate[a] (95% CI)	Unadjusted p[a]
Health care proxy			
Sociodemographic			
Age	59.9 (11.5)	−0.03 (−0.08, 0.03)	0.35
Female	200 (63)	0.84 (−0.45, 2.14)	0.20
White (versus other)	282 (89)	2.00 (−0.07, 4.07)	0.06
Child of resident	221 (70)	0.02 (−1.34, 1.38)	0.97
Married	216 (69)	1.57 (0.24, 2.90)	0.02
English primary language	309 (98)	−7.19 (−11.67, −2.71)	0.002
>High school education	237 (75)	−1.79 (−3.23, −0.35)	0.01
Works full time	160 (51)	−0.25 (−1.50, 1.00)	0.69
Level of engagement with resident			
Lived with resident before institutionalization	115 (36)	2.42 (1.15, 3.69)	0.0002
Visits >7 hours per week	67 (21)	2.79 (1.30, 4.29)	0.0003
Number of years as proxy	7.4 (5.8)	0.06 (−0.05, 0.17)	0.26
Mental health			
K6 (Depressive symptoms)[b]	2.2 (3.1)	0.79 (0.61, 0.97)	0.0001
Physical health			
SF-12 physical component[c]	51.2 (9.9)	0.04 (−0.03, 0.10)	0.26
Communication/preparedness			
Spent >15 minutes discussing advance directives with MD	150 (49)	1.38 (0.14, 2.62)	0.03
Physician counseled about prognosis	54 (17)	0.51 (−1.13, 2.15)	0.54
Life prolongation is the main goal of care	14 (4)	−0.06 (−3.07, 2.95)	0.97
Believes dementia is a terminal illness	198 (64)	0.97 (−0.34, 2.28)	0.15
Feels resident has <6 months to live	38 (13)	−1.35 (−3.31, 0.62)	0.18
Satisfaction with care			
SWC-EOLD[d]	30.6 (4.2)	−0.17 (−0.32, −0.02)	0.02
Resident			
Sociodemographic			
Age	85.2 (7.6)	−0.20 (−0.28, −012)	0.0001
Female	269 (85)	0.79 (−0.97, 2.54)	0.38
White (versus other)	282 (89)	2.02 (−0.05, 4.09)	0.06
Length of stay (days)	1388.3 (1215.4)	−0.0005 (−0.001, 0.00004)	0.07
Lives in special care unit	138 (44)	−0.73 (−2.02, 0.56)	0.27
Health status			
SM-EOLD[e]	36.8 (7.9)	−0.05 (−0.13, 0.02)	0.18
BANS-S[f]	20.9 (2.4)	0.06 (−0.20, 0.32)	0.66
QUALID[g]	22.6 (6.1)	0.06 (−0.04, 0.16)	0.23

Characteristic	Mean (SD) or Frequency (%)	Parameter Estimate[a] (95% CI)	Unadjusted p[a]

[a]Unadjusted linear regression models were used to analyze the association between each individual characteristic with the summary predeath grief scale that ranges from 10 to 50, with higher scores indicating greater grief symptoms. The p values and coefficient estimates (i.e., slopes) were derived from these unadjusted regressions models. Degrees of freedom (denominator) for the coefficient estimate = 293.

[b]Depressive symptoms—K6 (possible range 0–24 higher scores indicate greater depressive symptoms).

[c]SF-12 physical component—Medical Outcomes Survey 12-item Short Form (possible scores 10–70; higher scores indicate greater physical health.

[d]SWC-EOLD—Satisfaction with Care at End-of-Life in Dementia Scale (possible scores 10–40; higher scores indicate more satisfaction).

[e]SM-EOLD—Symptom Management at the End-of-Life in Dementia Scale (possible scores 0–45; higher scores indicate better symptom control).

[f]BANS-S—Bedford Alzheimer Nursing Scale—Severity Subscale (possible scores 7–28; higher scores indicate greater functional disability).

[g]QUALID—Quality of Life in Late-Stage Dementia (possible scores 11–55; lower scores indicate greater quality).

TABLE 2

Percent of Health Care Proxies Experiencing Symptoms of Predeath Grief and Depression (n = 315)

Predeath Grief Scale Items	Almost Never	Rarely	Sometimes	Often	Always
You feel yourself longing and yearning for the [resident] as she or he used to be before becoming ill	29	11	27	18	15
You feel disbelief over the [resident's] illness	76	9	8	3	4
You feel stunned, dazed, or shocked over the [resident's] illness	80	8	6	3	2
You go out of your way to avoid reminders of the [resident's] illness	85	5	7	2	1
You feel like you have become numb since the [resident] became so seriously ill	82	6	9	2	1
You feel bitter over the [resident's] illness	75	7	11	3	3
You feel like the future holds no meaning or purpose without the [resident] being healthy	89	4	5	1	1
You feel unable to imagine life being fulfilling without the [resident] being healthy	83	7	8	1	1
You feel that a part of you died when the [resident] became sick	72	7	16	2	2
Your emotional distress about [resident's] illness has significantly impaired your social, occupational or other areas of functioning	78	11	9	1	1

Depression Symptom Scale Items (K6)[a]	Never	A Little of the Time	Sometimes	Most of the Time	All the Time
During the past 30 days, about how often did you feel …					
• So depressed that nothing could cheer you up?	90	5	4	1	<1
•Hopeless?	92	4	3	<1	1
•Restless or fidgety?	64	12	20	2	2
•Everything was an effort?	72	6	17	2	2
•Worthless?	95	2	3	<1	0
•Nervous	67	8	20	3	1

[a] A validated six-item instrument assessing nonspecific psychological distress, particularly depression.

TABLE 3

Factor Loadings for Health Care Proxy Predeath Grief Symptoms and Depression Symptoms (n = 315)

Scale Items	Factor Loadings	
	Predeath Grief Symptoms Factor 1	Depression Symptoms Factor 2
You feel yourself longing and yearning for the[resident] as she or he used to be before becoming ill	0.49	0.31
You feel disbelief over the [resident's] illness	0.68	0.07
You feel stunned, dazed, or shocked over the[resident's] illness	0.65	0.28
You go out of your way to avoid reminders of the [resident's] illness	0.64	−0.12
You feel like you have become numb since the [resident] became so seriously ill	0.46	0.26
You feel bitter over the [resident's] illness	0.58	0.17
You feel like the future holds no meaning or purpose without the [resident] being healthy	0.65	0.06
You feel unable to imagine life being fulfilling without the [resident] being healthy	0.67	0.19
You feel that a part of you died when the[resident] became sick	0.65	0.20
Your emotional distress about [resident's] illness has significantly impaired your social, occupational or other areas of functioning	0.38	0.45
During the past 30 days, about how often did …		
•You feel so depressed that nothing could cheer you up?	0.28	0.70
•You feel hopeless?	0.16	0.69
•You feel restless or fidgety?	−0.03	0.60
•You feel that everything was an effort?	0.15	0.72
•You feel worthless?	0.13	0.58
•You feel nervous?	0.12	0.72

TABLE 4

Multivariate Analysis: Characteristics of Residents With Advanced Dementia and Their Health Care Proxies That Are Associated With Greater Predeath Grief Symptoms Among Health Care Proxies (n = 315)

Characteristic	Parameter Estimate[a] (95% CI)	Adjusted[a] p
Proxy		
Sociodemographic		
English primary language	−6.66 (−10.53, −2.79)	0.0008
Level of engagement with resident		
Lived with resident before institutionalization	1.48 (0.36, 2.60)	0.01
Mental health		
Depressive symptoms[b]	0.70 (0.53, 0.87)	0.0001
Satisfaction with care		
SWC-EOLD[c]	−0.13 (−0.25, −0.0003)	0.04
Resident		
Sociodemographic		
Age	−0.15 (−0.22, −0.08)	0.0001

[a]Multivariate adjusted linear regression was used to model the association between characteristics with the summary predeath grief scale (range, 10–50, with higher scores indicating greater grief symptoms). The p values and coefficient estimates (i.e., slopes) were derived from this regression model that adjusted for all characteristics presented in Table 4. Degrees of freedom (denominator) for the coefficient estimate = 289.

[b]Depressive symptoms—K6 (possible range 0–24 higher scores indicate greater depressive symptoms).

[c]WC-EOLD—Satisfaction with Care at End-of-Life in Dementia Scale (possible scores 10–40; higher scores indicate more satisfaction).