The Transition from Routine Care to End-of-life Care in a Nursing Home: Exploring Staff Perspectives

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Objectives: The objective of this study was to explore how nursing home staff members manage the transition from routine care to end-of-life care when a resident is dying.

Design: The exploratory descriptive study used qualitative methods.

Setting: A 122-bed nursing home on a continuum of long-term care campus.

Participants: Participants were 35 nursing home professionals (21 nurses, 9 CNAs, and 5 social workers).

Measurements: In-depth interviews that involved open-ended questions about the transition to end-of-life care were audi-taped, transcribed, and submitted to qualitative data analysis for the development of emergent themes.

Results: Three emergent themes characterize the central aspects of the transition in care as the management of (1) physical changes, (2) emotions, and (3) overlapping systems of care.

Conclusion: In balancing the sometimes conflicting expectations of routine, restorative, and end-of-life care needs, nursing home professionals have developed ways of managing the transition that can be important in developing specific end-of-life protocols. This study has 3 implications for practice: (1) focused end-of-life education and planning can help frontline staff prepare for the inevitable numbers of residents who will die in the nursing homes, (2) mechanisms for helping staff manage the intense emotional responses that accompany loss of long-term residents are important for long-term well-being of frontline staff, and (3) focused attention on the unique dynamics of “home” and “family” can assist nursing home professionals with ongoing losses and cumulative grief. (J Am Med Dir Assoc 2011; 12: 114–120)

Keywords: Care transitions; staff perceptions; end-of-life care

Current regulatory guidelines require nursing homes to take a restorative approach to resident care; however, nearly one quarter of all deaths in the United States occur in nursing homes, and projections indicate that this number will increase to 40% by the middle of the century. Clearly, dealing with death in long-term care environments is inevitable but nursing home professionals must navigate the sometimes conflicting goals of routine care and end-of-life care. Routine nursing home care is highly regulated and involves a focus on quality of life that often includes maintaining or improving function, keeping residents active, and getting them out of bed, dressed, and to meals, while focusing on increased independence and social interaction. End-of-life care involves attending to a resident’s declining status, which can be accompanied by physical, psychological, and spiritual distress; increased functional needs; and family concerns. Standards for routine nursing home care were established by the Nursing Home Reform Act and are regularly measured by the use of the Minimum Data Set (MDS). However, some routine quality measures that target, for example, residents’ activity levels and behaviors, are largely outside the control of the nursing home staff. Moreover, the decline in a resident’s activity level or changes in behavior may in fact, signal a transition to the terminal phase of an illness.

End-of-life care in nursing homes is often rated poorly but the provision of quality care at life’s end is important to nursing home professionals. Nurses, nursing assistants, and social workers have often had little formal education or training in providing end-of-life care. Although...
guidelines for nursing home–based end-of-life care have been developed, the philosophy of palliative care is not emphasized in the regulations.6,25 The introduction of hospice services can augment care for dying nursing home residents but this can also complicate the situation and yield tension between hospice and nursing home professionals about their roles, the extent and boundaries of care provided by each, and the specific regulations for hospice care.1,6 (See Appendix 1 for sources of palliative care information and education.)

Nursing home professionals balance the dual responsibilities of (1) maintaining nursing home residents’ function and well-being with (2) management of the transition to end-of-life care for residents who are dying and their families. Often with little formal training or regulatory guidance, nursing home professionals identify cues that signal the transition1,26 and ease any accompanying distress. How nursing home professionals conceptualize and manage the transition from routine care to end-of-life within a regulatory environment that is in conflict with good end-of-life care is not understood. Yet, nursing home professionals are the frontline caregivers for growing numbers of residents who are dying and their families, guiding them through uncertain times and significant final life transitions. The purpose of this study was to explore how nursing home professionals manage the transition from routine to end-of-life care.

METHODS

The study involved an exploratory descriptive design. Qualitative methods were selected to gather participants’ perspectives in their own words.27 The study setting was a nursing home that was established by a Protestant church and is located in a suburban community of a northeastern state. The 122-bed nursing home is part of a continuum of care that includes independent living, residential care, skilled nursing facility (SNF) for short-term rehabilitation, and a locked unit for people with dementia. The research procedures were developed with the administrative team. The protocol was approved by the University at Buffalo Social and Behavioral Sciences Institutional Review Board.

The data for the analysis presented here were collected during a larger parent study about how end-of-life care is provided in this facility. Initially all staff members were invited to participate. Participation was voluntary. Invitation letters were sent to 130 staff members (including both direct-care staff and those without resident contact). Forty-three responses were received yielding a participation rate of 33%. However, to explore the perspectives of direct-care staff on the transition to end-of-life care, only data collected from nurses, nursing assistants, and social workers were analyzed for the present study. The rationale for creating a subset of data was to explore the frontline perspectives of staff members who care for residents who are dying and their family members.

Interviews were conducted at the nursing home during a participant’s scheduled shift. Participants received a $15 gift card. An interview guide with questions about how care is provided at the end of life was used for the interviews, which lasted about 30 minutes (Appendix 2). Interviews were conducted by the primary author or 1 of 3 research assistants who had been trained on conducting research interviews.

Interviews were audiotaped and transcribed by a professional transcriptionist. Tapes and transcripts were de-identified and labeled with a letter-number combination (eg, CNA-1). Atlas ti software (Atlas.ti GmbH, Berlin) was used for data management and coding. The analysis was conducted by the primary author and 3 graduate social work students. Qualitative data analysis was iterative and involved several steps. First, the data set was separated into subsets or “bins” that held all participants’ answers to the same question. Each data bin or subset was then submitted to an iterative process of coding. Open coding, or the process of examining the data in a line-by-line fashion, was used to identify meaning units that were tagged with an identifying concept. Memoing, or the process of noting ideas in the margins, was used to begin adding identifiers to the data. Memos were also used to identify particularly salient quotes that characterized and illustrated participants’ perspectives. Memos were transformed into codes, or key concepts. Codes were collapsed into themes. Constant comparative analysis, or the process of going back over the data to ensure that it is coded in accordance with emerging themes, was used.28,29

Rigor, or trustworthiness in the qualitative data analysis was upheld in 2 ways. Observer triangulation, or the use of a research team to co-code each transcript was used to develop intersubjective agreement. Member checking, or the process of presenting findings for examination by participants was used. Preliminary themes were shared with a group of nursing home professionals, some of whom had participated in the study and some who had not, to eliminate researcher bias and seek verification that the themes were an accurate representation.28

RESULTS

Participants included 35 nursing home staff members with direct-care responsibilities: nurses (n = 21), certified nursing assistants (CNAs) (n = 9), and social workers (n = 5). Participants had an average (mean [M]) of 2.5 years of college education (Mnurses = 2.6, MCNAs = 0.5, Msocial workers = 4.4). Participants had an average of 7.1 years of experience in nursing homes (Mnurses = 12.4; MCNAs = 4.9; Msocial workers = 4.1). Two participants had formal classroom training in end-of-life care. All participants described on-the-job training in end-of-life care (Table 1).

Managing the Transition from Routine Care to End-of-Life Care

Three themes emerged that characterize participants’ perceptions of the transition from routine care to end-of-life care. The themes are: (1) Addressing Physical Changes, (2) Dealing with Emotions, and (3) Managing Overlapping Systems of Care. The themes and subthemes are described and
then illustrated with representative quotes. The relationship among the themes is presented to illuminate the transition in Figure 1.

**Addressing Physical Changes**

All participants discussed physical changes as a core aspect of the transition from routine to end-of-life care. Five subthemes illustrate elements of the care: (1) assessing and addressing symptoms of distress, (2) providing hands-on care (eg, administering medications or repositioning a dying resident), (3) assisting with decision making about options (eg, tube feeding or rehospitalization), (4) dealing with prognostic uncertainty (eg, sudden, unexpected death or residents who linger), and (5) facilitating a comfortable death.

**Distress**

Assessing and managing distress from the symptoms that accompany the final phase of an illness were described as signaling the need to assess and alleviate pain, agitation, and delirium. All nursing professionals specifically focused on challenges they experience while monitoring a resident’s status and on identifying ways to alleviate discomfort. Nurses discussed their responsibility for assessing and medicating residents’ symptoms. The words of a nurse illustrate.

> When the doctors order morphine toward the end, there are some nurses who are very hesitant to do it. I’m not one of those nurses that if the doctor orders a q 2 hours prn. I much prefer. Some nurses are more comfortable when the doctor doesn’t make it prn, just q 2 hours. And then they don’t seem to question it as much.

CNA, certified nursing assistant; NH, nursing home. * Mean.

**Hands-on care**

Increased hands-on care as a means for alleviating distress and discomfort was a central element of managing the physical changes. As a resident makes the transition to end-stage care, nurses and CNAs described intense challenges in the different kind of hands-on care they use to relieve symptoms (eg, repositioning, bathing, cool cloths). The words of this CNA illustrate hands-on interventions and underlying concerns:

> I get so nervous, is this turn going to be the last turn or when I’m trying to position them. They are so uncomfortable, am I hurting them, am I agitating a situation even worse?

**Decision making**

Nurses and social workers described involvement in multiple decisions about a resident’s end-of-life needs. Nurses identified the inability to swallow and decisions about whether or not to introduce tube feeding or rehospitalize a dying resident as challenges they face in the transition. A nurse illustrates decisions that accompany the inability to swallow:

> When someone can no longer swallow and is choking on everything, and turning purple in the face then we get the therapist in to see why. When you cannot swallow you only have 1 other option—a feeding tube or you will die of starvation.

Nurses and social workers expressed the centrality of alleviating distress during this transition.

**Routine, Restorative Nursing Home Care**

- Distress management
- Increasing hands-on care
- Decision-making
- Facilitating a comfortable death

**Nursing Home-based End-of-life Care**

- Loss of a resident
- Family responses
- Integrating personal-professional responses

**Managing Overlapping Systems for Care**

- Regulations
- Procedures

Table 1. Sample Demographics

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**Fig. 1.** The transition from routine to end-of-life care in nursing homes.
Facilitating a comfortable death

The importance of managing the aspects of care that contribute to a peaceful passing were described by nurses, CNAs, and social workers as an important component of managing physical changes. Ten participants directly stated that they work to ensure residents do not die alone. A nurse describes her perspective on facilitating a comfortable death:

I think when you die it’s important to have somebody there that actually cares and will make sure that you are taken care of. We set flowers near them, put on music, and put [family] pictures by them. We make them feel comfortable so it’s easier for them to make that transition. That’s meaningful, knowing that you made somebody’s last time here peaceful.

Other aspects of comfortable deaths that were identified by participants were placing stuffed animals by the person, making trips to purchase a favorite food, and using religious rituals (eg, a rosary, prayer).

Prognostic uncertainty

The subtheme of prognostic uncertainty emerged from participants’ descriptions of deaths that occur suddenly (eg, staff were unaware that the person would die on their shift) and deaths that take a long time (eg, the active dying stage becomes protracted). The words of a nurse illustrate the management of a lengthy dying process:

Sometimes you just get those residents who linger on and on. A lot of times, we just, want them to go for the sake of their families. It’s very hard seeing them [family] come in on a daily basis and deal with that. That is the hardest part, especially when you have become so close to them.

Dealing with Emotions

Emotional responses were identified by all participants but were coded into 3 distinct categories or 3 subthemes: (1) loss of the resident, (2) family reactions, and (3) integrating personal-professional feelings to death.

Loss of a resident

Twenty-one participants (13 nurses, 6 CNAs, 3 social workers) directly identified the greatest challenge in the transition from routine to end-of-life care as the loss of strong attachments to and close relationships with residents. Seven participants described distress (eg, nightmares, intrusive images) that remained with them after some resident deaths. Eight participants described feelings of sadness when residents die without family or social support. Six participants identified being present with residents who were nearing death and helping them with tasks of closure (eg, telling stories, expressing feelings) as the most meaningful. The words of a CNA illustrate the challenges:

I believe that the CNAs have the most difficult time because we’re with residents for 8 hours a day and we’re doing the personal care with these people. We’re the ones that know their personality, if it’s changed or if something funny is going on … we know them better than anybody else does. So I believe that we have the hardest part when it comes to the end of life.

A nurse described her observations by saying,

A lot of times it hits the staff just as much as the family. I know definitely that we all get attached to our residents, especially if they are here for a long period.

Another nurse described the distress she and a colleague experienced:

There have been a couple of residents’ deaths where I just went home and could not sleep. The resident that just died the other day, the other nurse came in and she said, I went home, I woke up in the morning and I was sick. She said “I could not get it out of my head.”

Family responses

This subtheme emerged from 15 participants’ descriptions of a wide range of family responses to the residents’ dying process: grief stricken and tearful; angry, blaming, and demanding; or grateful and appreciative. Participants described being on the frontline and receiving the full force of families’ responses to a resident’s end-stage transition. The words of a social worker illustrate management of an angry response:

You learn to bite your tongue a lot. The family can be in your face and you just want to say something, but you don’t. They’re just upset.

Integrating personal-professional responses to death

Participants’ accounts illustrated the tension that comes from integrating personal feelings of sadness with the appropriate professional response when caring for many other residents. The words of this nurse illustrate the challenge of balancing personal and professional responses within a resident population with differential needs:

It is emotional because you get so wrapped up with the [dying] resident and sometimes you feel that they are your parents or your grandparents or something because you see them every day, it is like your extended family. You’ve got to be enthusiastic with one resident, then you go into a room where someone is dying and you’re sad.

The words of another nurse illustrate the personal-professional integration:

It’s almost like what we do on a professional level, we care for everybody, but when we have somebody who is not doing well, personal feelings take over and direct a lot of how we treat it.

Participants’ responses underscored the breadth and intensity of emotions that accompany the transition from routine to end-of-life care.

Managing Overlapping Systems of Care

Nursing home care involves overlapping systems: (1) the policies of an individual nursing home, (2) state and federal
nursing home regulations, and (3) the fiscal challenges of the nursing home field. Conflict with policies and procedures was identified by 10 participants (7 nurses and 3 social workers). Two subthemes emerged to illustrate how these systems-level issues influence the transition to end-stage care: (1) regulations, and (2) procedures.

**Regulations**

Eight participants (5 nurses, 3 social workers) described challenges with regulations about the documentation of residents’ changes according to state health department criteria, using the MDS to identify significant changes in a resident’s overall health and behavior, HIPAA, DNR (do not resuscitate) status, and health care proxy issues. The words of a nurse illustrate tension between end-of-life changes and regulations:

> We have to show the Department of Health, that we have done everything we can but the reason they are getting sicker is because they’re dying. The reason they are having skin breakdown is because they’re not eating, it isn’t that we’re not caring for them. The most difficult part is the documentation.

**Procedures**

This subtheme underscores the conflict that 8 participants described as they simultaneously strive to balance the need for individualized care of residents who are at life’s end with the need for comprehensive care in a highly regulated environment. Nurses and CNAs illustrate the conflict that emerges from balancing the needs of a resident’s changing needs with expected procedures. One nurse’s words illustrate:

> You’re supposed to turn and position people but that seems cruel at times, especially if someone has a tumor or cancer. I chart that the person shouldn’t be on their left side if that’s where they are in the most pain. You can make exceptions … every situation is different.

**DISCUSSION**

In-depth interviews were conducted with 35 direct-care professionals to identify how they manage the transition from routine, restorative care to end-of-life care in a nursing home. Three emergent themes and their subthemes characterize this dynamic process. Addressing Physical Changes involved distress management, increased hands-on care, assisting with end-of-life decision making and facilitating a comfortable death. Dealing with Emotions involved managing feelings about the loss of a resident, family responses, and integrating personal and professional responses to death. Managing Overlapping Systems for Care involved balancing tension among regulations, procedures, and a resident’s needs at life’s end.

The nature of nursing home care for people with advanced frailty can involve long-term and sometimes intense relationships with professionals who provide daily care for months to years. Often staff members work with residents who are admitted for routine restorative care, following them over the course of a long, slow decline and through the transition to the terminal phase of an illness. Physical changes that accompany the terminal phase such as distress from pain, agitation, and delirium occur in all health care settings. However, challenges such as deciding about whether or not to rehospitalize or initiate tube feeding, together with the uncertainty and ambiguity of advanced frailty in long-term residents is a unique aspect of nursing home–based end-of-life care. Emotional responses to an approaching death vary according to the situation and staff often integrate personal experiences with their professional response to death. Navigating overlapping regulatory systems with sometimes contradictory policies and regulations creates a distinct set of environmental stressors that can complicate the provision of nursing home–based end-of-life care.

Direct-care professionals play key roles in assessing and addressing residents’ changes and family needs during the transition from routine to end-of-life care. The results of this study underscore the findings of 2 previous studies that have explored how nursing home professionals, as frontline caregivers, recognize that residents are dying and help to ease suffering. Porock and Parker Oliver identified a series of cues that precipitate staff members’ growing awareness that a resident is dying, which dovetail with centrality of managing physical changes in this present study. Moreover, with recognition of the conflicting message that nursing homes issue about getting better through rehabilitation (publicly) while the private reality is that many will not, Parker Oliver et al explored how nursing home professionals covertly provide end-of-life care (p. 196). Illumination of the tension between the public rehabilitation message and the unspoken pursuit of palliation for dying residents is supplemented by this study’s theme of overlapping systems for care. Finally, the importance of strong and valuable relationships with residents underscored the subtheme of loss of a resident in the present study.

With limited regulatory guidance, each nursing home establishes individual protocols for the care of residents who are dying, resulting in wide variation in the type and quality of nursing home–based end-of-life care. In the absence of established protocols, individual nursing home staff members are expected to assess and address the needs of dying residents while simultaneously providing routine nursing home care to the remainder of the residents. As formal caregivers who provide hands-on care, nursing home professionals develop enduring relationships with residents and their families. The intensity of the bonds that are formed from this shared caregiving contributes to nursing home staff members “feeling like family.” These bonds can influence family members’ adaptation to the loss. Nursing home professionals ease physical and emotional distress at the end of life and they assist family members make the most of the final moments of a relative’s life. Nursing home residents are admitted because some type of medical crisis made institutionalized long-term care necessary. Thus, all nursing home residents can be considered to be “dying,” although not imminently. The ambiguous nature of the transition to end-stage care in frail people with multiple co-morbid conditions creates a unique set of expectations for nursing home professionals.
This study builds on and contributes to the growing body of knowledge about nursing home–based end-of-life care. Standards for quality in routine nursing home care have become a central dynamic in the long-term care field; however, they focus predominantly on activity and restoration. Standards for end-of-life care conflict with federal and state regulations; thus, access to palliative care within nursing homes has been sparse. These results suggest that some elements of palliative care exist because direct-care staff uphold high standards for care, but participants’ words also underscore the difficulty they face in attending to distinct resident/family needs as death approaches.

This study had several important limitations to note. First, the study was conducted in only one nursing home; there may be variations of the staff experience. Second, the sample size was small. However, what the study lacks in breadth it makes up for in depth. Gathering the perspectives and experiences of people who manage end-of-life care on a regular basis in their own words adds depth to our knowledge, and the perspectives of those direct-care staff members who did not participate would be enlightening. It is possible that there are perspectives that did not get represented here.

CONCLUSION

Nursing home administrators can be informed by their direct-care staff about how they balance the sometimes conflicting expectations of routine, restorative, and end-of-life care for residents. Building on staff members’ existing strengths, nursing home administrations can adopt a focus on end-of-life education and planning and can help frontline staff prepare for the inevitable numbers of residents who will die in the facility. The following are implications for practice: (1) focused end-of-life education and planning can help frontline staff prepare for the inevitable numbers of residents who will die in the nursing homes; (2) mechanisms for helping staff manage the intense emotional responses that accompany loss of long-term residents are important for long-term well-being of frontline staff; and (3) focused attention on the unique dynamics of “home” and “family” can assist nursing home professionals with ongoing losses and cumulative grief.

ACKNOWLEDGMENTS

The authors thank the staff of Beechwood Nursing Home for their willingness to share their perceptions and describe approaches to caring for dying residents.

REFERENCES


APPENDIX 1

Online Sources of Information and Education in Palliative Care


End of Life/Palliative Education Resource Center. http://www.eperc.mcw.edu/

Social Work Hospice & Palliative Care Network (SWHPN) http://www.swhpn.org/


APPENDIX 2

Interview Instrument

Your current job title

Highest degree:

Number of years you have worked in your field:

Number of years you have worked as a nursing home professional:

Number of years you have worked for this nursing home:

What is the most difficult aspect of providing end-of-life care?

What is the most meaningful aspect of providing end-of-life care?

How comfortable are you talking with a resident/family member about dying?

Can you give a “best-case scenario”/ “worst case scenario” which illustrates nursing home-based end-of-life care?

How do you know when a resident is dying?

Are there concrete physical or behavioral symptoms that are indicators for you?

Does the way that you provide care change when you realize that someone is dying?

How does it change?

Do you work as a team? How?

How do you work with the family?

How does the family learn that the person is dying?

Who talks with the family about the resident’s changing situation?

How comfortable are you talking about dying with patients?

How comfortable are you talking about dying with families?