Factors That Influence End-of-Life Care in Nursing Homes: The Physical Environment, Inadequate Staffing, and Lack of Supervision

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Purpose: This study investigated the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. Design and Methods: Participant observation, interviews, and event analysis were used to obtain data in two proprietary facilities. Results: The physical environment was not conducive to end-of-life care. The rooms were crowded, there was little privacy, and the facilities were noisy. Inadequate staffing and lack of supervision were among the most significant organizational factors that influenced care. Often, residents did not receive basic care, such as bathing, oral hygiene, adequate food and fluids, and repositioning. A consequence of inadequate staffing was the development of pressure ulcers; 54% of the residents had pressure ulcers; 82% of these residents died with pressure ulcers. Implications: Findings suggest that the nursing home environment in these two facilities, as now structured, is an inappropriate setting for end-of-life care.

Key Words: Death and dying, Nursing homes, Inadequate staffing, Environmental factors, Palliative care

Mrs. Hanes (all names used are pseudonyms), a 63-year-old woman, moved to California to be near her only daughter and to care for her grandson while her daughter was at work. Suddenly, her plans were disrupted. Following a fall, she was admitted to an acute care hospital where the doctors found that she had a fractured right humerus. She had been diagnosed with breast cancer 4 years earlier and now learned that the cancer had metastasized to her lungs, liver, and bones.

She was transferred from the hospital to a nursing home and placed in a small three-bed room. Although her mother and father had died in a nursing home, she never imagined that she would be in one. She felt isolated. There was not a telephone jack in the room, and she could not call her family and friends. Her greatest wish was to die at home. “I have only 4 months left,” she said. “I just want to be near my family.” She often complained of pain. “Every part of my body hurts. It’s more painful than childbirth. It grabs on and won’t let go.” When she asked for medication, sometimes the nurses came right away, but once she had to wait for 5 hours. She was nauseated, and her mouth was dry. “I just can’t get enough fluid, and the water in the pitcher is old,” she said. After refilling the water container with ice water, we offered her a drink. “Oh, that tastes so good. I’ll just sip it to make it last,” she said.

Her sister was concerned about the care Mrs. Hanes had been receiving. “The care is inconsistent,” she told us. When Mrs. Hanes slipped down in bed and asked to be repositioned, the nursing assistant said: “You can do that yourself.” “What an awful thing to say,” her sister said. “She showed no compassion.” There was not a bedpan in the room, and when she asked for one, the staff told her that she did not need one. She was told to just “go in the diaper,” and then they would clean her up, but Mrs. Hanes did not want to do this. “It’s a dignity issue,” her sister said. Mrs. Hanes received her wish; her physician arranged for her to be discharged with...
home hospice care. Although Mrs. Hanes had a conscientious physician and an attentive family, her care in the nursing home fell short of what it should have been. Her care illustrates many of the problems we observed in the study reported here.

About one in every five deaths in the United States occur in nursing facilities (Keay, 1999), and the pressure to decrease hospital costs is likely to increase the use of nursing homes as a site for terminal care (Zerzan, Stearns, & Hanson, 2000). Although many people die in nursing homes, there is limited research on the process of death and dying in this setting. Previous research on death and dying in nursing facilities has focused on the role and responsibilities of certified nursing assistants (CNAs), licensed practical nurses (LPNs), registered nurses (RNs), and physicians who provide care to dying residents (Hanson & Henderson, 2000); the experience of living-dying in a nursing home as reported by African American and White residents (Engle, Fox-Hill, & Graney, 1998); and the role of hospice and palliative care in nursing homes (Casarett, Hirschman, & Henry, 2001).

Although nursing homes are the place of death for many older Americans, residents have limited access to palliative care (Zerzan, Stearns, & Hanson, 2000). Palliative care, which has its origins in the hospice movement, is "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount" (World Health Organization, 1990). Furthermore, it is comprehensive interdisciplinary care designed to promote quality of life for patients and families living with a terminal or incurable illness (Zerzan, Stearns, & Hanson, 2000). Although some studies have found that nursing home residents benefit from palliative care, these studies are retrospective (Baer & Hanson, 2000) and based on facility resident assessment data (Minimum Data Set data), prescription drug information, and Medicare claims data (Miller, Gozalo, & Mohr, 2000). The investigators found, for example, that although residents on hospice care were more likely to receive adequate pain management, a high proportion of residents receiving hospice care did not receive pharmacological treatment for pain regularly. They note that further research is needed to understand why this occurred (Miller, Gozalo, & Mohr, 2000). In the prospective, ethnographic study reported here, we identified factors in the nursing home environment that were barriers to the implementation of palliative care principles.

As part of a larger study that investigated the process of providing end-of-life care to terminally ill nursing home residents (i.e., residents who were dying or expected to die within 6–12 months), we addressed the research question: What are the social, cultural, clinical, and environmental factors that influence the care of dying residents? This article will focus on two environmental factors (i.e., physical and organizational issues) that influenced residents' care.

Conceptual Framework—Environment and Aging: The Physical and Organizational Environment

In her book, Notes on Nursing (1859/1946), Florence Nightingale discussed the importance of the environment when providing nursing care. In 1859, Nightingale wrote:

In watching diseases, both in private houses and in public hospitals, the thing which strikes the experienced observer most forcibly is this, that the symptoms or the sufferings generally considered to be inevitable and incident to the disease are very often not symptoms of the disease at all, but of something quite different—of the want of fresh air, or of light, or of warmth, or of quiet, or of cleanliness, of each or of all of these. (p. 5)

There is an extensive literature on how the environment affects older people (see reviews of early research by Lawton [1980] and Reizenstein [1981]). Investigators have found that the physical setting has long-range effects on the cognitive functioning and physical well-being of residents and their participation in social activities. For example, a study that examined the effects of the organizational environment on residents' involvement in activities disclosed that residents were more likely to participate in facility-organized activities if, on average, they functioned at a lower level, if staffing was higher, and the activity programs more structured (Lemke & Moos, 1989). In an intervention study, investigators found that, by improving the physical environment of the dining room (e.g., flowers on the tables and background music), the mean body weight increased significantly in the experimental group (Matthey, Vanneste, de Graff, de Groot, & van Staveren, 2001). Rule, Milke, and Dobbs (1992) reviewed the literature on how the physical environment can accommodate, to a greater or lesser extent, the sensory, cognitive, and social deficits that occur in older people. For example, Lawton (1970) found that the circular arrangement of residents' rooms around the nursing station and a large central living space promoted social interaction between staff and residents as well as among residents.

The design of the physical environment is important in the care of people with Alzheimer's disease and other dementias. A review of 70 empirical research studies from 1981 to 1995 on the physical design of environments for people with dementia included studies on relocation, respite and day care, special care units, sensory stimulation, lighting, and space (e.g., bathrooms, dining rooms, and residents' rooms; Day, Carreon, & Stump, 2000). A discussion of the findings of these studies is
beyond the scope of this article. In general, however, the authors concluded that, on the basis of existing research findings, dementia care units should consider certain recommendations. Among their suggestions are: (1) place cognitively unimpaired residents on units separate from people with dementia; (2) relocate residents as an intact unit rather than individually; (3) provide higher lighting levels; (4) incorporate accessible outdoor areas for residents; and (5) eliminate environmental factors (e.g., bath tub lifts, cold shower rooms, and inadequate handrails) that increase stress during bathing.

The environment is especially important to residents and their families when death is imminent. However, despite the large body of research on the effects of the environment on older people, to the best of our knowledge, there has been no ethnographic research on how the environment influences the care of terminally ill nursing home residents. This paper will focus on how the physical and organizational (i.e., levels of staffing and extent of supervision) environment affected end-of-life care in two facilities.

Methods
Setting and Sample
Data were gathered in three facilities, two proprietary nursing homes (one with 174 beds and the other with 138), and one government-owned facility. Only data from the proprietary facilities are presented here. Facilities were chosen to provide variation in resident, provider, and setting characteristics. A profile of the 117 residents who died during the data collection period is in Table 1.

Data Collection
Data were collected over a 30-month period from January 1999 through June 2001. Participant observation, in-depth interviews with residents (n = 35), their families (n = 52), nursing staff (n = 66), and physicians (n = 36), and event analysis were used to obtain data. Event analysis, a detailed description and analysis of a specific event, was the strategy used to obtain data on the care of the terminally ill residents. An event is something that happens or takes place that is important to the investigation. In this study, death and dying was the event examined. This methodology allowed us to observe prospectively the factors that influenced the care of residents who were dying, to interview those involved in their care, and to examine the issue contextually with an aim toward understanding how multiple factors influenced end-of-life care.

The care of these residents was observed from the time they were identified as being terminally ill until they died; this period of time ranged from 1 day to 15 months. The mean period of observation was 45 days. The care of each resident was observed several times a week, and sometimes (e.g., when death was imminent) observations were made 2 or 3 times a day. Observations were made from early morning until late evening, 7 days a week by the principal investigator (J.K.J.), the project director (E.S.S.), and six research assistants (doctoral students in nursing and medical sociology). To obtain data on the factors that influenced the experience of dying, observations focused on the dynamics of providing care during the process of dying. Data, for example, were obtained on how nursing and medical care were provided; who provided the care; and whether factors—such as age, cognitive status, ethnicity, reimbursement for care, and the physical and organizational environment—influenced care.

Data Analysis
Field notes, event analysis, and interview data were analyzed using qualitative analytic methods.
Results

Physical Environment

In both facilities, residents were accommodated in small, crowded, multibed rooms. There was little privacy. In some rooms, there were no chairs, and there were no recliners for families who wanted to stay all night with a dying relative. Some families slept in sleeping bags on the floor, which were often unclean. The facilities were noisy. Loudly playing televisions were ubiquitous. When the staff entered a room to provide care, they often turned on the television set, which remained on throughout the day. A resident reported that when the staff entered her room at 10 p.m. to care for her roommate, the CNA turned on the television while she provided care to the non-English-speaking Chinese resident. We walked into the room of a woman who was actively dying. She was alone with the television on.

The family of a 93-year-old Chinese woman moved her to a private room in another facility. The grandson said they wanted a quiet place where televisions were not playing and where he could stay all night with his grandmother. “I try to be here with my grandmother so that she knows she is not alone. It is important to have a peaceful place to try to relieve some of the spiritual suffering,” he said. In the for-profit facility (which accepted only private-pay residents) to which his grandmother was transferred, there were comfortable chairs and a recliner in the room. “They clean the hallways 2 to 3 times a day. Everything is so clean,” a family member remarked.

In the research sites, there was an inadequate supply of linens, and other items such as oral health supplies; sometimes equipment was used inappropriately. A resident suffering from nausea asked for an emesis basin and was given the metal plate cover from her tray, and a bunch of grapes had been placed at a resident’s bedside in an emesis basin. Dead flowers and other clutter remained on the bedside stands for days.

Mr. Wong, a 50-year-old man, was admitted to the nursing home in a semicomatose condition. His wife came every day to care for him, and on weekends his two sons, aged 7 and 9, came to visit. They had visited their father in the hospital, and when they came to the nursing home they were upset. “The children keep asking me, ‘Why don’t you put daddy in a better place?’” their mother remarked. “I tell them that I don’t have a choice; they’re young; they don’t understand. They don’t like to come here, but I tell them they need to come. It’s good for their father to have visitors.”

Organizational Environment: Inadequate Staffing and Lack of Supervision

Inadequate staffing and lack of supervision were among the most significant factors that influenced care. It was difficult to obtain data on staff/resident ratios; staffing changed from week to week, day to day, and sometimes within an 8-hour shift. Typically, however, on the day shift, there was one licensed staff, an RN or LPN for 15 residents, on evenings one for every 22 residents, and on the night shift, one nurse was responsible for the care of 45 to 47 residents. The CNA/resident ratios were as follows: On the day shift, 1:8–10; on the evening shift, 1:15; and on the night shift, each CNA cared for 23 residents. On some units, however, there was only one licensed staff on the daytime and evening shifts for 45 to 47 residents. An LPN, working the day shift, was the only licensed staff on the unit with 47 residents. “There really should be more staff,” she said. “They keep telling us that they’re going to get us more help. They’ve said that for the last 2 years that I’ve been here. To be honest, sometimes I ask myself, ‘Why am I such a martyr? Why do I stay here?’ It’s hard work and really stressful. They complain about our working overtime. But who wants to work overtime? I want to go home and be with my family.”

Families, nursing staff, and physicians repeatedly noted that staffing was inadequate. Mr. Pope’s daughter said: “They just don’t have time to do the care that he needs. They work hard, but there’s not enough help.” Another family member said: “The staff are overwhelmed. They have so many people to take care of. The residents are neglected. I see people lying in feces and urine for hours; there’s no supervision.” An LPN observed: “The number one problem is staff shortages.” A physician who had once worked as a CNA said: “They need more staff so that they can pay more attention to residents. Aphasic or quiet residents deserve as much care as anyone else.”

The problem of inadequate staffing was augmented by the fact that supervision of the CNAs was minimal. Some of the licensed staff stated that they did not like to supervise the CNAs. An LPN when asked about supervision said: “Well, it’s not really full supervision here. We have so much paperwork, but I always tell the CNAs that if they are in doubt,
they should ask. If they are concerned about anything, they should come and tell us.”

Lack of Basic Nursing Care: Bathing, Oral Hygiene, and Providing Adequate Fluids and Food

Bathing.—Although the facilities had a detailed description of the procedures for bathing, whether a resident was bathed depended on the CNAs and their workload. Some CNAs gave residents a shower twice a week and a bed bath on other days. Others did not. The daily work assignment for the CNAs was not always equitable. When reviewing the daily shower schedule, for example, we found that some CNAs had 5 to 7 showers to give, others had 1 or 2, and some had none. We asked a CNA why he had 7 residents to shower while another had none. “Well, it wouldn’t matter if she did have any,” he replied, “She wouldn’t do them. She never does her showers.” “Really?” we queried. “Yeah, that lady in 509B never gets a shower. Hasn’t had one in months, I don’t think.” “Are you able to shower seven residents?” we inquired. He replied that one day he was responsible for the care of 11 residents; 7 were to be showered. However, he showered only 3 of the 7. The type of bath given was also determined by the CNA. Mr. Saunders’ wash basin was at his bedside. “Are you getting up to take a shower?” we asked. “No, I only do that about once a month,” he said. “I really don’t enjoy it. They take me in there, and I tell them the water’s too hot, and then they switch the water, and it’s too cold.” “What do you do in between showers?” we inquired. “Well, I just wash up here a little bit at the bedside.” “Do they fill the basin with water?” “No,” he replied, “I just have a damp washcloth.” One man complained that once he did not have a shower or bath for two weeks. Finally, he reported it to the charge nurse. When the nurse aide was approached, she insisted that she had given the man a shower. “I pulled up my shirt and saw the dry skin and the dirt flaking off.”

Oral Health Care.—Similar to bathing, providing residents with oral health care depended primarily on the CNA. Some gave excellent oral health care; others did not. Based on our observations of the appearance and condition of the lips and oral cavity, about 50% of the residents did not receive adequate oral health care. Mrs. Kaspar, a 63-year-old nurse, was dying of cancer. When visiting Mrs. Kaspar, our research assistant (RA) recorded in her field notes: “Her lips are dry, severely cracked, and red from bloody scabs. Her tongue is red and swollen, and her lips are covered with blisters.” Her husband stated that she was in pain all over and referred to her swollen tongue and blistered lips. Although the doctor visited 4 days before she died, he did not order medication to treat the oral mucositis.

The non-English-speaking residents, especially those without family, were at risk for poor oral hygiene. A 56-year-old man from Laos was dying of hepatocellular cancer; he spoke limited English, had no family, and few friends. He was admitted to the nursing home from an acute care hospital and died 5 days later. During the 5 days that we observed his care, it appeared that he was not bathed and that he received little mouth care. His mucous membranes and lips were dry. A CNA came into the room; she looked at the resident, but she did not give him mouth care. A few minutes later, an LPN entered the room to check the resident’s oxygen saturation. Although he was visibly in need of oral care, she, too, did not provide any. On the day that he died, the RA recorded in her field notes: “This resident had a very distinct odor that got worse over the course of his five days in the nursing home. It was the odor of an unwashed body. He received poor mouth care. His lips and mouth were extremely dry, and a thick, pasty mucus had built up on his lips.”

Providing Adequate Fluids and Food.—Residents often stated that they were thirsty, and they frequently asked for something to drink. The containers of water were often out of reach, and in one facility, there was a shortage of water pitchers; thus, each resident did not have one at his/her bedside. Mrs. Fung was thirsty. There was nothing to drink in the room. Her dinner tray arrived with a can of supplement. We opened the container and handed it to her. She drank the entire 8 ounces in the span of 5 minutes. “Thank God you came along,” she said. “Who knows when I would have gotten something to drink.”

Mrs. Carson, an 88-year-old woman was admitted to the nursing home with a diagnosis of bacteremia. The plan was to discharge her home. We inducted her into the study and observed her care until she died, 26 days later. During those 26 days, we made 13 visits. On 11 of those 13 visits, she asked for and took fluids: “Water, water, I want water. Help me.” She rapidly drank 4 ounces of water. We offered her another cup, and she drank another 8 ounces. We offered her a glass of milk, and she drank 8 ounces. Within a few minutes, she drank 600 mL of liquids. “I want water at night, and they won’t give me any,” she said. “I get so thirsty. I get hungry.” Although the staff reported that she pushed them away when they offered her fluids, during our visits, she drank 350 mL each time liquids were offered. Orange juice, milk, and a supplement were on the bedside table, about 2 feet away from her bed. When we asked if Mrs. Carson had eaten any breakfast, the CNA replied: “I just left it there; she can call me if she wants any.” Four days later, Mrs. Carson was reaching for a carton of milk on her bedside table. She was weak and her hand was shaking. She had
lost 19 pounds in 1 month. She was too weak to suck on the straw, but using the straw as a pipette, the RA was able to give her 120 mL of milk. She died the following day.

Mrs. Denton, a 73-year-old woman, was admitted to the nursing home with a diagnosis of lung cancer. She repeatedly asked for water, often there was none at her bedside. Her tongue was crusted and her mouth was dry. There was no oral health equipment in the room. On request, the CNA brought some mouth swabs. We spent 10 minutes cleaning her mouth, after which she asked for water. She had difficulty swallowing; therefore, initially, we offered her a small amount of water with a spoon. “I want a big glass of water,” she stated emphatically. Concerned that she might aspirate, we replied, “Let us give you a little more water with a spoon.”

Looking directly at us she said: “Give me a big glass of water,” she stated emphatically. “I want a big glass of water,” she stated emphatically. Concerned that she might aspirate, we replied, “Let us give you a little more water with a spoon.”

Looking directly at us she said: “Give me a big glass of water, or I’ll kill you!” She drank 8 ounces of water.

Although receiving inadequate fluids was a major problem for residents, their families’ greatest fear was that they would not be fed. When death is imminent, some people become anorexic. However, in the weeks and months before death, residents often had a good appetite, and families felt obligated to be at the nursing home to feed them. Mrs. Dickson, an 82-year-old woman, came every other day to visit her husband. “I’m not well myself,” she said. “I wish I could come more often to feed him. I wish they would spend more time with him. I never see anyone in here but to drop a tray off and ask me to feed him. I want to do that when I’m here, but I wonder what happens when I’m not here?” Trays of food were sometimes left in front of residents who were incapable of feeding themselves.

An 88-year-old woman came every day to feed her husband. She had pain in her legs and slept poorly. “It’s a struggle to get out of bed in the morning,” she said. “But I have to see him every day. I have to come to feed him. We have to be here for every meal. They won’t make sure that he eats. I don’t dare leave him alone at mealtime.” Another woman came daily to feed her husband. When leaving the nursing home one day, she said: “I wasn’t going to come tomorrow. I really need a day off, but I worry if I don’t come. I don’t know how much longer I’ll be able to come every day, I’m so tired.” She had fallen twice, once while climbing the steps into the nursing home. She had bruises on her arm from the fall and confided that she had spent over $500,000, paying privately for her husband’s care.

A Brief Case Study: Mr. and Mrs. Larkin

Shortly after beginning data collection, we met the Larkins. Mr. Larkin was a 90-year-old mentally alert retired pharmacist. He had cancer of the prostate with metastases to the bone and was admitted to the nursing home for terminal care. His 91-year-old wife was also mentally alert and astute. She had a university degree and had taught high school for 40 years. Mrs. Larkin was not terminally ill. She was receiving treatment for venous stasis ulcers of her lower legs, but because she was sharing a room with her husband, we inducted her into the study, too.

Mrs. Larkin was quite independent; she could feed herself and do most of her care. Because of severe pain from the bone metastases, however, Mr. Larkin was dependent on the staff for his care. He could not, for example, open cartons of milk or cut his meat. Despite his need for help, the staff seldom assisted him at mealtime. Furthermore, he was often short of CNAs. “Why do you think that is?” we inquired. “I think it’s due to the salary,” she replied. “Nobody can live on $6 to $7 an hour. We are the heroes; heroes without a salary, the ones that do the work. It would be good if we had only 6 patients. If you have 6 patients, it’s great. You have time to talk with them, to feed them well, and you can check them often.”

Pressure Ulcers.—A consequence of inadequate staffing was that many residents remained in bed and developed contractures and pressure ulcers. Fifty-four percent of the residents (n = 63) had pressure ulcers; 82% of these residents died with pressure ulcers. These 63 residents had a total of 167 pressure ulcers; one woman had 13; 61% of these residents were admitted to the facility with pressure ulcers. When we asked the staff if they had time to turn residents every 2 hours, a CNA replied: “Quite honestly, we can’t do it every 2 hours. We’re really able to do it about 2 or 3 times a shift.” Our observations confirmed her statement. Although we did not collect quantitative data on the residents’ positions, our field notes documented that residents were usually lying on their backs.

The administrators in both facilities were aware of the need for more staff; they explored various strategies to attract new employees. In one facility, they posted and mailed flyers offering a $1,000 bonus to newly hired RNs or LPNs. In another facility, the administrator, an RN, and the director of nursing sometimes worked overtime as staff, covering the units that otherwise would have been without a licensed nurse. One administrator said: “Our staffing is horrendous, and it scares me to death.” Although efforts to recruit staff were admirable, salaries remained low. A CNA said: “We’re always short of CNAs.” “Why do you think that is?” we inquired. “I think it’s due to the salary,” she replied.

“Nobody can live on $6 to $7 an hour. We are the heroes; heroes without a salary, the ones that do the work. It would be good if we had only 6 patients. If you have 6 patients, it’s great. You have time to talk with them, to feed them well, and you can check them often.”
in four times in 45 minutes. I finally went in and said, ‘Look, you have called for repositioning four times since 10 o’clock.’ I told him that I had other patients with more critical problems who needed my attention.” Mr. Larkin died 4 days later. At the time of his death, he had five pressure ulcers on his back.

After Mr. Larkin died, we continued to visit his wife. During one visit, she told us about the last day of her husband’s life. “They didn’t give him anything to eat all day,” she said. “They brought the breakfast tray in but no one helped him.” When her lunch came, she gave him a cup of yogurt from her tray. She sensed that her husband was dying. “I just knew that I had to be near him. He kept saying, ‘Help me, help me.’” She asked to have her bed moved closer so that she could hold his hand. “He gave my hand a little squeeze, and then his hand dropped back.” “Did you know that he had died?” we inquired. “I didn’t know what was happening. I called the nurse. She checked his heart and said, ‘He’s gone.’”

Mrs. Larkin was frail, but the ulcers on her legs healed. She was able to walk and had planned to move to a nursing home near her nephew, who was a physician and also her guardian. She had a stroke, however, and died a few days later. After her death, we sent a sympathy card to her nephew; we told him that we had enjoyed meeting his aunt. He replied saying that Mrs. Larkin had enjoyed our visits. Also, unknown to him, while in the nursing home, she had kept a diary. He enclosed a copy of the diary.

Mrs. Larkin’s diary confirmed our observations about the lack of basic care. Many of the entries focused on her efforts to get food and water. One evening she wrote: “Dinner not served til [sic] 5:35 PM. with milk, orange juice, and salad missing.” On a day that had been difficult for her, she wrote: “To add to the day’s misery, I was left without water from noon til [sic] midnight, even tho [sic] they have a ruling that no patient is ever to be left without water, and even tho [sic] I kept requesting it.” Another diary entry read: “No supper tray was made up for me. Instead I was brought 1/2 a tuna sandwich in a bag. I demanded a full sandwich on a plate. Finally, after several messages to the kitchen to get tableware, I was also sent ice cream, but no spoon!” A few days later: “No water pitcher all day til [sic] midnight!” And again: “No water til [sic] noon and only after being requested.” On April 22nd, she wrote “Bob (her nephew and guardian) and Carol came. Brought pink roses, candy and Bob’s stuffed zucchini, a very special, delicious treat. Also brought two bags of chocolate kisses to replace the three that were stolen on April 16th.” (She kept candy in her room as a way of treating the staff who were good to her.) One week later, she wrote: “The chocolate kiss monster struck again, and cleaned out most of what Bob had just brought.” This was the last entry in her diary. Ten days later, she had a fatal stroke. When her nephew sent the diary to us, he said, “If this is the kind of care my aunt received when she was mentally alert and could ask for what she needed, I wonder what kind of care others receive who are not able to ask for what they need?”

Discussion

This study identified environmental factors, physical and organizational, that influenced end-of-life care. Privacy and space, which are necessary so that residents can have time with their families and bring closure to their lives, emerged as an important theme. The family that transferred their 93-year-old grandmother to a facility where they could have a private room illustrates the importance of privacy, a quiet environment, and the need for space so that families can stay comfortably with a dying relative. A lack of supplies may give the impression that residents are not valued, and a noisy environment detracts from the respect and dignity that residents and their families want and deserve. It was our impression that the televisions were often playing for the entertainment of the staff rather than for the benefit of the residents. Although there has been limited research about the physical environment in settings where people are dying, it is a significant factor that must be considered. Some hospitals are creating a home-like environment on palliative care units (Milbank Memorial Fund, 2000).

Although the physical environment is important, the organizational environment also affects care. Inadequate staffing and lack of supervision were critical factors in the care of the residents. Palliative care guidelines usually focus on core principles such as: (1) alleviation of pain and other symptoms; (2) assessment of psychological, social, and spiritual problems; (3) the need to respect the physician’s professional responsibility to discontinue some treatments; (4) the necessity of obtaining advance directives; and (5) the importance of supporting the family’s decision about end-of-life care (Cassel & Foley, 1999; Milbank Memorial Fund, 2000). Whereas these are important principles, providing basic care—such as bathing, oral health care, assisting residents in meeting their need for fluids and food, and repositioning them to prevent pressure ulcers—was also found to be important. Inadequate staffing levels and lack of supervision, however, appeared to cause these facilities to fall short in these domains. Personal cleanliness is highly valued, and a bath, given properly, can provide comfort and convey an attitude of care. In a study in which respondents (patients, families, physicians, and other care providers, e.g., nurses and social workers) were asked to rate the importance of 44 items, 99% of the respondents in each category rated “being kept clean” as very important at the end of life (Steinhauser et al., 2000).
Oral hygiene is not only an important comfort measure, it is necessary to prevent infections. The lack of oral health care can affect the ability to eat and speak. Also, xerostomia is common among older people, and radiation, chemotherapeutic agents, and medications may cause or contribute to xerostomia (Rounds & Papas, 1981). Some residents were receiving oxygen, which further contributed to dryness of their mucous membranes. Anorexia may occur at the end-of-life, which leads to reduced food and fluid intake and a resultant dry mouth. Also, mouth breathing is a common exacerbating problem. The lack of oral hygiene can cause great discomfort at the end of life. Kerr (1989) states that optimum mouth care for dying patients is an important concern of palliative care. He describes how an atomizer can be used to spray a fine mist over the entire oral mucosa, keeping it moist and promoting the comfort of the patient.

Elsewhere, we have described how inadequate staffing and lack of supervision contributed to a poor quality of care at mealtime, and to malnutrition, dehydration, and weight loss (Kayser-Jones & Schell, 1997; Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999). Anorexia, as mentioned previously, might occur at the end of life. However, in the weeks and months before death, we found that many residents were hungry and thirsty, and families, at great personal cost, were at the nursing home daily, fearful that their relatives would not be fed. Food and fluids are important physiologically, psychologically, socially, culturally, and symbolically. Food symbolizes love, security, care, and concern. Although we would not uniformly advocate artificial nutrition and hydration, people who are terminally ill, but hungry and thirsty, should not be denied food and fluids during the last days and weeks of their lives.

It is significant that 54% \( (n = 63) \) of the residents had pressure ulcers, and that more than half of these residents were admitted to the nursing home with pressure ulcers. Pressure ulcers may occur despite optimal nursing care, especially when people are terminally ill. We believe, however, that failure to reposition residents may have contributed to this problem.

Although we planned to obtain data on basic nursing care, our major goal was to focus on the assessment and management of pain and other symptoms, the expectations and concerns of residents and their families, and the event history/trajectory of the dying residents. These data were obtained and will be reported in future papers. The problems described herein, however, emerged early and remained prominent throughout the data collection period.

**Implications and Future Research**

The findings of this study disclosed that the nursing home environment in these two facilities, as now structured, is an inappropriate setting for end-of-life care. To ensure that people who die in nursing homes receive adequate care, changes must be made. First, a separate unit for residents who are terminally ill, where the philosophy of palliative care can be implemented, could provide the space and quiet atmosphere that residents and families desire. Next, to achieve the goals of palliative care, it is essential that an interdisciplinary team meet with residents and families to establish a plan of care that will ensure a safe and comfortable death for residents and effective support for families. Continuing education and in-service programs for nursing home staff on providing palliative care would assist them in achieving the goals of palliative care. Finally, the problems described herein will not be alleviated until adequate staffing and professional supervision of care are provided.

Inadequate staffing in nursing homes has been a problem for decades. The recent shortage of nursing staff in all facilities, however, exacerbated the problem to a crisis level, placing an unreasonable burden on the staff who often worked double shifts several days a week. Inadequate staffing causes physical, psychological, and emotional pain to residents and their families and inadequate care for dying residents. Furthermore, the staff felt overwhelmed, overworked, and frustrated, knowing that they could not provide a high standard of care. We are not suggesting that all of the staff were uncaring. During data collection, we met RNs, LPNs, CNAs, social workers, physicians, administrators, and others who provided excellent care under challenging conditions.

The findings from this study are not generalizable, because the research was conducted in only two nursing homes. The facilities selected, however, are representative of American nursing homes; they are proprietary and part of a major chain. Numerous studies and reports have documented the relationship between staffing and quality of care in nursing homes (Aaronson, Zinn, & Rosko, 1994; Cherry, 1991; Munroe, 1990; Spector & Takada, 1991). A recent study found that 90% of the nation’s nursing homes lacked adequate staffing (U.S. Centers for Medicare and Medicaid Services, 2001). Harrington (2001) notes that, despite decades of public concern, government surveys, and research studies, a poor quality of care continues in many facilities. Further research is needed to determine if the conditions found in this study exist in other facilities, and intervention studies could document how the environment can be altered to provide palliative care. Also, quantitative studies building on the findings reported here are necessary. Studies focusing, for example, on how staffing levels influence outcome variables—such as pain management, pressure ulcers, bathing, oral hygiene, and the provision of food and fluids to residents who are hungry and thirsty—are necessary.
Providing basic nursing care at the end of life does not require expensive, technological interventions, but it cannot be achieved without improving the physical environment, adequate staffing, professional supervision, and interdisciplinary collaboration. If steps are not taken to correct these problems, they may become the “standard of care.” Or, have we already created a culture of poor to mediocre care that is now accepted as the norm? If this should or has occurred, people will die in pain and discomfort and without the dignity and care they deserve. Nightingale’s words written 144 years ago are still relevant today:

... that the symptoms or the sufferings generally considered to be inevitable and incident to the disease are very often not symptoms of the disease at all, but of something quite different—of the want of fresh air, or of light, or of warmth, or of quiet, or of cleanliness, of each or all of these.

(Nightingale, 1859/1946, p. 5).

References

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