

Original Article

Caring for Dying Patients in the Nursing Home: Voices From Frontline Nursing Home Staff



John G. Cagle, PhD, MSW, Kathleen T. Unroe, MD, MHA, Morgan Bunting, BS, Brittany L. Bernard, BS, and Susan C. Miller, PhD, MBA

University of Maryland (J.G.C., M.B.), Baltimore, Maryland; Indiana University Center for Aging Research (K.T.U., B.L.B.), Indianapolis, Indiana; Regenstrief Institute, Inc. (K.T.U., B.L.B.), Indianapolis, Indiana; Brown University School of Public Health (S.C.M.), Providence, Rhode Island, USA

Abstract

Context. Nursing homes are an important site for end-of-life care, yet little is known about the perspectives of the frontline staff who provide a majority of this care.

Objective. To describe, from the staff perspective, positive/negative experiences related to caring for dying residents.

Methods. Qualitative analysis using survey data from staff working in 52 Indiana nursing homes.

Results. A total of 707 frontline staff who provide nursing, nurse aide, and social work services responded to open-ended prompts. Study data included responses to open-ended prompts asking participants to describe one positive experience and one negative experience caring for a dying patient. A thematic content analysis was conducted using the constant-comparative method. Respondents were largely female (93%), white (78%), 31–50 years (42%), and 53% had >5 years of nursing home work experience. Experiences were described from three perspectives: 1) first-hand experiences, 2) observed experiences of dying patients, and 3) observed experiences of family members. Selected themes for positive experiences include the following: creating close bonds; good patient care; involvement of hospice; being prepared; and good communication. Selected themes for negative experiences consisted of the following: challenging aspects of care; unacknowledged death; feeling helpless; uncertainty; absent family; painful emotions; and family discord.

Conclusion. Findings reveal the richness and many complexities of providing end-of-life care in nursing homes and have implications for improving staff knowledge, coordination of care with hospice, and social support for patients. *J Pain Symptom Manage* 2017;53:198–207. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Long-term care, hospice, palliative care, person-centered care, quality of dying, death

Introduction

Nearly 1.5 million people reside in nursing homes (NHs) in the U.S.,¹ and approximately 30% of deaths among older adults (65+ years) occur within the NH setting.² Past research has identified a number of important concerns about the quality of care for dying NH residents including inconsistent assessment and treatment of pain,³ lack of attention to resident quality of life,⁴

and missed opportunities for patient-centered decision making.⁵ The need for high-quality end-of-life (EOL) care in NHs is projected to increase in lock step with the fast growing number of older adults in the U.S.^{6,7}

NHs rely on frontline NH staff to provide hands-on care to patients. Previous studies suggest that NH staff may not be properly trained and supported to care for dying patients.^{8,9} The traditional model of NH care focuses on rehabilitation and restoration.¹⁰ However,

Address correspondence to: John G. Cagle, PhD, MSW, School of Social Work, University of Maryland, 525 West Redwood Street, 3W13, Baltimore, MD 21201, USA. E-mail: jcagle@ssw.umaryland.edu

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when a patient with life-threatening illness nears EOL, staff must often make a difficult shift from a restorative approach to a model more consistent with palliative care.^{10,11} Good communication, comprehensive training in EOL care, and staff support may help NH staff facilitate this shift.^{12–14} In addition to staff communication, psychosocial support⁷ and previous experience with death and dying¹³ may also influence staff members' comfort level with providing EOL care.

There has been tremendous growth in the number of external hospice agencies providing services to dying NH patients in the U.S.¹⁵ However, among NH staff, there are mixed attitudes and receptivity regarding the value of hospice services in the NH.⁹ Dedicated investigation focusing on NH staff attitudes toward hospice is needed to understand the disconnect between some NH and hospice staff. Unroe et al. (2014) quantitatively analyzed NH staff perceptions about hospice and found that the majority viewed hospice as generally positive, but more beneficial for patients and families than for the NH staff themselves. The study also found that staff frequently reported poor communication between NH and hospice staff, which could contribute to poorly coordinated care,¹⁶ and ultimately lower the quality of care for dying patients.

Understanding NH staff perceptions about death and dying is critical to better understand and address the many challenges of providing high-quality EOL care in the NH environment. Although a substantial proportion of U.S. deaths occur in NHs, few studies have qualitatively explored frontline staff perceptions about EOL experiences in the NH and the various factors that contribute to quality of dying for residents. This study addresses this knowledge gap. As part of a larger study examining perceptions of staff toward palliative care and hospice,¹⁶ we conducted a qualitative content analysis to identify recurring themes related to positive and negative descriptions of experiences caring for dying patients.

Methods

Design

This qualitative study used open-ended survey data from frontline NH staff—including registered nurses (RNs), licensed practical nurses (LPNs), certified nursing assistants (CNAs), and social workers (SWs)—working in 52 facilities from two large NH chains in Indiana. Although survey items were identical, one chain was given hardcopies during a staff meeting while the other chain completed the same survey items using Survey Monkey, an online survey tool. Study procedures were approved by the Indiana University IRB.

Measures

Survey measures asked about basic demographic information; general knowledge, attitudes and opinions about EOL care in the NH; and to describe positive and negative experiences caring for a dying patient. Specifically, for this study, we focused on responses to the following two prompts:

1. Describe a POSITIVE experience taking care of a dying patient.
2. Describe a NEGATIVE experience taking care of a dying patient.

Analysis

Sample characteristics were summarized using frequencies and percentages. The survey response rate was computed based on the number of completed surveys versus the total number of staff given an opportunity to complete the survey. Open-ended responses were initially coded for thematic content by the primary author and a working codebook was developed. The constant-comparative method¹⁷ was used to identify recurrent/emergent themes within the data. Raw data were unitized using open coding. Coded excerpts with similar themes were grouped together. After the initial round of coding and categorization, findings were reviewed by Drs. Cagle and Unroe for corroboration and peer oversight.

Responses from a subsample of randomly selected cases ($N = 39$, 5%) were reviewed and independently coded by three members (K. U., B. B., and M. B) of the interdisciplinary (medicine, social work, and gerontology) research team with >80% concordance. The team resolved conflicting themes/categorizations and revised the codebook accordingly. Direct quotes that encapsulated identified themes are presented as exemplars. In particular, we selected quotes that presented either multiple themes or especially rich detail about the concepts being described. All identifying content was changed or removed to preserve respondent anonymity. To ensure validity of results, preliminary themes and subthemes were reviewed and critiqued by a subsample of 15 staff members (four RNs, four LPNs, five CNAs, and two SWs) from four of the participating facilities, two from each chain.

Results

As summarized in [Table 1](#), among the 707 participants who responded to the open-ended prompts, the majority were female (93%), white (78%), and 31–50 years old (42%). Respondents were largely frontline clinical staff consisting of CNAs (40%), LPNs (30%), RNs (15%), and SWs (4%). The sample was relatively seasoned as 53% had >5 years of NH experience. A minority (4.6%) of respondents reported they had not had a negative experience when

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