

Family Perspectives on End-of-Life Care Experiences in Nursing Homes

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Purpose: The purpose of this study is to expand knowledge regarding end-of-life care received in nursing homes through the use of narrative interviews with family members close to the decedents. **Design and Methods:** We conducted follow-up qualitative interviews with 54 respondents who had participated in an earlier national survey of 1,578 informants. Interviews were taped and transcribed and then coded by a five-member, multidisciplinary team to identify overarching themes. **Results:** Respondents report that the needs of dying patients are often insufficiently addressed by health care professionals. Their low expectations of nursing homes and their experiences cause many to become vigilant advocates. Respondents report that physicians are often "missing in action," and they desire more and better trained staff. They indicate that regulations reinforce task-focused rather than person-centered care and add to patient and family burden. Although hospice services are reported to enhance end-of-life care, respondents also report late referrals and occasional misunderstandings about the role and scope of hospice. **Implications:** Sustained efforts on many fronts are needed to improve end-of-life care in nursing homes. Policy recommendations are suggested.

Key Words: *End-of-life care, Nursing homes, Family perceptions of nursing home care, Nursing home policy reform, Hospice in nursing homes*

Whereas most Americans died at home at the beginning of the 20th century, the majority of deaths now occur in institutions (Centers for Disease Control and Prevention [CDC], 2002). Nursing homes in particular are becoming a common setting for end-of-life care. Though about one fourth of Americans presently die in nursing homes and the percentage is likely to grow (Brock & Foley, 1998), the experience of dying nursing home residents has received little systematic attention.

Increasingly, nursing home residents have diverse needs and are medically precarious (Holtzman & Lurie, 1996; Weitzen, Teno, Fennell, & Mor, 2003). Almost two thirds of today's nursing home residents have three or more chronic conditions (Harrington, Carrillo, & Wellin, 2001); more than half of nursing home deaths are among persons with dementia (Travis, Loving, McClanahan, & Bernard, 2001); and hospital patients are increasingly transferred to nursing homes in the last weeks of life (Bourbonniere, Teno, Roy, & Mor, 2003; Engle, 1998; Tolle, Rosenfeld, Tilden, & Park, 1999). Furthermore, the role of family members in the nursing home setting (Litwak, 1985; Pillemer, Hegeman, Albright, & Henderson, 1998; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shield, 2003) is subject to greater pressures at the end of life.

The challenges to providing humane and compassionate care to dying nursing home residents are formidable. The 1987 Nursing Home Reform Act's goal of achieving maximal functional independence in nursing home populations, although worthy for many residents, can operate at odds with the palliative care needs of residents who are nearing the end of their lives. As with any care setting, providing compassionate end-of-life care in nursing homes is hindered by the difficulty in determining who is nearing death (Travis et al., 2001). Pain and other symptoms may be both unrecognized and inappropriately managed, especially among those with cognitive impairments (Cohen-Mansfield & Lipson 2002a, 2002b; Parmelee, Smith, & Katz, 1993; Reynolds, Henderson, Schulman, & Hanson, 2002; Teno, Weitzen, Wetle, & Mor, 2001).

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In contrast, nursing home residents receiving hospice services experience fewer hospitalizations and invasive treatments near the end of life, and they receive better analgesic management for daily pain (Miller, Gozalo, & Mor, 2000, 2001). Family members of persons who died in nursing homes perceived improvements in care after hospice admission (Baer & Hanson, 2000). In this way, there is wide variation in experiences of end-of-life care in the nursing home setting.

Given the challenges of providing compassionate end-of-life medical care in a nursing home setting, this study complements previously reported results from a national study (Teno et al., 2004) with the nuance and detail of in-depth, qualitative interviews. These interviews reveal insights of the lived experiences of the informants and the decedents and reveal insights that cannot be achieved by means of a quantitative methodology alone (Curry, Schwartz, Gruman, & Blank, 2000).

Methods

On the basis of the sample of a national survey, we conducted in-depth qualitative telephone interviews with 54 informants, usually close family members of a deceased resident of a nursing home or, in a very few cases, assisted care (hereafter referred to as nursing home residents). Of the original sample of 1,578 interviews, only 29 (< 2%) spent time in the last month in an assisted living facility. Some respondents in the qualitative sample were unclear as to the specific site of care to which they were referring. Most respondents were spouses, sons, daughters, parents, or siblings. Those categorized as "other" included nieces, nephews, grandchildren, or, in rare cases, close friends or guardians. All respondents were a subset of informants who had participated in the national survey and had agreed to a follow-up interview. The qualitative interview occurred approximately 1 year after the initial survey.

The Quantitative Survey

A mortality follow-back methodology used death certificates from 22 states to identify decedents who died from nontraumatic causes and were likely to have received health care for at least 48 hr in the last month of life (Bourbonniere et al., 2003; Teno, Casey, Welch, & Edgman-Levitan, 2001; Teno et al., 2004). The sampling strategy was designed to provide national estimates of the dying experience of persons who died in home, hospital, or nursing home settings throughout the United States. The person listed on the death certificate as the "informant" was asked to participate in the survey if he or she was the person who knew best how the decedent fared in the last month of life, or, if not, to identify such a person. Institutional Review Board (IRB) approval was

obtained from Brown University and each participating state. A total of 1,578 surveys were completed, representing a weighted sample of 1.97 million deaths in 2000.

The Qualitative Study

We conducted qualitative telephone interviews with 54 respondents for decedents who had spent at least 48 hr in a nursing home during the last month of life, matching the minimum time criterion used for the quantitative sample. We contacted 141 family members of decedents who died in all sites of care to participate in a qualitative interview. Thirty refused, sometimes citing sad memories. Of the resulting 111 interviews, 54 decedents had been in nursing homes or assisted care facilities. There was some oversampling for those who had received hospice care. The duration of the nursing home stay among decedents varied; 2 decedents spent more than 10 years in a nursing home, 8 spent less than 1 month, 25 spent between 1 and 12 months, and the remainder spent more than 1 year (with an estimated median time of 6 months to 1 year). Telephone interviews were semistructured and open-ended, lasting between 35 and 90 min each, depending on how much detail the respondent chose to provide. Following extensive pretesting of the interview instrument, three people (including R. Shield and L. Welch) conducted the interviews by using an interview guide (see questions in the following paragraph).

To provide the long perspective leading to the events prior to death, as well as to capture transitions among sites of care the decedent may have experienced, the interviewers asked respondents to "tell the story" of the decedent's last year of life. To learn about the actual "dying experience," the interviewers also asked respondents to focus on the last week of life. Follow-up questions probed "what went well" and "what could have gone better" regarding pain control, decision making, transfers between sites of care, communication with health care providers, satisfaction with care, quality of the dying experience, the dying person's preferences for end-of-life care, hospice care, emotional support, and financial burden. We structured the questions to elicit narratives in the respondents' own words and to allow respondents to create their own chronicles. Some examples of specific questions and probes are the following:

1. Please tell me about [his or her] and your experience in the last year or so of [his or her] life.
2. Where was [he or she] in the last year of life?
3. Tell me about how things went in the [type of institution].
4. Was there a time when you or [name of deceased] realized that [his or her] health was failing? Did you discuss this together? (*Probe*) Did you talk to a doctor or nurse about that? (*Probe*)

5. Was there ever a discussion about the possibility of starting certain treatments? (*Probe: Were choices offered?*)
6. Is there a particular conversation with a health care provider that stands out? (*Probe*)

The full research team analyzed the recorded and transcribed interviews and coded them by using Atlas.ti ethnographic software (www.atlasti.de/). The team was a physician–researcher specializing in end-of-life care (J. Teno); a health policy–health services researcher (T. Wetle); an anthropologist experienced in qualitative nursing home research (R. Shield); a health services researcher with expertise in hospice care (S. Miller); and a doctoral candidate in sociology, also experienced in qualitative methods (L. Welch). The team used group discussion in a line-by-line reading of the transcribed interviews to identify concerns and perceptions voiced by the respondents. The team concentrated on how utterances were worded and they noted repetition, emphasis, and emotionality in the text.

In order to determine how to code qualitative responses, each team member separately selected and coded quotes. Quotes were chosen from among text that had been marked as an utterance related to emerging concepts and themes and most succinctly captured a concept that was represented in several interviews. In weekly meetings the transcripts were discussed line by line and the coding was reconciled, to represent ultimate team consensus about the meaning of the utterances. Quotations from the narratives often received multiple codes. For example, a respondent’s description of a productive discussion with an aide about pain medication was coded both for “satisfactory communication” as well as for “positive symptom relief.” Often, single utterances contained negative as well as positive components and were coded accordingly. The research team later clustered the resulting codes into unifying themes by using an iterative process. After weeks of transcript review and coding development by the entire team, two team members reconciled the remaining coded transcripts and, for each transcript, developed a jointly coded document. These coded transcripts were then circulated within the group so that individuals could point out additional places to code or raise discrepant interpretations. Areas of disagreement were then discussed at subsequent meetings and resolved in the aforementioned process. In addition, for each interview, the research team referred back to the previous quantitative interview to provide context and describe illness trajectories and sites of service.

Results

Decedent and Respondent Characteristics

Table 1 provides information regarding the quantitative survey sample for decedents who spent

Table 1. Characteristics of Decedents

Characteristic	Quantitative Survey	Qualitative Study
No. of decedents	1,578	54
Spent at least 48 hr in nursing home in last month	587 (37.2%)	54 (100%)
Mean age (years)	83.2	83.9
Gender (female)	67.2%	70.4%
Race		
White (non-Hispanic)	90.5	77.4
Black (non-Hispanic)	5.2	11.3
Hispanic	2.9	7.6
Asian	0.9	1.9
American Indian or Alaskan	0.5	1.9
Marital status		
Married	23.0	24.1
Widowed	60.0	59.3
Divorced or separated	10.7	9.3
Never married	6.4	10.8
Education		
< high school graduate	42.2	47.2
High school graduate	31.6	26.4
Some college, graduate, or more	26.1	26.5
Cause of death		
Stroke	12.8	1.1
Cancer	15.8	22.2
Heart disease	46.5	22.2
Dementia	12.8	27.8
Advance directive (yes)	82.2	81.1
Hospice involvement (yes)	23.6	42.6

Note: Table data are unweighted comparisons.

at least 48 hr in a nursing home during the last month of life, and it compares them with the decedent characteristics of the subsample of individuals for whom there was a qualitative interview. Of the total 1,578 respondents in the quantitative survey, 587 (37.2%) spent at least 48 hr in a nursing home during their last month of life. Because the qualitative interviewees were selected with deliberate oversampling of decedents who had received hospice services in the nursing home, a higher percentage (42.6%) of the decedents received hospice care in a nursing home environment (compared with 23.6% in the quantitative sample). Gender, race and ethnicity, marital status, and educational attainment for the two groups of decedents were relatively similar. Table 2 compares respondent characteristics for the qualitative subgroup and the quantitative survey.

Thematic Analysis

Our two primary goals of the analysis were (a) to develop themes and constructs to inform policy and practice; and (b) to illuminate and improve our understanding of the findings from the quantitative

Table 2. Characteristics of Respondents

Characteristic	Quantitative Survey	Qualitative Study
Spouse or partner	14.0%	14.8%
Son or daughter (or in-law)	43.0	40.7
Parent	9.5	3.7
Sibling	6.3	5.5
Other (primarily nieces, nephews, grandchildren, and friends)	27.2	35.3
Gender (female)	68.9	64.8
Education		
< high school graduate	8.5	3.7
High school graduate	27.0	24.1
Some college, graduate, or more	65.1	72.2

Note: Table data are unweighted comparisons.

survey. A thematic analysis of the interview transcripts identified six themes (Table 3; Wetle, Teno, Shield, Welch, & Miller, 2004). Bearing in mind that the narratives describe the respondents' perceptions of emotionally charged experiences and sometimes may be based on mistaken assumptions or misunderstandings of the medical situation, we find that the themes nonetheless articulate distinctive and troubling patterns. Further, although each respondent's answers to our questions included complex, positive, negative, and qualified components, well more than half of the respondents had troubling things to say about the nursing home experience. Respondents reported that the needs of dying patients were often insufficiently addressed by health care professionals. Health care professionals did not always recognize when nursing home residents were dying and did not alter their caregiving approaches accordingly. Respondents' generally low expectations of nursing homes transformed many into vigilant advocates. They reported that physicians were often "missing in action" and they desired more and better trained staff. They perceived that regulations reinforced task-focused rather than person-centered care and added to patient and family burden. Although hospice services were reported to often enhance end-of-life care, respondents also reported late referrals and misunderstandings about the scope of hospice services.

These themes are described in the paragraphs that follow; we illustrate them with quotations from the narratives.

Theme 1: Symptoms, Needs, and Illness Trajectories of Dying Nursing Home Residents Are Insufficiently Recognized by Professionals, Resulting in Missed Opportunities for Advance Care Planning and Palliative Intervention.—Although some residents were admitted known to be terminally ill with a short life expectancy (often with a cancer diagnosis), the majority died after a long and slow decline in function. Family members

Table 3. Key Themes From Qualitative Study

Theme 1: Symptoms, needs, and illness trajectories of dying persons are insufficiently recognized by professionals, resulting in missed opportunities for advance care planning and palliative intervention. Failure to recognize symptoms or terminal phase Symptom management and palliative intervention. Inappropriate treatments and/or transfers, late or problematic decisions, and unnecessary suffering
Theme 2: Low expectations of nursing homes and experiences with poor quality of care turn many family members into vigilant advocates for their dying loved ones. Family expectations regarding care Low expectations at outset; higher expectations at outset, then disappointed
Advocacy Heightened vigilance; speaking out and communicating concerns
Theme 3: Physicians are viewed as "missing in action" in nursing homes Physician presence Finding physician; knowing patient Physician role Problematic communication; inadequate information
Theme 4: More and better trained staff desired by respondents Lack of staff Burden too high for existing staff; high turnover rates Staff need better training Staff undertrained for certain tasks
Theme 5: Regulations Task-focused regulations add to resident and family burden Misinterpreted and misunderstood regulations Positive aspects of care in nursing home compared with hospital
Theme 6: Hospice services often enhance the care of dying persons in nursing homes, but referral is frequently made late in the illness or not at all, preventing full benefit from such services, and conflicts are sometimes reported between hospice and nursing home staff. Referral to hospice Late or no referral to hospice; referral too late for benefit of hospice services Role of hospice Hospice considered valuable; hospice often misunderstood

reported inappropriate treatments or transfers, a focus on wrong or late decisions, and unnecessary suffering. For example, the daughter of an 89-year-old woman with end-stage dementia reported that even though she demanded that the nursing home stop transferring her mother to the hospital, staff members continued to pressure her to approve hospital visits. She told us: "The first year that she was in nursing home care, I believe she made 11 trips to the hospital . . . it just took so much out of her when they did that. . . . Now that's unnecessary."

Over 80% of the nursing home residents in this study had completed advance directives. However, respondents rarely commented on advance directives guiding end-of-life care. They noted that health care workers often failed to recognize that a resident had begun to die. They reported that the health care workers only rarely initiated conversations about end-of-life care preferences and that the lack of clarity about the resident's prognosis sometimes led to urgent and difficult decisions. They described how the tendency to focus on small and fleeting signs of improvement—by family members, health care workers, or both—sometimes led to lost opportunities for discussions about quality-of-life issues connected to the likelihood of imminent death. For example, one woman expressed anguish about whether her 76-year-old mother with dementia should have had a feeding tube inserted:

We were trying to decide whether we would introduce tube feeding and we had decided that we would not . . . and then, she suddenly came into a period of consciousness that made us rethink the game plan and then we did decide to do the tube placement. We obviously didn't want to withhold food from somebody . . . pretty alert . . . and by the time we got the tube placement in, she had lapsed into unconsciousness again.

Respondents were troubled about being asked to make urgent decisions without adequate consideration of their implications for ultimate goals of treatment. For example, one woman whose 84-year-old mother developed septicemia following intestinal surgery said this:

Basically things started shutting down; they rushed her across the street to the local hospital. They [intubated her] and they called [my brother] to give them permission to do that. Probably we should have let her go right then. . . . They rushed her back to the teaching hospital . . . and . . . she never fully regained consciousness.

Pain and trouble breathing were among the symptoms reported to be inadequately treated, and scant attention was paid to the emotional needs of either the dying resident or the family members. Respondents reported that they received insufficient information from nursing home staff, thus limiting their understanding of the conditions of their loved ones.

Instead of focusing on the resident's goals and palliative needs, more attention was reported as paid to restorative and rehabilitative services. One respondent noted an extreme instance of this disjuncture in goals in the treatment of her father, a 77-year-old man with dementia. Not recognizing that he was comatose, nursing home staff "had given him a whirlpool bath. And he was bruised from head to

toe. . . . But they were so proud that they had given him a whirlpool bath. They must have struggled to hold this man up." She added that the staff restrained her father in a geriatric chair the next day, again not realizing that he was in a coma.

Despite these accounts, some respondents also related positive experiences. They were grateful for staff members who kept them informed and provided compassionate attention to them and to their loved ones. Several family members cited instances of staff members going "beyond the call of duty" to provide humane and attentive care. The comments of an 85-year-old man's daughter attests to this kind of care: "as far as the last few hours that my Dad was alive . . . some of [the nursing home staff members] were in there constantly . . . [including] a couple of young teens . . . they were phenomenal . . . they stopped in every few minutes . . . they were extremely compassionate . . . and other [off-duty staff] . . . came in and stayed all night."

Theme 2: Low Expectations of Nursing Homes and Experiences With Poor Quality of Care Result in Many Family Members Who Are Vigilant Advocates for Their Dying Loved Ones.—Many respondents had low expectations of nursing home care at the outset, whereas others were surprised and dismayed by their negative experiences. One son of a 75-year-old man with congestive heart disease reported, "It's just reality that you don't go into a nursing home expecting to be staying at the Hilton. . . . Everything [my father] had heard about a nursing home, about the bad horror stories, came true."

Although some respondents had positive experiences and many were sympathetic to the staff, they also worried when low staffing levels seemed to prevent the proper administration of basic care. The son of a 77-year-old man with dementia told us, "there's not enough people to . . . take them to the toilet. . . . It's really . . . degrading." A daughter reported that her 95-year-old father with colon cancer was not kept clean. "They would just wheel him into the bathroom and hand him a washcloth and tell him he's on his own, where he needed more help." Insufficient supplies and inattention to equipment maintenance plagued many of the nursing homes featured in the narratives and added to respondent lack of trust in these facilities. Some family members reported how they attempted to fix equipment and supplement supplies; one described that the staff used the disposable briefs she had bought for her father for other residents.

Numerous family members related how they became advocates as a result of the poor care they witnessed. They were often more attuned than staff members to a resident's changing condition. The niece of a 99-year-old man with dementia stated, "I can remember having to speak with the staff about [his cough] and they were right on it. But I was right

on them when I was there. If I had said, 'Could you check into it?' and walked away, I don't think it would've been taken care of." A daughter of an 89-year-old woman with dementia declared,

I didn't set out to make waves, but I think I've lived long enough that I have the right to speak up especially with my mother. I didn't go looking for a fight, but I sure was there enough to keep an eye on things. And I'd advise anybody that has a family member or whatever in a nursing home, that's what you have to do.

Respondents in our study expended much effort, time, and money to be watchful advocates, sometimes at the expense of personal and professional obligations.

Theme 3: Physicians Are Viewed as Missing in Action in Nursing Homes.—Many respondents were dissatisfied that physicians were rarely seen in the nursing home. A relative of an 84-year-old woman with complications from intestinal surgery said, "the doctor was supposed to have been in every day. We never saw him." Some family members reported that they had wanted more information and communication regarding the condition of their loved ones and were dismayed by the lack of contact. "I never saw the doctor. I don't even know his name!" was a plaintive objection from a 97-year-old man whose 96-year-old wife had died of a heart attack in the nursing home.

Other family members reported dissatisfaction with the quality of interaction with the physician, and a few expressed unhappiness that nurse practitioners and physician assistants were used as "physician extenders." A physician guardian of a 93-year-old woman with chronic obstructive pulmonary disease was frustrated by his experience and told us this:

I thought that her medical care was not maybe what it should be ... the medical care wasn't done by the physician himself. It was done by his intermediary, a nurse, and ... that kind of irritated me. ... I shudder to think if a crisis had occurred, things would have taken time to get done.

Theme 4: Family Members Reported a Need for Consistency of Care.—This wish often focused on a complaint about the insufficient numbers of staff as well as their lack of compassion. The daughter of a woman with dementia stated, "a big thing is people who work there ... need to be much more understanding." The interviews contained repeated expressions of concern that nursing home residents did not receive timely care as a result of inadequate staff coverage. Respondents noted how call buttons went unanswered and their loved ones experienced

delays or neglect in personal care and assistance. For example, the niece of an 83-year-old woman with heart disease and dementia was convinced that her aunt's death was hastened by staff inattention. She commented, "they put feeding precautions that she needed to be sitting up to be fed, and it was difficult in the nursing home to get them to feed her the way she was supposed to be fed. ... [T]hey were very inadequately staffed for the kind of patients they had."

Family members often made a connection between the difficult working conditions at the nursing home and the high turnover rates among staff members. Although they conveyed considerable understanding for staff members who had to work under troubling conditions, they were distressed at the negative impact these circumstances had on their loved ones. A husband and wife made the following observation about the wife's 102-year-old mother, who had lived in a nursing home for 13 years:

These nursing homes are hard hit. The people that are doing all the hard labor don't make enough to live on. ... And, so the help comes and goes really fast. And that's bad ... she'd get attached to the nurses that were good to her. And, then when they left ... that bothered her quite a bit.

Theme 5: Regulations That Reinforce Task-Focused Rather Than Person-Centered Care Add to Patient and Family Burden.—Some respondents were concerned that filling out charts and abiding by rules impeded staff from providing compassionate care to residents. The husband of an 82-year-old woman with brain cancer said this:

It seems like they want to get this job done. ... "Do that lady and do it now," that kind of stuff. ... They had to get this thing done so they could write it on the chart. And then they'd get credit for it. ... And it irritates you when you see them almost torturing the patient to do these things so they can put it on a chart.

Some respondents believed that staff members misinterpreted the rules and unnecessarily restricted the autonomy of nursing home residents. Others attributed problems to state and federal mandates as well as management constraints that discourage individualized and palliative care for dying persons. They also observed that facilities did not always adjust the rules to better serve the changing conditions of the dying person. A few were distressed that the nursing home, concerned with a potential fall and following restraint reduction guidelines, moved a dying resident's mattress to the floor, as this daughter of an 89-year-old woman described: "My mother was at the point where she was not going to get out of bed and I just felt that they could have

made an exception and put her in a decent bed. And I don't know why that bothers me, but it does."

Sometimes nonexistent or misunderstood rules held sway, as the woman who had power of attorney for her 83-year-old aunt with dementia learned: "I went to the nursing home and told them that I wanted to make her a DNR. . . . And they told me I couldn't do that. I would have to get all of her nieces and nephews to sign because she had no children or siblings. And I was in the process of doing that when she died."

Facility limitations also influenced respondent reports of satisfaction with end-of-life care. Respondents noted the limitations of assisted care facilities, for example. One family gave up a familiar facility for one that could provide needed services but was less comfortable for the resident. Transfers between facilities were often considered burdensome. Lack of coordination in discharge from hospital to nursing home, for example, resulted in a substantial delay in receiving proper pain medication for one of the respondents. His wife reported that "When we got [to the nursing home] it was almost time for his medication again [but] . . . they couldn't get into any place until tomorrow that actually had this stuff. . . . I think they gave him a substitute." Similarly, hospital trips from the nursing home were often reported as difficult for the dying person and family alike.

In some important ways, however, nursing home care was perceived as superior to that experienced in the hospital. One daughter criticized hospital care when she said, "I was probably most impressed at the hospital with the cleaning staff. They were more compassionate." Respondents appreciated nursing home staff demonstrations of caring and sensitivity to the unique needs and wishes of the resident. They were grateful to staff and facilities when they stretched their resources to provide care *despite* facility limitations and shaped the rules to focus on residents and their needs. Some respondents recognized how difficult their family members were to manage. They noted that some staff members went beyond their assigned duties to acknowledge the resident as a person and to show respect for his or her life. Family members who experienced good care sometimes refused the hospice option when it was offered them, preferring current care.

Theme 6: Hospice Services Often Enhance the Care of Dying Persons in Nursing Homes. However, There Are Misunderstandings About the Hospice Benefit, and Referral is Frequently Made Late in the Illness or not at All, Preventing Full Benefit From Such Services.—Hospice care was hailed as highly valued by many respondents who reported that hospice helped nursing homes provide better quality care to dying residents. The niece of an 80-year-old woman remarked on the ease of her aunt's death

with hospice, saying, "They brought in hospice . . . they were great. . . . It was just so simple, so easy. She just went to sleep." Respondents reported that hospice workers provided symptom relief and lent support to both the dying person and loved ones. The daughter of an 84-year-old woman said, "They were there . . . [as] often [as] they were supposed to turn her on this side and change sides and all that stuff, they were there. Right on the money, right on time." The niece of a 91-year-old woman expressed contentment about the quality of her aunt's death under hospice care: "We felt like her passing was a gentle passing . . . we did feel very . . . supported and . . . the people we had were great."

The daughter of a reserved 71-year-old woman with lung cancer was impressed that hospice workers respected her mother's preference for privacy. She said they "were kind and loving and treated my mom like there was no one else in their lives at that moment. . . . They were there specifically for her. . . . They allowed her to be who she was, a quiet reserved person who did not share a lot of feelings."

In several narratives reporting problems with symptom management and other end-of-life treatment, the care improved when hospice became involved. One respondent was pleased by an increase in attention in the care of her 86-year-old aunt with pancreatic cancer with hospice services: "They had counselors in talking with her everyday. . . . There was a tremendous amount of support available."

However, misunderstandings about the role, scope, and regulations governing hospice care were reported as well. Some family members had unfulfilled expectations about what hospice would provide in the nursing home setting, as this family member of a 76-year-old woman with lung cancer noted:

I had heard that [when] you are terminal that hospice just takes over and they make your last days as pleasant as possible. . . . And I found that not to be true. . . . I found that . . . there are limitations. . . . There are certain things they will do and certain they won't do and there's a time limit and all those things.

Some families were not sufficiently informed about the Medicare Hospice benefit and noted that they expected hospice to be more present. "It was only a couple hours a week or so," said one disappointed family member.

Finally, referrals to hospice for nursing home residents were frequently not made or were too late to be useful. Difficulties in acknowledging that a resident was dying were reported to have contributed to some instances of late hospice referral. In addition, some residents would have been required to leave the nursing home in which they lived in order to receive hospice care because hospice was not an option at their facilities. For

example, the niece of a 93-year-old woman who had suffered a stroke told us, “They were going to provide hospice if she was going back home or if she was going to stay with anybody.”

Discussion

This analysis reveals important areas for concern and suggests directions for improvement. Sustained effort on many fronts, including increased funding—for increased staffing, staff training, and staff career training—is needed to improve end-of-life care in nursing homes. Improved care of dying residents should start with enhanced education of health professionals regarding the physical and emotional signs, symptoms, and needs of dying residents. Education regarding palliative care is uneven and lacking across the country, especially for physicians. We recommend providing incentives under General Medical Education (GME) funding to support physician training in palliative care and geriatrics. In their residency training, physicians also should be required to follow dying patients in all settings, especially nursing homes. Although the nursing profession has done more than other professions to enhance training in this area, our data indicate the need for more effort across the professions.

To improve the care of persons dying in nursing homes, the education of nursing home administrators and staff members should focus on person-centered as opposed to task-focused care and on implementing existing regulations and guidelines to improve quality assurance in end-of-life care. Current policies and regulations, some of which are the result of the well-intentioned Nursing Home Reform Act of 1987, require services for nursing home residents that are aimed to achieve the highest possible level of functioning and reward facilities that promote restorative programs. Although advocacy that has helped improve and maintain function in most nursing home residents is beneficial, it is important to be mindful that some of these efforts may be inappropriate for those who are dying. Best practice models that illustrate exemplary care should be encouraged, disseminated, and shared to (a) improve the management of symptoms; (b) identify decision points in the dying trajectory; (c) enhance communication among dying residents, families, and health care providers; and (d) improve staff training, oversight, and retention, including the development of a palliative career track for nursing assistants because they are the staff members providing the most direct care.

Although the public is often reluctant to learn and prepare for troubling eventualities, the confusion surrounding the hospice benefit indicates the need for a public information campaign devoted to explaining end-of-life options for care, as well as information regarding what to expect over the

course of a terminal illness. Current regulatory disincentives to palliative care for dying persons should be corrected. The CMS State Online Survey Manual should reflect state-of-the-art palliative care options for dying residents. Disincentives, including nonpayment, that discourage physicians from caring for dying patients should be ended. Nursing home residents and their families should have clear information regarding the hospice benefit. Finally, well-funded Centers of Excellence for End-of-Life Care should be developed that would provide resources to identify best practices, offer career education, and develop models for continuing education.

The Limitations of the Study

Because the number of respondents in the sample was not large by quantitative standards—though the sample is robust by qualitative standards—the ability to generalize the results beyond the qualitative sample may be limited. We partially addressed this shortcoming by comparing the qualitative data against the full sample from the quantitative survey, which indicated similar characteristics between the two groups. While quantitative methods help define the magnitude of a subject, qualitative methods provide more “trustworthy” results (Berkwits & Inui, 1998) from detailed descriptions that illuminate the intricacy of relationships and situations (Clark, 2002; Kaufman, 2002).

Although a small minority of the 54 decedents spent time in assisted care facilities rather than in nursing homes, it is difficult to ascertain the exact number residing there at the end of life, because of varying state definitions, multiple transitions within and between facilities by the decedent, and respondent understanding and memory. Narrative interviews occurred as long as 2 years after the death of the family member. Although memory of events may have been more reliable if the interviews had occurred closer to the time of the death, some respondents in this survey may have put the emotional events surrounding the death of a loved one in perspective given the greater time interval. Respondents with extreme feelings about their experiences—either positive or negative—may have been more eager to participate in the second interview. Prospective studies would provide valuable information, but the expense involved as well as the difficulty in identifying potential decedents limits the usefulness of this research design.

The interpretation of narrative interviews is subjective, and telephone interviews offer particular complexities because nonverbal cues may be missed. However, the richness of data from open-ended interviewing helps compensate for the self-selected content provided to open questions. In fact, some respondents may actually prefer this modality,

appreciating the anonymity afforded by the telephone, and they may have been more forthcoming because of it. Moreover, subjectivity in interpretation is a concern with any type of data, including forced-choice survey data that are analyzed quantitatively. In this study, the consensus process of the multidisciplinary-team approach to interpreting the narrative material aided validation as well as helped clarify the findings from the quantitative data through the analytic process.

Conclusion

For Americans dying of chronic illnesses, nursing homes are potentially ideal sites of care because staff members who have time to know residents well can deliver compassionate palliative care over time. However, the varied experiences of family members of dying nursing home residents reflected in our narratives underscore that truly satisfactory end-of-life care in nursing homes is rarely achieved. Although much is known about how to improve end-of-life care, much more action toward this goal has to be taken. As nursing homes increasingly become the site of death for more Americans, lessons from the experiences of their family members should be heeded in order to improve the care of those who die in them.

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