Original Article

How Well Are We Caring for Caregivers? Prevalence of Grief-Related Symptoms and Need for Bereavement Support Among Long-Term Care Staff

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Abstract
To define the prevalence and correlates of grief-related symptoms among long-term care staff who care for patients near the end of life, a cross-sectional survey was conducted at six Program of All-inclusive Care for the Elderly (PACE) organizations that provide long-term care in the home and in institutions. All clinical and non-clinical program staff were surveyed to examine the prevalence of 20 grief-related symptoms and assess current sources of bereavement support, as well as willingness to use additional sources of support. Suveys were completed by 203/236 staff (86%), who described a wide variety of symptoms they attributed to the death of one of their patients in the past month. Most staff (147/203; 72%) reported at least one symptom. Staff with more symptoms had experienced more patient deaths in the past month (Spearman rho = 0.20, P = 0.007), had worked for a longer time at a PACE organization (Spearman rho = 0.16, P = 0.031), and reported a closer and longer relationship with the last patient who died (Spearman rho = 0.32, P < 0.001; rho = 0.24, P = 0.001). Although staff identified several informal sources of bereavement support (mean 2.3 sources, range 0–6), almost all (n = 194; 96%) said they would use additional support services if they were offered. These community-based long-term care staff experience a variety of symptoms attributable to the deaths of their patients, and would welcome additional sources of bereavement support.   J Pain Symptom Manage 2005;30:227–233. © 2005 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Bereavement, palliative care, PACE, long-term care, hospice

Introduction

During the last years of their lives, older adults may spend several years in nursing homes, assisted living facilities, and intensive community-based organizations such as the national Program of All-inclusive Care for the

Elderly (PACE). During the course of their care in these facilities and organizations, many older adults develop close relationships with program staff. Indeed, for many of these patients, formal caregivers become surrogate families.

The grief and bereavement experiences of family members who provide long-term care for their relatives have been well described by previous studies, including recent work that has systematically examined risk factors and correlates of grief-related symptoms.[1–7] Past research has also described the grief and bereavement experience of selected groups of professional health care providers.[8–13] These studies have defined significant emotional, social, and physical effects of grief and bereavement.

Little is known, however, about the grief experiences of professional caregivers in long-term care settings. Previous studies of this population that have used qualitative methods to explore staff responses to patients' deaths suggest that staff may experience symptoms of grief.[14,15] However, many questions remain unanswered. For instance, it is not known what proportion of long-term care staff experience emotional or physical symptoms after the death of one of their patients. Although we hypothesized that the number of grief-related symptoms would be associated with the number of deaths that each staff member had recently experienced, this is not known. Nor is it known what staff or patient characteristics are associated with an increased likelihood of grief-related symptoms. Finally, it is not known which informal sources of support staff use after the death of one of their patients, or whether they feel they would benefit from additional formal sources of support, such as support groups or counseling.

These questions have important implications for the design and delivery of long-term care. As older adults increasingly live and die in these settings, it will be important to ensure that their health care providers have access to support that enhances their ability to provide compassionate, high-quality care. Therefore, the goals of this study were to define the prevalence and correlates of grief experiences among long-term care staff, and to define their perceived needs for additional bereavement support.

Methods

Setting and Sample

This study was conducted in cooperation with six PACE or pre-PACE organizations. PACE is a comprehensive, community-based, geriatric managed health care organization that serves patients aged 55 and older who are certified by their state to need nursing-home care. PACE offers medical care, home health care, social work services, adult day care, prescription coverage, and other services to its participants in their homes, adult day centers, or long-term care facilities. Pre-PACE organizations are distinguished from PACE organizations by reimbursement through mixed capitated/fee-for-service payments rather than by a fully capitated system. Although PACE organizations are designed to support older adults in the community setting as long as possible by preserving function and promoting activity and interaction, PACE organizations also become the providers of care in long-term care facilities. Therefore, PACE organizations offer a unique opportunity to evaluate providers' responses to deaths that occur in both home care and institutional settings.

The six organizations that participated in this study were selected for their geographic representation, and the diversity of their staff and patients. These organizations were located in McKeesport, PA, Pittsburgh, PA, Philadelphia, PA (2 organizations), Rochester, NY, and Wichita, KS. All full- and part-time staff members at each PACE site were eligible to participate. In order to include all staff who have patient contact and who might, therefore, be affected by patient deaths, we particularly encouraged participation by support staff (e.g., transportation workers, clerks, dietary workers).

Data Collection

Anonymous surveys were sent to each PACE organization and distributed at staff meetings. Staff members were encouraged to complete a survey but were told that participation was voluntary. Each organization collected completed surveys and returned them to the study office for data analysis. In order to evaluate the representativeness of the study sample, all organizations also provided a description of

aggregate staff characteristics. This study was approved by the University of Pennsylvania's Institutional Review Board.

Each survey included five sections. First, staff provided demographic information about themselves and described their past health care work experience. Next, staff estimated how many of their patients had died in the past month, and then identified (from a checklist) the symptoms that they experienced as a result of those deaths. This approach was used because many typical symptoms of grief (e.g., feelings of sadness or trouble sleeping) are non-specific. Symptoms were selected based on a review of the literature, with an emphasis on classic and recent review articles.[16–21] In developing this list, a variety of grief-related responses were considered for inclusion, including both physical and psychological responses to the death of a patient. Collectively, all of these responses are referred to here as "symptoms."

Third, in order to better characterize the effects of patient deaths on staff members, the survey asked respondents to consider the patient who had died most recently and to describe the strength of the relationship that had developed between the staff member and the patient ("not at all close," "somewhat close," and "very close"; scored as 0,1, and 2). Staff then described the effect that this death had on them in six domains: physical health, work, emotions, relationships with family, relationships with co-workers, and relationships with other patients. For each domain, staff were asked to rate how much that death affected them ("not at all," "somewhat," and "a lot"; scored as 0, 1, and 2). Staff also described those effects (both positive and negative) in an open text space.

Fourth, respondents described the informal sources of support they turned to after the deaths of patients. Finally, the survey described several potential formal sources of grief and bereavement support, and staff indicated whether they would use each service if it were offered. These sources of support were selected on the basis of a review of the literature, pilot interviews with PACE organization staff, and their potential feasibility for implementation in a long-term care setting. These included a support group, informal discussions, individual counseling, the opportunity to send a condolence card to the remaining family, memorial services, education about death and dying, and an Internet-based monitored bulletin board.

Data Analysis

Descriptive statistics were generated to summarize staff characteristics and responses to categorical items. Analysis used either the χ^2 test or non-parametric tests to evaluate associations. Linear regression models were used to identify variables that were independently associated with the number of grief-related symptoms that staff reported. Because we hypothesized that staff who had experienced more patient deaths in the past month would also report more grief-related symptoms, a sample size of at least 175 respondents was planned to provide adequate power (> 0.80) to detect a correlation of >0.30 (Pearson product-moment coefficient) between these 2 variables ($\alpha = 0.05$).

Results

The study sample included a wide variety of PACE team members, including nurses, physicians, and social workers, as well as transportation and administrative staff, and others (Table 1). Of the 236 staff who were eligible, 203 completed surveys (86%). There were no differences between study sample characteristics and characteristics of all potential respondents.

Staff reported a wide variety of grief-related symptoms that they attributed to the death of a patient in the past month, and 72% (147/203) reported at least one symptom (Table 2). Of these, by far the most common was a feeling of sadness ($n = 109$; 54%). Staff also reported crying ($n = 53$; 26%) and feeling unable to accept a patient's death ($n = 51$; 25%). Although several staff reported physical symptoms (e.g., trouble sleeping, $n = 10$; 5%), these were much less common.

The mean number of grief-related symptoms varied among participating organizations (range 1.4–4.5; Kruskal Wallis test $P = 0.003$). Staff who reported more symptoms had experienced more patient deaths in the past month (Spearman rho $= 0.20$, $P = 0.007$). The number of reported symptoms was also

Table 1
Demographic Characteristics of PACE Employees (*n* = 203)

Respondent's position at PACE program, *n* (%)	
CNA/Home Health Aide	58 (29)
Nurse/Nurse Practitioner	31 (15)
Driver/Transportation Staff	28 (14)
Office/Clerical Staff	17 (8)
Social Worker	17 (8)
Administrator	15 (7)
Recreational Staff	12 (6)
Occupational Therapist	7 (3)
Physical Therapist	6 (3)
Physician	5 (2)
Dietician	4 (2)
Other/Unknown	3 (1)
Years at this PACE program, mean	2.2
Age: mean (range)	42 (21–69)
Female, *n* (%)	155 (78)
Ethnicity, *n* (%)	
African American	59 (29)
White	133 (66)
Other/Unknown	11 (5)
Education, *n* (%)	
Less than high school/Completed high school	36 (18)
Some college/vocational school	75 (37)
Completed college	38 (19)
Advanced education beyond college	53 (26)
Marital status: *n* (%)	
Single (never married)	50 (25)
Married/Living with partner	118 (58)
Divorced/Separated	25 (12)
Widowed	8 (4)
Number of patients cared for per day, mean	31
Number of patients who died in the last month, mean	2.2

Not all totals sum to 100% because of missing data.

Table 2
Symptoms That Staff Attributed to the Death in the Past Month of One of Their Patients

	n (%)
Feeling sad	109 (54)
Crying	53 (26)
Feeling unable to accept the death of the patient	51 (25)
Feeling helpless	27 (13)
Thinking about my own death	24 (12)
Having difficulty concentrating	20 (10)
Dreaming about a patient who died	17 (8)
Feeling angry	15 (7)
Feeling guilty	15 (7)
Feeling restless	11 (5)
Feeling irritable	10 (5)
Having trouble sleeping	10 (5)
Feeling that the patient is not really dead	9 (4)
Seeing the patient who had died	7 (3)
Having less energy	5 (2)
Expecting to see the patient who has died	4 (2)
Having mood swings	4 (2)
Feeling anxious	3 (1)
Having a change in appetite	3 (1)
Withdrawing from social activities	3 (1)

correlated with the number of years worked at PACE (Spearman rho = 0.16, P = 0.031) and a higher level of education (Spearman rho = 0.15, P = 0.045). Staff who reported more symptoms also described closer and longer relationships with their last patient who died. (Spearman rho = 0.32, P < 0.001; rho = 0.24, P = 0.001). The number of reported symptoms was not related to the patient's site of care (nursing home vs. community), or with concordance between staff and patient ethnicity or gender.

In a linear regression model, four variables were independently associated with the prevalence of grief-related symptoms: PACE site (coefficient = 0.22; 95% confidence interval [CI] 0.05–0.4; P = 0.013), self-reported closeness with the most recent patient who died (0.90; CI 0.41–1.39; P < 0.001), duration of relationship with that patient (0.52; CI 0.16–0.89;

P = 0.005), and time (in weeks) since that patient's death (-0.04; CI -0.07 to -0.01; P = 0.005).

Most staff (*n* = 185; 91%) reported that the death of their last patient affected at least one of six domains. The death was most likely to affect their emotions (*n* = 159, 78%) and relationships with other patients (*n* = 73, 36%). Staff also described effects on relationships with their own family members (*n* = 52, 26%) and co-workers (*n* = 54, 27%), as well as effects on their work (*n* = 49, 24%). Fewer reported effects on physical health (*n* = 21, 10%).

Staff described several informal sources of support they turned to after a patient's death (mean = 2.4, range 0–6). Of these, the most common were conversations with co-workers (*n* = 132, 65%), family (*n* = 116, 57%), friends (*n* = 80, 39%), and support from religious/spiritual groups (*n* = 44, 22%). Staff who relied on more informal sources of support also reported more grief-related symptoms over the past month (Spearman rho = 0.24, P = 0.001).

Most staff also said that they would use additional sources of support if they were

offered. The sources of support they said they would be most likely to use were sending a condolence card to the patient's family ($n = 167$; 82%) and attending a memorial service if one were offered at the PACE organization ($n = 163$; 80%). Staff also said they would use a support group ($n = 149$; 73%), an Internet-based monitored bulletin board ($n = 123$; 60%), information and education about grief ($n = 116$; 57%), and individualized counseling ($n = 110$; 54%). Although staff described varying preferences for additional support services, almost all ($n = 194$; 96%) reported willingness to use at least one source of support if it were offered.

Discussion

In this study, long-term care staff who work in the home and in institutional settings experienced a variety of grief-related symptoms that they attribute to the deaths of their patients. As long-term care programs increasingly take on the difficult task of caring for older adults near the end of life in diverse settings, it will be important to carefully consider the effects that these deaths have on staff. It will also be important to identify ways in which long-term care organizations can better support their caregivers. These results have three key implications for opportunities to better meet the bereavement needs of long-term care staff.

First, staff responded to the deaths of patients in very different ways, and described a wide variety of grief-related symptoms. Although some staff reported experiencing several symptoms, others reported few or none. Therefore, broad characterizations of the grief experience of long-term care staff are unlikely to be useful. Instead, effective strategies for providing bereavement support to long-term care staff should be tailored to the needs of individual staff, whose experiences of grief-related symptoms, and needs for support, may vary considerably.

Second, staff who worked longer at PACE organizations reported more grief-related symptoms. This is somewhat counterintuitive, as one might expect that more experienced staff become accustomed to grief and loss and report fewer grief-related symptoms. One

might also expect that staff who are particularly troubled by the deaths of their patients might seek employment elsewhere. Both of these factors would tend to reduce the prevalence of grief-related symptoms among experienced staff. However, the opposite was observed, and experience does not appear to "protect" staff from the experience of grief. On the contrary, there may be a cumulative component of staff grief that has not been previously examined in these settings.

Third, we found that staff were interested in additional sources of bereavement support, and almost all said they would use at least one source of support if it were available. Many expressed an interest in simple interventions (e.g., condolence cards), but others indicated that they would also use more intensive services, such as support groups and individualized counseling. Therefore, it will be important to develop a minimum set of bereavement interventions that focus on relatively simple measures, such as condolence cards or memorial services that do not require a large investment of time or resources. Such interventions serve a dual purpose: they are valued by staff, and they provide additional support to patients' families.[17]

More intensive interventions might be appropriate in certain circumstances. For instance, these data suggest that staff who face high death rates or who have characteristics that are associated with a higher prevalence of grief-related symptoms might benefit from more intensive bereavement interventions. These interventions, such as support groups or individual counseling, will require a greater commitment of time and resources, and personnel (e.g., bereavement counselors) with appropriate clinical skills and training. These requirements may make it difficult for many organizations to implement these intensive interventions. However, hospices are required to provide these services to families[22] and typically also provide them to professional caregivers.[23] Therefore, organizations whose staff members have significant bereavement needs may wish to develop relationships with community hospice programs who are better equipped to provide support.

This study had two principal limitations. First, the results reported here may not be generalizable to other long-term care settings

such as nursing homes. However, nursing homes have similar patient populations, and this study found that the prevalence of reported symptoms is the same for patients receiving care at home and in the nursing home. Therefore, it is likely that grief experiences of nursing home staff may be similar, but further research is needed to better define the prevalence and correlates of grief-related symptoms among staff in a variety of long-term care settings. Second, this study did not use a validated instrument to define the prevalence of grief-related symptoms, as none is currently available for use in professional caregivers. Nevertheless, this survey was developed using an exhaustive literature review and extensive pilot testing in order to ensure adequate face validity and appropriateness for this population of respondent.

As older adults increasingly die in long-term care settings, the front-line staff who provide care will face increasing challenges in coping with these deaths. Although it has received little attention to date, it will be important to include provisions for long-term care staff in the planning process and ensure that their health and well-being receive the same attention as the older adults for whom long-term care is designed.

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