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Grief among Family Members of Nursing Home Residents with Advanced Dementia

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Abstract

Objectives—To describe pre-loss and post-loss grief symptoms among family members of nursing home (NH) residents with advanced dementia, and to identify predictors of greater post-loss grief symptoms.

Design—Prospective cohort study.

Setting—22 NHs in the greater Boston area.

Participants—123 family members of NH residents who died with advanced dementia.

Measurements—Pre-loss grief was measured at baseline, and post-loss grief was measured 2 and 7 months post-loss using the Prolonged Grief Disorder scale. Independent variables included resident and family member sociodemographic characteristics, resident comfort, acute illness, acute care prior to death, family member depression, and family member understanding of dementia and of resident's prognosis.

Results—Levels of pre-loss and post-loss grief were relatively stable from baseline to 7 months post-loss. Feelings of separation and yearning were the most prominent grief symptoms. After multivariable adjustment, greater pre-loss grief and the family member having lived with the resident prior to NH admission were the only factors independently associated with greater post-loss grief 7 months after resident death.

Conclusions—The pattern of grieving for some family members of NH residents with advanced dementia is prolonged and begins before resident death. Identification of family members at risk for post-loss grief during the pre-loss period may help guide interventions aimed at lessening post-loss grief.

Keywords

dementia; grief; nursing homes

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OBJECTIVE

Dementia is the fifth leading cause of death among Americans over the age of 65,¹ and provides a common context in which family members experience grief. Although bereavement is often a natural process without lasting consequences, for some, the loss of a loved one is associated with increased risk of psychiatric and medical morbidity as well as mortality.²⁻³ The majority (70%) of deaths among patients with dementia occur in the nursing home (NH)⁴ where bereavement services are limited,⁵ and where family member grief symptoms may be unrecognized.

Much of the prior work describing grief has focused on family members of patients with cancer or other terminal illnesses. This research found that a subgroup of family members have high levels of grief symptoms, associated with worse quality of life and mental health.⁶⁻⁸ However, little attention has been paid to grief of families of patients with dementia, particularly in the NH setting. Such study is warranted because the pattern and consequences of grief associated with dementia are likely to be distinct due to the prolonged and progressive course of illness, the failure to recognize dementia as a terminal illness,⁹ and the potential loss of personhood associated with the disease from the perspective of the family member.¹⁰ Furthermore, for families of NH residents, there can be an additional sense of loss, sometimes also accompanied by a sense of relief, upon institutionalization, which when combined with the loss of the unique qualities of the individual and the final loss upon patient death comprise a phenomenon referred to as “triple grief”.¹¹ Much attention has been paid to caregiver burden among families caring for patients with dementia in the community,¹²⁻¹⁴ and greater burden is one of the predictors of prolonged grief in this population, along with family member depression and greater patient cognitive impairment.¹⁵

To date, the full spectrum of grief symptoms experienced by family members of NH residents with advanced dementia has not been explicitly studied. Prior work using data from the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE)¹⁶ study has focused on pre-loss grief, documenting that pre-loss grief symptoms are distinct from those of depression and are related to dissatisfaction with care provided to the resident.¹⁷ While there is recognition that grief symptoms may vary among individuals,¹⁸ no study known to us has rigorously examined predictors of greater post-loss grief among family members of NH patients with advanced dementia. The objectives of this study were to: 1. describe post-loss grief symptoms; and 2. to identify risk factors associated with greater post-loss grief symptoms. Specific factors hypothesized to be associated with greater post-loss grief included resident characteristics (younger age, less functional and cognitive impairment, lower comfort, lack of hospice referral, recent hospitalization or acute illness), and family member characteristics (greater pre-loss grief, lower importance of religion, greater pre-loss or current depression and poorer understanding of the resident’s prognosis).^{15, 19-21}

METHODS

Sample

Participants were from the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study; a prospective cohort study of NH residents with advanced dementia and their health care proxies (HCPs). Details of the CASCADE study methodology are described elsewhere.^{16, 23} Residents were from 22 NHs within 60 miles of Boston having at least 60 beds. Participant eligibility criteria were: 1) age > 60; 2) dementia (any type); and 3) Global Deterioration Scale (GDS)²⁴ score of 7 (cannot recognize family, minimal verbal communication, total functional dependence, incontinence

of urine and stool, inability to ambulate independently). Residents had to have a designated HCP who could provide informed consent and communicate in English. For these analyses, only HCPs who were family members were included. The institutional review board of Hebrew SeniorLife approved the conduct of this study.

Data Collection

Resident assessments were conducted at baseline and quarterly using medical record reviews, nurse interviews and brief clinical examinations. HCP data were obtained at baseline and quarterly by telephone interviews. Residents and HCPs were followed for 18 months or until resident death. After a resident died, a chart review and a nurse interview were conducted within 14 days, and HCP interviews were conducted 2 and 7 months post-resident death.

Pre-loss and Post-loss Grief

Symptoms of pre-loss and post-loss grief were measured using modified versions of the Prolonged Grief Disorder (PGD-12) scale.⁶ This scale is designed to measure grief symptoms and assess criteria for a diagnosis of prolonged grief disorder, based on extensive testing and validation.^{25–26} The PGD-12 consists of 12 items. However, because the CASCADE study was designed prior to finalization of the PGD-12, only 11 of these 12 items were collected. The pre-loss grief (described in detail in our prior report)¹⁷ is designed to capture grief symptoms prior to the death of a loved one.

In both the pre-loss and post-loss scales, respondents were asked to rate how often they experienced specific grief symptoms over the past month on a Likert scale ranging from 1 (almost never) to 5 (always). These grief symptoms have been grouped into 4 domains based on prior psychometric testing:⁶ separation, cognitive/emotional, social impairment and duration (Table 2). In the post-loss scale, two symptoms comprised the domain of separation: preoccupation with thoughts of resident death, and longing or yearning. Seven symptoms were included in the cognitive/emotional domain: avoidance of reminders of the resident, numbness, feeling stunned, disbelief, a sense of emptiness, loss, and bitterness. A single item in the social impairment domain asked the extent to which grief symptoms have impaired the respondent's social functioning with Likert scale responses from 1 (no impairment) to 5 (complete impairment). A final item asked whether or not symptoms have been present for at least 6 months (yes/no). The pre-loss grief scale items are nearly identical to those in the post-loss scale except that questions are worded to reflect grief during the course of the resident's illness, rather than after the resident's death. In addition, the pre-loss scale differs from the post-loss scale in three ways: 1. only one item from the separation domain is included (longing and yearning); 2. there is an additional cognitive/emotional domain item (unable to imagine life being fulfilling without the resident being healthy); and 3. there is no duration item.

To meet criteria for a diagnosis of prolonged grief disorder, respondents must endorse one item in the separation domain at a frequency of often or always (Likert scale 4 or 5), at least 3 items in the cognitive/emotional domain at a frequency of often or always (Likert scale 4 or 5), have at least some social impairment due to grief (Likert scale 3 or greater), and have symptom duration of at least six months. Due to the low rate of respondents meeting the full criteria for prolonged grief disorder in this study, we analyzed the pre-loss and post-loss grief scales as continuous measures by summing the Likert scale responses. Summary scores range from 10 to 51 for the post-grief and 10–50 for the pre-grief scale (duration item not included), with higher scores indicating higher symptom levels. The pre-loss grief scale was administered to HCPs at the baseline interview; the post-loss scale was administered at the 2 month and 7 month post-loss interviews.

Independent Variables

In order to identify factors associated with post-loss grief, resident and HCP characteristics were selected from the CASCADE dataset based on 'a priori' hypotheses and review of the literature.^{15, 19-21}

Resident variables ascertained at baseline included age, duration of dementia and residence on a special care dementia unit. Resident variables obtained at the follow-up assessment just prior to resident death included functional status as ascertained from a nurse using the Bedford Alzheimer's Nursing Severity Subscale (BANS-S)²⁷ (range 7–28, higher scores indicate greater disability), and whether or not the resident was referred to hospice. At the resident death assessment the following data were obtained: the number of acute medical events occurring in the last 90 days of life (e.g. pneumonia, febrile episode, hip fracture, myocardial infarction, stroke, gastrointestinal bleed), whether the patient was hospitalized in the last 90 days of life, and comfort in the last 7 days of life. Comfort was measured using the Comfort Assessment in Dying with Dementia scale (CAD-EOLD),²⁸ and was obtained by interview with a nurse who cared for the resident. The CAD-EOLD quantifies the frequency of symptoms during the last 7 days of life including: discomfort, pain, restlessness, shortness of breath, choking, gurgling, difficulty swallowing, fear, anxiety, crying, moaning, serenity, peace and calm. Scores range from 14 to 42 with higher scores indicating greater comfort.

Baseline HCP variables included age, gender, race (white vs. other), education (college or greater vs. less), relationship to resident (spouse vs. other), importance of religion (dichotomized as very important vs. somewhat or not at all important), whether the HCP felt they understood the health complications expected in advanced dementia, whether the HCP lived with the resident prior to NH entry, and the number of hours per week that the HCP provided direct care (e.g. bathing, dressing feeding, administering medications etc.) to the resident prior to NH entry (dichotomized as none vs. at least one hour per week for analysis). HCP variables obtained at the follow-up interview conducted just prior to the resident's death included the number of hours spent visiting the resident per week (4 or greater vs. fewer), whether the HCP believed the resident had at least 6 months to live and the presence of depression (Short Form Composite International Diagnostic Interview).²⁹ Depression was also measured at the 7 month post-death assessment.

Analysis

Means with standard deviations or proportions were calculated for all continuous and categorical variables respectively. Internal consistency of the pre-loss and post-loss grief scales was measured using Cronbach's alpha.

In order to compare levels of HCP grief over time, the mean scores for the pre-loss and post-loss scales were calculated for all HCPs and compared using one-way analysis of variance, adjusted for clustering at the level of the individual. The next analysis aimed to identify factors (independent variables) associated with greater post-loss grief symptoms (outcome). As only one HCP in the cohort met the criteria for prolonged grief disorder, both pre-loss and post-loss grief scales were analyzed in their continuous forms, as previously described. The 7-month post-loss grief measure (rather than 2-month measure) was used as the outcome for this analysis because persistent grief symptoms at this time are most strongly associated with subsequent medical and psychiatric morbidity (i.e., cardiac disease, hypertension and suicidal ideation).⁷ Linear regression was used to examine the association between independent variables and the post-loss grief scores. As post-loss grief scores were not normally distributed, a natural log-transformation of this measure was used. All reported regression coefficients and 95% confidence intervals (CI) generated from the analyses are

back-transformed for presentation. Unadjusted analyses were conducted to examine the association between each independent variable and post-loss grief. Variables associated with the outcome in these bivariable analyses at the level of $p \leq 0.1$ were included in the multivariable model. Due to clustering at the level of the NH, all models utilize inflated standard error (robust standard error) estimates to account for intraclass correlations.^{30–31} All statistical analyses were performed using STATA SE version 10.0 (STATA Corporation, College Station, TX).

RESULTS

A total of 323 residents with advanced dementia were recruited into the CASCADE study, and 177 residents died over the study period with no loss to follow-up. Among these decedents, 170 residents had HCPs who were family members (7 were legal guardians or friends). From these 170 HCPs, we excluded those without a full 7 month post death assessment ($n=47$), yielding a final analytic sample of 123 HCPs. Comparisons between the HCPs in our analytic sample ($N=123$) and those excluded ($N=47$) revealed no statistical differences between all baseline characteristics presented in Table 1 with the exception that those in the analytic sample were more likely to be white (92.7% vs. 80.9%) (Fisher's exact test, $p = 0.05$).

The resident and HCP characteristics of the final sample are presented in Table 1. The residents' mean age was 86.1 years ($\pm$ standard deviation [SD] 7.3), the average duration of dementia was 6.7 years ($\pm$ SD 4.7), and 48.8% lived in a special care dementia unit. The HCPs' mean age was 59.6 years ($\pm$ SD 10.6), 61.0% were female, 92.7% were white and 74.8% had at least a college education. The HCP's relationship to the resident was as follows: 7.3% were spouses, 69.9% children, 13.8% nieces or nephews, 4.9% siblings, and 4.1% were grandchildren or in-laws. Prior to NH entry, 30.9% of HCPs lived with the resident, 82.1% provided at least one hour of care per week to the resident and 39.8% provided between 11–20 hours per week.

Post-loss Grief

The frequency of item responses for HCPs completing the post-loss grief scale at the 7 month post-loss interview are presented in Table 2. Grief symptoms were relatively infrequent with the exception of the 2 items in the separation domain. For these items, 43.9% of HCPs experienced preoccupation with thoughts of the resident's death, and 47.2% experienced longing or yearning at a frequency of sometimes, often or always.

Pre-loss and Post-loss Grief

Mean values for HCP grief symptoms were as follows: pre-loss grief 14.84 ($\pm$ SD 4.79) ($N=122$); post-loss grief at the 2-month post-death interview 15.86 ($\pm$ SD 5.19) ($N=106$); and post-loss grief at the 7 month post-death interview 15.62 ($\pm$ SD 5.50) ($N=123$). One-way analysis of variance revealed that mean values were not statistically different from each other ($p=0.08$) (F-statistic = 2.61, 2 and 122 df). Cronbach's alpha values for the pre-loss and 7 month post-loss grief scales were 0.77 and 0.82 respectively.

Factors Associated with Post-Loss Grief

Table 1 displays the unadjusted and adjusted linear regression coefficients and 95% CI predicting greater grief symptoms scores at 7 months post-loss. In the final multivariable model, the HCP having lived with the resident prior to NH entry ($p = 0.02$) and higher pre-loss grief symptoms ($p<0.001$) were independently associated with higher post-loss grief scores.

CONCLUSIONS

To our knowledge, this is the first prospective study to describe the pattern of pre-loss and post-loss grief symptoms among family members of NH patients dying with advanced dementia. Overall, the frequency with which family members experienced grief symptoms was relatively low both before and after the resident's death. However, grief symptoms specifically related to feelings of separation were not uncommon. Family members who lived with the resident prior to NH entry and those with higher levels of pre-loss grief were most likely to suffer higher levels of grief symptoms during bereavement. Our findings indicate that for some, grieving is a prolonged process which begins in the pre-loss period.

Little is known regarding the grief experienced by family members of residents who die in NHs with advanced dementia. The most frequently endorsed symptoms at both the pre-loss and post-loss measurements were those relating to preoccupation with thoughts of the resident's death, and feelings of longing or yearning. These are also the most prominent symptoms of prolonged grief disorder found among families whose loved ones died from causes other than dementia.⁶

Grief symptom levels among family members in this cohort remained unchanged from pre-loss to 2 and 7 months post-loss measurement. This profile is in contrast to a community-based study of grief among family members of patients who died following hospitalization for a variety of illnesses, which noted a sharp decline in grief symptoms in the months following patient death.⁷ The unique stability of grief symptoms among families of patients dying of advanced dementia is likely explained by the protracted course of illness and the loss of personhood that characterizes dementia. Very few individuals in our cohort met criteria for complicated grief, in contrast to 20% meeting such criteria in a community-based sample which differed from ours in having a greater percentage of spouses.¹⁵ As ours is the first study to document grief among families of NH patients with dementia, it is difficult to know whether our results reflect the effect of NH placement on future grief, or underlying differences in the characteristics of the populations studied.

While the stability of grief in this population illustrates the prolonged suffering that some family members endure, the presence of pre-loss symptoms offers an opportunity to identify individuals most likely to benefit from interventions to prevent post-loss grief. Although some posit that pre-loss grief is a healthy adaptation which prepares the individual for later loss, there is currently no consensus as to whether pre-loss grief is helpful or harmful, or how it influences post-loss grief.³² In our results, pre-loss grief symptoms do not appear to be protective of future grief, but rather to be a marker for persistent symptoms post-loss. Studies of post-loss depression among families of patients with dementia reveal a heterogeneous pattern, with certain individuals experiencing persistent symptoms.^{21, 33} Similarly, in our sample, although overall levels of grief were low, there was a subgroup of family members who experienced persistent grief symptoms.

Our findings suggest that interventions to improve family member pre-loss grief may impact on grief after patient death. Prior reports from the CASCADE study have indicated that greater pre-loss grief symptoms are related to lower satisfaction with resident care and family member depressive symptoms.¹⁷ These factors can be addressed within the NH through the provision of high-quality patient care and outreach to families. Efforts likely to increase family member satisfaction with resident care include greater communication, decision-making support and improved medical and nursing care. Furthermore, supportive psychosocial and skills-training interventions can be effective at reducing prolonged grief among community-dwelling families of patients with dementia,¹⁵ and may be effective in the NH setting as well.

Our results should be interpreted in light of certain limitations. Participants in our study were predominantly white, well-educated and resided in the Boston area, which may limit the generalizability of our findings. Our sample may have lacked sufficient power to observe significant associations between independent variables and our outcome of higher grief scores, particularly in the case of depression which has been associated with prolonged grief in the community.¹⁵ Further, due to the low levels of HCPs meeting criteria for PGD, we were unable to use this as an outcome and so we analyzed grief symptoms as a continuous variable. Although guided by *a priori* hypotheses, a large number of candidate variables were tested for association with our outcome of post-loss grief, which increases the chance of a type I error. Although participant HCPs were all family members of the decedent, not all were necessarily close relatives or visited frequently, which may explain the low levels of grief in this population. Strengths of this study include the use of validated measures of pre-loss and post-loss grief, a prospective design, and the evaluation of several potential confounders in our analyses.

As a leading cause of death, dementia places millions of family members at risk for grief symptoms, and associated psychiatric and medical morbidity.^{2–3} Our results indicate that for some family members of loved ones with advanced dementia, patterns of grieving begin long before the patient's death, and persist beyond the normal six-month grieving period. In general, NHs do a poor job of providing bereavement services to families of patients with dementia.⁵ Although the routine provision of bereavement counseling is not recommended, 34³⁵ research suggests that effective pre-loss interventions¹⁵ and treatments for grief symptoms³⁶ can be potentially developed. Our results indicate that awareness of pre-loss grief symptoms in family members of patients with dementia can help to identify those most likely to benefit from such interventions.

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Table 1

Characteristics of decedent nursing home residents with advanced dementia and their family member health care proxies, and their unadjusted and adjusted associations with health care proxy grief symptoms 7 months post-loss

Characteristic	N=123	Unadjusted linear regression coefficient (95% CI) ¹	Adjusted linear regression coefficient (95% CI) ²
Resident			
Age, mean (SD)	86.1 (7.3)	0.99 (0.98, 0.99)	1.00 (0.99, 1.00)
Years with dementia, mean (SD)	6.7 (4.7)	1.00 (0.99, 1.02)	n/a
Resident on special care unit, n (%)	60 (48.8)	0.99 (0.89, 1.09)	n/a
BANS ³ at last assessment, mean (SD)	22.0 (2.0)	1.00 (0.97, 1.03)	n/a
Hospice referral at last assessment, n (%)	35 (28.5)	0.96 (0.85, 1.08)	n/a
Acute events ⁴ 90 days prior to death, n (%)	88 (72.7)	0.98 (0.86, 1.10))	n/a
Hospitalization in 90 days prior to death, n (%)	12 (9.8)	1.19 (0.96, 1.47))	1.06 (0.90, 1.25)
Comfort during last week of life, ⁵ mean (SD)	34.3 (4.4)	1.00 (0.99, 1.01)	n/a
Health care proxy			
Age, mean (SD)	59.6 (10.6)	1.00 (1.00, 1.01)	n/a
Female, n (%)	75 (61.0)	1.05 (0.93, 1.20)	n/a
Race, white vs. other, n (%)	114 (92.7)	0.90 (0.63, 1.27)	n/a
College education or greater, n (%)	92 (74.8)	0.91 (0.77, 1.08)	n/a
Spouse vs. other, n (%)	9 (7.3)	1.28 (1.08, 1.53)	1.05 (0.83, 1.32)
Believes religion is very important, ⁶ n (%)	73 (59.4)	1.08 (0.97, 1.20)	n/a
Understood complications of dementia, n (%)	101 (83.5)	1.09 (0.97, 1.23)	n/a
Provided resident at least 1 hour/week of personal care prior to NH admission, ⁷ n (%)	101 (82.1)	1.12 (0.94, 1.33)	n/a
Lived with resident prior to NH admission, n (%)	38 (30.9)	1.18 (1.05, 1.31)	1.14 (1.03, 1.27)
Visited at least 4 hours a week at last assessment, n (%)	47 (38.2)	1.06 (0.95, 1.17)	n/a
Believed resident had at least 6 months to live at last assessment, n (%)	83 (72.2)	1.07 (0.96, 1.20)	n/a
Pre-loss grief scale at baseline, ⁸ mean (SD)	14.84 (4.79)	1.04 (1.03, 1.05)	1.03 (1.02, 1.05)
Depression at last assessment, ⁹ n (%)	6 (5.3)	1.35 (0.94, 1.95)	1.09 (0.69, 1.72)
Current depression at 7 months post-loss, ⁸ n (%)	10 (8.6)	1.39 (1.13, 1.71)	1.18 (0.99, 1.40)

¹ T-test with robust standard error, df = 19

² n = 111 due to missing data values on post-loss depression measure (6 values), pre-loss depression (5 values) and pre-loss grief (1 value). T-test with robust standard error, df = 19

³ Bedford Alzheimer's Nursing Severity Subscale (range 7–28, higher scores indicate greater disability)

⁴ Pneumonia, febrile episode, hip fracture, myocardial infarction, stroke or gastrointestinal bleed

⁵ Comfort Assessment in Dying with Dementia scale

⁶ vs. somewhat or not at all important, measured at baseline

⁷ Personal care includes bathing, bathing, dressing, feeding, administering medications, changing bandages, using medical devices, getting groceries, or transportation to medical appointments

⁸ Prolonged Grief Disorder (PGD-12) scale

⁹ Composite International diagnostic Interview-Short Form

Table 2

Percent of health care proxies of nursing home residents with advanced dementia experiencing symptom of grief 7 months post-loss (n=123)

Grief Scale Items [/]	Almost never	Rarely	Sometimes	Often	Always
Separation					
You are preoccupied with thoughts of [resident's] death	40%	16%	29%	9%	6%
You feel yourself longing and yearning for [resident]	37%	15%	32%	11%	5%
Cognitive/Emotional					
You go out of your way to avoid reminders that [resident] is gone	84%	11%	2%	3%	0%
You feel like you have become numb or detached since the death of [resident]	80%	8%	11%	1%	0%
You feel stunned, dazed or shocked over [resident's] death	87%	8%	4%	0%	1%
You feel disbelief over [resident's] death	86%	4%	9%	1%	0%
You feel that life is empty or meaningless without [resident]	85%	5%	8%	0%	2%
You feel that a part of yourself died along with [resident]	60%	15%	18%	5%	2%
You feel bitter over [resident's] death	87%	2%	7%	1%	2%
Social Impairment					
You believe that your grief has resulted in impairment in your social, occupational or other areas of functioning	None 89%	Slight 7%	Some 3%	Marked 1%	Complete 0%
Duration					
You have experienced the above feelings for at least 6 months	No 42%	Yes 58%			

[/] Prolonged Grief Disorder (PGD-12) scale