End of Life in Nursing Homes: Experiences and Policy Recommendations

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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FOREWORD

At the beginning of the 20th century, most people died in their own homes—usually after a relatively brief bout with an infectious disease. Today, most people die in hospitals or nursing homes after a lengthy experience with one or more chronic conditions. In 1999, nearly three-fourths of all deaths took place either in hospitals (51 percent) or in nursing homes (22 percent). Among those age 85 or older, 43 percent of deaths occurred in nursing homes.

Even though more people are dying in nursing homes, this report by researchers from Brown University shows that nursing facilities too often are ill prepared to address the needs of dying residents and their families. The report uses intensive interviews with surviving family members to provide an intimate perspective on the experience of dying in a nursing home. Through their stories, we can hear the anguish of seeing a loved one suffer needlessly from inadequate pain management and unnecessary transfers to and from hospitals. We can experience the frustration of family members who struggled with the lack of physician involvement and effective, sensitive palliative care. But we can also catch their moments of pride in helping a dying relative through difficult times, and we can witness their gratitude toward staff members who went out of their way to provide an extra level of care and support.

The members of the Brown research team—Terrie Wetle, Ph.D., Joan Teno, M.D, M.S., Renée Shield, Ph.D., Lisa Welch, M.A., and Susan C. Miller, Ph.D.—have elicited the poignant voices of bereaved family members while skillfully drawing out important themes from their experiences. These themes suggest systematic recommendations for improving services to dying residents in nursing homes and to their families. Practitioners will especially benefit from important, specific recommendations related to physicians, licensed nurses, and direct service workers. Public policy decision-makers will also benefit from recommendations related to public reimbursements and regulations. AARP offers this report in the hope that it will contribute to the ongoing dialogue on ways to change the culture of long-term care to offer more humane and life-affirming support at the end of life.

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EXECUTIVE SUMMARY

I. INTRODUCTION

About one in four American adults died in a nursing home in 2001, a proportion that has been increasing in recent years. Despite the growing importance of nursing homes in caring for the dying, little is known about the experiences or care of terminally ill nursing home residents.

II. PURPOSE

This report describes end-of-life care in nursing homes from the perspective of bereaved family members or others close to the decedents in order to identify policy issues and to make recommendations for policy change and educational initiatives. The report focuses on:

- the experiences of people dying in nursing homes, including symptom management, decisions regarding care, and communication with physicians and other care providers;
- the experiences of family members, including their communications with care providers, expectations and perceptions of nursing home care, and their perceptions of the burden of providing care and support to a loved one at the end of life;
- the perceptions family members have of the professionals providing care, including problems with sharing information, decision-making processes, sensitivity to the needs and dignity of the patient, and caregiver support; and
- the experiences of decedents receiving hospice services in nursing homes, including respondents' perspectives on electing hospice care for their dying relatives, coordinating hospice and nursing home services, and satisfaction with care.

III. METHODOLOGY

The primary data for this study are drawn from 54 in-depth telephone interviews with relatives and others close to people who had lived in a nursing home or assisted living facility during the last month of their lives. (See detailed description of methods in the appendices.) These qualitative interviews were conducted between November 2001 and October 2002, one to two years after the death of the family member. The qualitative interviews were a follow-up to a larger, quantitative telephone survey. The key informants for the quantitative survey (n = 1,578) were interviewed about their relatives’ end-of-life care and experiences (Teno et al., 2004). Respondents in the qualitative research were sampled from family members who had indicated a willingness to do follow-up interviews. An oversample of families that had experiences with hospice services was included. The average age of the decedents in the qualitative study was 83.9 years, 70.4 percent were women, and 77.4 percent were white. The median length of stay in the nursing home was between six months and one year.

This report focuses on the in-depth qualitative interviews, but information from the matched quantitative interview for each decedent was used to clarify trajectories of care, diagnoses, and other factors. The quantitative data were also used to describe the population more fully and to make comparisons with other decedents in the larger sample. A detailed review of relevant literature and expert consultations were also used to develop this report’s recommendations.
IV. KEY FINDINGS

Experiences of Dying in a Nursing Home

1. The symptoms, needs, and illness trajectories of dying people are insufficiently recognized by professional caregivers with the result that opportunities for palliative intervention and advance care planning are missed.

The illness trajectories of terminally ill nursing home residents vary considerably and may be difficult to predict. Some nursing home residents are recognized as terminally ill at admission. Others may live in a facility for some time before they are identified as having a terminal prognosis. For still others, the terminal phase is indistinguishable from a long, slow decline in function. Some respondents reported inadequate communication with nursing home staff, inappropriate treatments or transfers, additional caregiving burdens, incorrect or late decisions, and unnecessary suffering. Some residents find that their pain is not properly identified and treated, their dyspnea (difficulty breathing) is poorly managed, and their emotional suffering is not addressed.

Experiences of Family Members

2. Low expectations of nursing homes and experiences with poor-quality care turn many family members into vigilant advocates for their dying relatives.

Some family members report feeling grateful for the excellent end-of-life care that their loved ones received in nursing homes, but many do not always trust staff to provide competent and compassionate care. Out of concern for their relatives’ well-being, many family members act as advocates for their relatives to shield them from harm and ensure that they receive basic care. Despite the considerable burden they experience, many family members and friends report feeling substantial gratification from providing the care.

Professionals Who Provide Care to Dying Persons

3. Physicians are viewed as “missing in action” in nursing homes.

Respondents noted infrequent communication with physicians. Many reported that physicians were rarely seen in the nursing home, and many were dissatisfied with the level of attention and care the physicians provided.

4. Family members report a need for more and better-trained staff.

Nursing home staff members are often perceived as caring and compassionate, but they are also seen as overworked and lacking the training and time needed for compassionate care. Although respondents are sympathetic to the problems nursing home staff members face, they also worry about the safety and well-being of their relatives.
Institutions That Shape the End-of-Life Experience

5. Regulations that reinforce task-focused rather than person-centered care add to the burden of residents and families.

Respondents frequently reported that nursing home staff focused more on following rules (federal and state regulations as well as facility rules) than on the needs and preferences of individual residents. Respondents attribute some problems to state and federal mandates and management constraints that, from their perspective, discourage individualized and palliative care for dying people. Some respondents reported unwanted transfers from one facility to another that, in their opinion, were driven not by the preferences or needs of the residents or their caregivers but rather by facility policies and staff limitations.

Hospice Care in Nursing Homes

6. Hospice services in nursing homes often enhance the end-of-life care of dying residents, but respondents report that referral is frequently made late in the illness or not at all, thereby preventing residents from receiving the full benefit of such services. Respondents sometimes report conflicts between hospice and facility staff.

Respondents reported that hospice services often help nursing homes provide better-quality care to dying people. But misunderstandings and conflicts about the role, scope, and regulations governing hospice care were common among nursing home staff. Some respondents were disappointed with the services delivered and reported disagreements between hospice and nursing home staff over care responsibilities. Other respondents reported that their family member would have been required to leave the nursing home in order to receive hospice care, because such services were not offered at their facilities.

V. TRAINING AND POLICY CONSIDERATIONS

The experiences shared by family members suggest the need for improved end-of-life care in nursing homes. Achieving this goal will require a sustained effort on many fronts, including better education of health professionals, enhanced training of nursing home staff, better public information about end-of-life care, policy changes, and adequate financial support for training and staffing. The following recommendations are suggested:

Educating Health Professionals

1. Improve career education and continuing training of health professionals in the following areas:
   - the care of dying patients, including managing their physical symptoms (e.g., pain and dyspnea) and emotional distress;
   - knowledge of illness trajectories and physical function to allow more accurate prognoses; and
   - communication with dying patients and their families about their individual preferences and expectations, and improved advance care planning consistent with these preferences.
2. Advocate for federal funding to support career education and continuing training of health professionals in end-of-life care.

**Training Physicians in End-of-Life Care**

3. Use incentives under general medical education (GME) funding to improve physician training in end-of-life care. Such training might include:
   - requiring that internal medicine, family practice, pediatric, and obstetrics and gynecology residents follow a panel of patients, including terminally ill people, over their period of residency training;
   - requiring that physician residents follow individual patients as they leave the hospital to enter a nursing home; and
   - providing GME funding to support training in palliative care and geriatric fellowships.

**Training Nursing Home Staff and Administrators**

4. Provide education and mid-career training for nursing home staff, such as the End-of-Life Nursing Education Consortium (ELNEC) Project and the National Board for Certification of Hospice and Palliative Nurses, and develop career tracks in palliative care for nursing assistants to improve the following:
   - management of symptoms associated with dying;
   - communication with residents and family members clarifying individual preferences and describing what to expect in the dying process;
   - identification of decision points in the dying process; and
   - focus on resident-centered care.

5. Train and educate nursing home administrators to:
   - improve their understanding of quality assurance in end-of-life care;
   - clarify regulations and guidelines for covering and implementing the Medicare hospice benefit in nursing homes;
   - enhance strategies for responding appropriately to family advocates;
   - encourage best practices in staff training, oversight, and retention, including career-track incentives for certified nursing assistants in end-of-life care; and
   - ensure that Nursing Home Administrator certification includes adequate content on end-of-life-care.

**Informing the Public About End-of-Life Care in Nursing Homes**

6. Develop a public information campaign with educational materials targeted to nursing home residents experiencing a terminal illness and the people who care for them. The information provided would include:
   - how to be an effective advocate for dying nursing home residents;
   - what to expect of end-of-life care in nursing homes;
   - what to expect when people in nursing homes die;
   - why one should consider the availability of hospice care when selecting a nursing home;
   - how Medicare hospices provide care and what the Medicare/Medicaid hospice benefit pays for;
strategies for communicating effectively with doctors and other health professionals; and
educational resources for learning more about the end of life in nursing homes.

Developing New Knowledge and Improved Practices

7. Develop and support centers of excellence for end-of-life care.
   ▪ Use private/public partnerships to develop research and educational centers focused on
     improving symptom management and care and developing innovative models for caring
     for dying people.
   ▪ Advocate for federal funding to support such centers.

Policy Issues
8. Create incentives (and address disincentives) for physicians to visit and care for dying
   patients in nursing homes more regularly.

9. Increase reimbursements to nursing homes to enhance staffing and resources, improve
   quality of care, and avoid unnecessary hospitalizations.

10. Examine the quality of end-of-life care in nursing homes to:
    ▪ improve strategies and methods for monitoring quality;
    ▪ understand the unintended consequences of quality assurance strategies and measures;
    ▪ encourage quality improvement organizations (QIO) to conduct projects related to end-
      of-life care;
    ▪ train nursing home surveyors to address the quality of symptom control and end-of-life
      care; and
    ▪ resolve potential conflicts between the goals of rehabilitation and maintaining function
      and the goals of palliative care at the end of life.

11. Study the adequacy of the Medicare skilled care benefit for addressing the end-of-life
    palliative care needs of nursing home residents.

12. Provide incentives (and remove fiscal disincentives) for nursing homes to contract with
    Medicare-certified hospices, and hold nursing homes accountable for achieving high quality
    outcomes specific to end-of-life care regardless of whether or not they contract with or fully
    use hospice or palliative care services.

13. Identify and disseminate best practices, policies, and procedures to enhance collaboration
    between nursing homes and hospice providers.

14. Include the right to hospice care in the Patients’ Bill of Rights.

15. Add currently lacking content on pain management, fluids and hydration, and other aspects
    of end-of-life care to the Centers for Medicare and Medicaid Services (CMS) State On-Line
    Survey Manual.
VI. CONCLUSION

As nursing homes become the site of death for increasing numbers of Americans, much more must be done to ensure appropriate and compassionate care, improve the caregiving workforce, and reform the policies and regulations that guide care in institutional settings. A sustained effort on many fronts, including increased funding for training and adequate staffing, is needed to improve end-of-life care in nursing homes.
End of Life in Nursing Homes:
Experiences and Policy Recommendations

The 54 respondents told compelling stories about their loved ones’ experiences at the end of their lives in nursing homes. The following brief case summaries illustrate the world of the nursing home as experienced by dying residents and their families.

Illustrative Case Summaries

Case I: Mr. M was a 79-year-old man who was diagnosed with terminal cancer after what appeared to be successful coronary bypass surgery. He was referred to hospice services while in the hospital but he was forced to leave the hospital because of a “21-day hospital hospice limit.” Mr. M was discharged at night without adequate planning to ensure that the correct pain medications were available at the nursing home. Mr. M’s wife expressed concern about pain control at the nursing home, noting that staff members were unresponsive to her husband’s symptoms. She was also concerned about quality of care, observing that Mr. M was “dropped onto a nursing home bed” with little regard for his comfort. Because his roommate’s wife was deaf, the television’s volume was too loud, giving Mr. M little peace in his last hours of life.

Case II: In keeping with Mrs. L’s wishes, her niece refused to have tests and treatment for a possible malignancy done to Mrs. L. Through successful family advocacy and what the niece called the “training” of nursing home staff members, Mrs. L’s preferences were honored. In contrast to Mrs. L’s excellent care in the nursing home, the family encountered brusque emergency room practitioners during several visits to the hospital. The hospital staff disregarded the family’s expertise about the patient. After each hospital visit, Mrs. L and her family were relieved to return to the nursing home, where they were respected and treated well. Mrs. L was referred to hospice care late in her illness. When the decision was made to introduce hospice care, aides in the nursing home were initially upset, thinking that the patient would be abandoned. However, very positive hospice experiences were noted by the family with good symptom relief and emotional support.

Case III: The nursing home sent 89-year-old Mrs. X to the hospital on numerous occasions. These visits involved long waits in the emergency room while Mrs. X’s daughter agonized over the burden that repeated emergency room visits and hospitalizations created for her mother. Despite the daughter’s insistence that Mrs. X be treated in the nursing home, the nursing home staff continued to urge hospitalization. Mrs. X’s mattress was placed on the floor of her room in the nursing home to prevent injuries from falling, an action her daughter considered demeaning. Increasingly vigilant about her mother’s care, Mrs. X’s daughter was dismayed by inadequate staffing, medication errors, insensitive staff, inadequate facility responses to her complaints, and inadequate information from the staff and doctors. One doctor mistakenly talked with her about a different person’s care. When ownership of the nursing home changed, hospice care was added, and, according to the respondent, conditions improved.
Case IV: Mr. G was a 77-year-old male with Alzheimer’s disease and Parkinson’s disease. His daughter described extensive neglect in the nursing home, including toileting and personal care delays, little help with feeding, failure to provide the family with adequate information, an absent physician, and insufficient staffing. Her father was in pain, and when he couldn’t swallow, medication was stuffed into his mouth. His mattress was placed on the floor, which horrified his daughter. The staff, who did not realize that Mr. G was dying at that point, gave him a whirlpool bath and placed him in a geri-chair, allegedly to prevent falling. When Mr. G’s daughter appealed to his doctor, he was unaware that Mr. G was in a coma.

I. INTRODUCTION

A person’s home was the most common site of death at the turn of the 20th century, but hospitals and nursing homes are the usual sites of death today. Despite the desire of most people to die “at home” (Fried et al., 1999), at least 25 percent of those with chronic illnesses die in nursing homes (Happ et al., 1999; Mezey et al., 2002). According to data from the National Mortality Followback Survey (NMFS), the percentage of non-traumatic deaths among people aged 15 and older that occurred in nursing homes rose from 16.2 percent in 1989 to 23.2 percent in 2001, a 43.2 percent relative increase in 13 years (Brown University, 2004). Despite the growing importance of nursing homes in caring for the dying, relatively little is known about the experience of terminally ill individuals in nursing homes.

II. PURPOSE

This qualitative study describes end-of-life care in nursing homes from the perspective of bereaved family members or others close to the decedents. The interviews provide the respondents’ perspectives on:

- the experiences of people dying in nursing homes, including symptom occurrence and management, decisions about their care, and communication with physicians and other care providers;
- the experiences of family members, including their communications with care providers, expectations and perceptions of nursing home care, perceived caregiving burden, and support received;
- the perceptions family members have of the professionals providing care, including their willingness and ability to share information, their involvement of family in processes of decision-making, their sensitivity to the needs and dignity of the patient, and their support for the caregiver; and
- the experiences of decedents receiving hospice services in nursing homes, including the election of hospice care, coordination of hospice and other nursing home care and services, and satisfaction with care.

III. METHODOLOGY

Four sources of information were used to prepare this report. The first source is a literature review about end-of-life care in various settings, including nursing homes. A second source is a large quantitative study funded by the Robert Wood Johnson Foundation of people who died in
various settings. The third and primary source of data is a set of in-depth, qualitative telephone interviews with respondents close to people who spent time in a nursing home prior to death. Finally, analysis and interpretation of these three prior sources of information are informed by the experience of the interdisciplinary team conducting this research.

The in-depth qualitative interviews followed up a large-scale mortality follow back survey of 1,578 key informants. The context and sampling frame for the qualitative interviews grew out of the larger quantitative study. In addition, data from the quantitative survey were used to describe the qualitative sample in more detail. (See the appendices for more details on the methodologies used.)

**Quantitative Survey**

A mortality follow back methodology used death certificates from a two-stage probability sample of 22 states to identify decedents who were likely to have received end-of-life care. People who died traumatic deaths (e.g., homicide or motor vehicle accident victims) were excluded. The sampling strategy (see appendix A) was designed to provide national estimates of the dying experience. Institutional Review Board approval of the research protocol was sought from Brown University and from each participating state.

Death certificate data provided the date and cause of death and the name and address of the informant. The informant, usually a close family member, was contacted to request participation in the survey. Trained interviewers used a computer-assisted telephone interview system and a validated survey questionnaire. Each participant provided informed consent before responding to the survey. The quantitative survey encompassed 1,578 interviews, representing 1.97 million deaths when extrapolated back to the population.

The survey asked about various aspects of the decedent’s end-of-life care, including whether the informant believed that health care providers (1) provided the desired level of physical comfort and emotional support, (2) supported shared decision-making and communication, (3) treated the patient with respect and dignity, (4) attended to the family’s needs for information and emotional support, and (5) coordinated care among providers and settings.

**Qualitative Study**

Between November 2001 and October 2002, the Brown University research staff conducted 54 in-depth, qualitative interviews with a sample of informants who had participated in the quantitative survey and had agreed to be contacted again. The interviews took place between one and two years after the death of the family member.

Respondents were selected based on the decedents having spent at least 48 hours in a nursing home during the last month of life, with modest and deliberate oversampling for decedents who received hospice care. The median length of time between the first nursing home stay and death was between six months and one year with a range of 2 days to 13 years. More than one-third of the decedents had spent more than a year in a nursing home, and one in seven had been in a nursing home less than a month prior to death.
The average age of the decedents in the qualitative study was 83.9 years. Seventy-four percent were women, and 77.4 percent were white. As with any qualitative study using a small number of respondents, these results are not necessarily representative of the entire population of decedents.

The telephone interviews were semi-structured and open-ended, lasting 35 to 90 minutes each. Respondents first were asked to tell the “story” of the decedent’s last year and last week of life. Follow-up questions, organized around “what went well” and “what could have gone better,” focused on pain management, 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.

The interviews were recorded and transcribed and then analyzed by the full research team. (See appendix B for a complete description of the analysis.) Using a line-by-line coding system and group discussion, the research team identified issues, concerns, and perceptions and organized them into themes. For each interview, the research team used the previous quantitative interview to provide context and to clarify the illness trajectory and the sites of service. Representative quotations were selected to illustrate themes and sub-themes and are presented in this report.

Development of Policy and Training Recommendations

During the qualitative analysis, the research team flagged issues relevant to policy and training. At the same time, team members contacted experts and reviewed the literature, congressional testimony, and other professional materials. Current and previous research conducted by team members also informed the potential recommendations. Using all these sources, the team developed a detailed list of policy and training recommendations to address problems and improve end-of-life care.

IV. LITERATURE REVIEW

The following review of relevant literature provides a context for interpreting the qualitative narratives collected in this study and informs the policy and practice recommendations presented in this report.

Our Aging Population and Nursing Home Residents

Over the next several decades, the number of people in the United States ages 65 and older is expected to grow at an unparalleled pace. As this happens, the nursing home may grow in prominence as a site of care as well as a site of death. In 1999, 1.6 million people lived in nursing homes in the United States, 90 percent of whom were 65 and older and almost half were 85 and older (CDC, 2002). Diversity among nursing home residents is increasing. For example, the proportion of nursing home residents who were African American increased from 6 percent in 1985 to nearly 8 percent in 1999 (CDC, 2002).
The Changing Mission of Nursing Homes

A convergence of two trends has resulted in a population of nursing home residents with more complex illnesses, disabilities, and care needs. The first trend is the shifting of patients from hospitals to nursing homes because cost constraints have shortened hospital stays. As a result, nursing homes are more likely to care for a medically precarious population with serious functional impairments (Holtzman and Lurie, 1996; Weitzen et al., 2003). Although some nursing home residents with complex medical conditions improve and return to living independently, others remain in the facility for the rest of their lives. In other cases, hospital patients are transferred to nursing homes in the last weeks of life (Bourbonniere et al., 2003; Engle, 1998; Tolle et al., 1999). Either way, nursing homes are asked to provide more intensive medical services.

The second trend increasing the care needs of nursing home residents has been the effort to serve people with disabilities in non-institutional settings. Younger people with disabling conditions are unlikely to be in nursing homes until their conditions reach the terminal stage. Also, many older people have been able to avoid or postpone entering a nursing home because of the growing availability of supportive housing options, especially assisted living. The availability of alternatives to institutional care means that people are entering nursing homes with much higher levels of disability and more complex care needs than before. Almost two-thirds of residents have three or more chronic conditions (Harrington et al., 2001), and 50 to 60 percent of nursing home deaths occur in people with dementia (Travis et al., 2001).

The Nursing Home Reform Act of 1987 requires that nursing home residents achieve the highest possible level of functioning, and it financially rewards facilities that successfully implement restorative programs. This care paradigm, however, does not adequately address the changing mission of nursing home care. The systems that measure and promote the highest possible functioning focus on activities that avoid or minimize functional decline.

Although the goal of achieving maximum function has had beneficial effects for many residents, it can run counter to the preferences and palliative care needs of dying people and their families (Forbes, 2001; Hanson et al., 2002; Moseley, 1994; Travis et al., 2001). Determining when curative intervention in chronic illness is more burdensome than beneficial is especially difficult. An inappropriate focus on restorative services may lead nursing home staff to provide terminally ill residents with interventions rather than comfort and palliation in an effort to avoid deficiency citations and litigation.

Advocacy that has helped improve and maintain function in most nursing home residents must continue, but such efforts may be inappropriate and burdensome for those who are dying.

Caring for Dying Nursing Home Residents

Providing compassionate and appropriate end-of-life care is complicated by the difficulty in determining who is dying (Tilden et al., 2002) and when to shift from curative to palliative care (Travis et al., 2001). Hope that the resident’s condition will improve, disagreement about the
resident’s prognosis, and the lack of a definitive diagnosis often delay the shift to palliative care (Ellershaw and Ward, 2003). Cultural factors that favor continued curative treatment are also barriers to palliative care (Mehr et al., 2003). Recognizing that a resident is dying often comes only after a hospitalization or some other health crisis (Travis et al., 2002).

Nursing home staff who are unclear about who is dying may inadequately address resident needs. Pain, especially in women and people with cognitive impairments, may be both unrecognized and inappropriately managed (Ahronheim, 1997; Bernabei et al., 1998; Cohen-Mansfield and Lipson, 2002a, 2002b; Parmelee et al., 1993; Reynolds et al., 2002; Teno et al., 2001b). Some physicians and nurses are reluctant to prescribe or administer narcotics, in part because of adverse press surrounding the misuse of oxycontin, an effective pain medication.

Pain is one measure provided to consumers as a marker of nursing home quality. However, recent research has raised concerns about the quality and consistency of pain reporting (Wu et al., 2003). Physicians may underreport pain in their patients more often than do direct care providers (Flacker et al., 2001; George, 2002). Chochinov (2002) and Chochinov et al., (2002a, 2002b) focus on the needs and preferences of terminally ill residents to better address their symptoms and conserve their dignity. Some researchers have described limited but heartening educational initiatives to encourage compassionate care among nursing home staff members (Burack and Chichin, 2001; Degner et al., 1991; Dowding and Homer 2000; Ersek et al., 2000; Linn et al., 1983).

**The Role of Family Members**

Most family members maintain a relationship with their older relatives whether their elders live in the community, supportive housing, or nursing homes. They visit, call, and assist their relatives (Rowles and High, 1996). The benefits and burdens associated with caregiving have been extensively noted in the literature (e.g., Harper and Lund, 1990; Janzen, 2001; Port et al., 2001; Ryan and Scullion, 2000; Shield, 2003). Families stay connected with their older relatives when they are dying, often critiquing the quality and quantity of care their loved ones receive (Baer and Hanson, 2000; Cartwright, 2002; Danis et al., 1991; Emanuel et al., 1999; Forbes et al., 2000; Hanson et al., 1997; Reynolds et al., 2002; Teno et al., 2001a). One less-studied aspect of caregiving is the family members’ conviction that they must be advocates for the dying person to ensure that necessary care is performed (Teno et al., 2001a).

Family members report that making end-of-life care decisions was difficult, and they wish that they had more help and support (Forbes et al., 2000, Hanson et al., 1997). Despite the emphasis on individual autonomy, many frail people rely on their families and doctors for help with making decisions. Some researchers question the primacy of autonomy in some decision-making (George, 2002; Callahan, 2002). Other researchers report a lack of concordance about such decisions between those who are dying and their proxies (e.g., Wette et al., 1988; Gerety et al., 1993). Communication problems among health care providers, patients, and their families occur for many reasons, including time limitations; power differentials among health care providers, such as doctors, nurses, and certified nursing assistants (Solomon, 1998); the gulf between the languages and expectations of the health care world and that of patients and families (Kaufman, 2002; Segal, 2000); health care workers’ uneasiness about death (Baider and Wein, 2001; Shield,
Families members report feeling gratified when nursing home staff communicate well and when they are informed about what to expect and how to prepare emotionally (Degner et al., 1991; Hanson et al., 2002). Although evidence exists that older people welcome discussions of advance care planning (Siegler and Levin, 2000), such conversations rarely happen (Kass-Bartelmes et al., 2003; Wetle et al., 1988).

Making Care Decisions

The Patient Self-Determination Act of 1991 has encouraged institutions to execute advance directives such as living wills, durable powers of attorney for health care, and do not resuscitate (DNR) orders. Although more individuals are initiating advance directives, racial, religious, and ethnic differences are still evident in their use (Blackhall et al., 1999; Eleazer et al., 1996; Kiely et al., 2001; Lahn et al., 2001). Arrangements made in advance are sometimes not taken into account by health care providers (Danis et al., 1991; Teno et al., 1997; Virmani et al., 1994), and directives too often are limited to decisions about using cardiopulmonary resuscitation, are inconsistent, or offer inadequate guidance (Forbes, 2001; Happ et al., 1999, 2002; Mitchell and Lawson, 1999; Teno et al., 1998).

Sometimes an advance directive may seem to be ignored when the real issue is determining whether the patient is at the terminal stage at which the directive should go into effect (Teno et al., 1998). Some state laws require that two physicians certify that the patient is in the terminal phase of the illness. Determining the terminal phase accurately can be difficult in residents with chronic diseases.

Family members are often asked to make difficult care decisions if the decision-making capacity of the dying person is compromised. But family members as well as physicians can misinterpret the dying person’s preferences (Coppola et al., 2001; Ditto et al., 2001), and other health care proxies may not be available (Teno et al., 1998).

The use of artificial nutrition and hydration varies, and some researchers have questioned its value (Ahronheim et al., 2001; Mitchell et al., 1998; Onwuteaka-Phillipsen et al., 2001). Gessert and Calkins (2001) found that feeding tube use is significantly higher in urban counties than in rural ones, perhaps because feeding tubes are more available in urban areas. Gessert, Curry, and Robinson (2001) and O’Brien and colleagues (1997) report that African Americans take a more aggressive approach to feeding tube use than do whites. Preferences expressed in advance directives have also come under scrutiny. O’Brien and colleagues (1997) note that among residents who were competent to make decisions, 25 percent of those who initially indicated they would choose tube feeding changed their minds when they learned that restraints are sometimes applied in the process.
Physicians and Staff in Nursing Homes

Vladeck (1996) notes, “The physician’s active participation is vital if we are to ensure that every nursing home is one where we would send our parents to live, or where we would be content to live ourselves.” Mehr and colleagues (2003:91) report that families and physicians are better able to plan care in Dutch nursing homes, where physicians are always present. In contrast, residents and their families in this country have reported that physicians are absent in nursing homes (Hanson et al., 1997, 2002; Kayser-Jones, 1995, 2002). Negative incentives such as low Medicaid reimbursements contribute to the problem, as does the increased use of physician assistants and nurse practitioners (AGS, 2001; Kane, 1993).

Higher staffing levels in nursing homes are associated with improved resident safety and fewer medical errors (AHRQ, 2003), lower staff turnover, and fewer problems with quality of care (Abt Associates, 2001; Eaton, 2002; Harrington et al., 2003; HCFA, 2000; Kayser-Jones, 1997; Kayser-Jones et al., 2003; Munroe, 1990; Spector and Takada, 1991). But because reimbursement rates have not kept pace with the increased care needs of the nursing home population, recruiting appropriately skilled staff has become difficult. According to the Bureau of Labor Statistics (2002), the median hourly wage for nursing aides in 2000 was $8.61, and the median yearly income in 1995–97 was $11,000 (Leavitt, 1998). These rates are similar to low-wage jobs that require less training and are viewed as safer. Even if pay rates were higher, recruiting and retaining staff might be difficult when other industries are perceived as having better working conditions.

Institutional Issues

Each care setting has its own philosophy of care and financial constraints that affect the care provided. Although nursing homes are increasingly likely to be the place where people eventually die, they do not generally consider themselves to be facilities for the dying (Mezey et al., 2002). Nursing homes focus on enhancing residents’ physical functioning, a goal that is reflected in regulations and reimbursement incentives. These regulations and incentives, however, do not always encourage policies that meet the needs of dying residents. Hanson and colleagues (2002) have found that “the myth of rehabilitation” creates barriers to palliative care (see also Kayser-Jones et al., 2003; Zerzan et al., 2000). The time and care involved in providing compassionate palliation for dying people fits uneasily into the increasingly medicalized environment of nursing homes.

Dying people often undergo numerous transfers among sites of care in the last year and last month of life. These transitions are associated with problems in coordinating care and burden the person who is dying (Bourbonniere et al., 2003). Nursing home residents are sometimes transferred to hospitals for emergency care (Ackermann et al., 1998; Brock and Foley, 1996; Lynn, 1997, 2002; Saliba et al., 2000) when they could be treated in the nursing home (Fried et al., 1997). Physically frail residents are most likely to be hospitalized (Fried and Mor, 1997). For many people near the end of life, hospitalization may cause more harm than benefit, because it is often not clear whether the treatment goal is curative or palliative, and most hospitals are not equipped to adequately manage the chronic care needs of these patients.
Residents may also be transferred to the hospital to demonstrate that everything possible has been done to avoid deterioration. Moreover, nursing homes can receive financial benefits for such transfers: After a three-day hospital stay, some residents can be readmitted under the Medicare skilled nursing home benefit, which increases the nursing home’s reimbursement rate.

**Hospice Care in Nursing Homes**

Hospice care offers nursing homes the opportunity to provide intensive palliative services to dying residents without increasing their staffing levels. Nursing homes can offer Medicare hospice care by developing working relationships (including formal contracts) with Medicare-approved hospice providers (Gage et al., 2000). In 1996, an estimated 24 percent of Medicare hospice beneficiaries in Kansas, Maine, Mississippi, New York, and South Dakota resided in a nursing home. But Miller and Mor (2001) found that only 6 percent of nursing home residents in these states who died between 1992 and 1996 were enrolled in Medicare hospice programs. Gozalo and Miller (in press) found that among nursing home residents who died between 1995 and 1997 in Kansas, Maine, New York, Ohio, and South Dakota, hospice enrollment was 8 percent. Both studies found tremendous variation in hospice enrollment of nursing home residents across states.

Medicare prohibits residents who receive Medicare Part A skilled nursing care from simultaneously receiving Medicare hospice benefits, a restriction that keeps the enrollment of nursing home residents low. Still, 66 percent of nursing home residents dying in 1996 had payer sources other than Medicare Part A and were theoretically eligible for Medicare hospice enrollment (Rhoades and Sommers, 2000).

Compared with non-hospice residents in nursing homes, residents receiving hospice services experience fewer hospitalizations near the end of life, have fewer invasive treatments (i.e., enteral tubes, intravenous fluids, and intramuscular medications), and receive analgesic management for daily pain that accords with guidelines for the management of chronic pain in long-term care settings (Miller et al., 2000a, 2001a). Family members of decedents perceived improvements in care after admission to a hospice (Baer and Hanson, 2000).

Non-hospice residents in nursing homes also appear to benefit from hospice presence. Research has found that in nursing homes with a greater proportion of residents enrolled in hospice, non-hospice residents were less frequently hospitalized at the end of life and more frequently assessed for pain than residents in facilities without hospice care (Miller et al., 2001a).

The U.S. Office of the Inspector General (OIG) has raised concerns about Medicare “double dipping” when hospice care is provided in nursing homes (US Department of Health and Human Services, 1997). The OIG report estimated that the average hospice stay in nursing homes was 181 days and questioned whether hospices provide the same volume of services in nursing homes as they do in the community. After the OIG investigation, Miller and colleagues conducted a five-state study showing that the mean length of hospice stay was 91 days, the median was 35 days, and the mode was 2 days (Miller and Mor, 2001). Contrary to the OIG’s assumptions, short stays have become a major policy and clinical care concern (Last Acts, 2002). In nursing homes, hospice stays of seven days or fewer have become increasingly prevalent.
Miller et al., 2000a; Miller et al., 2003). Miller and colleagues (in press) have found that short-stay residents are less likely to receive appropriate analgesic management for their pain than hospice residents with longer stays. Miller and colleagues (in press) speculate that nursing homes do not allow adequate time to implement care plan changes for residents referred to hospice care shortly before death.

Although hospice care appears to benefit nursing home residents, collaboration between nursing homes and hospices can be problematic. Interviews with facility leaders, administrators, and staff describe how challenging it is for hospice and nursing home providers, with their differing care philosophies and conflicting regulatory guidance and oversight, to achieve successful collaborations (Gage et al., 2000; Miller et al., 2000b). These challenges are apparent in the coordination of billing, staffing, and other operations; the integration of clinical care practices across program and staff lines; and the maintenance of consistent and coherent communication at the administrative, clinical, and supervisory levels. Collaborators interviewed in one research study discussed the learning curve required to establish a good relationship and cited problems that were present early in the collaboration (Miller et al., 2000b). In addition, family members of enrollees in nursing home hospices, although highly satisfied with hospice care, cited problems with the coordination of care between hospice and nursing home staff, and many wondered aloud why they did not learn earlier of the availability of hospice care (Miller et al., 2000b).

A set of guidelines recently issued by the Centers for Medicare and Medicaid Services (CMS), Promising Practices for Implementing the Medicare Hospice Benefit for Nursing Home Residents (DHHS, 2002), clarifies the role of nursing homes and hospices in end-of-life care and emphasizes a coordinated plan of care. The guidelines identify the services to be provided by the hospice (nursing, physician, medical social services, and counseling) as well as the financial responsibilities of the hospice versus the nursing home. The guidelines also address the development, documentation, and ongoing evaluation of a care plan coordinated between the nursing home and the hospice. The guidelines state that the “hospice assumes full responsibility for professional management of patient’s care,” but they also state that hospices and nursing homes must maintain compliance with local, state, and Federal laws and regulations. Because these regulations hold both nursing homes and hospices responsible for a resident’s professional management, the CMS guidelines do not adequately resolve the issue of which provider is ultimately responsible when disagreements about care arise.

Conclusions from the Literature Review

Changing demographics of an aging society and evolving policy regarding nursing homes, hospice services, and health care influence the characteristics of the nursing home population and how services are delivered. As nursing homes serve greater numbers of residents with complex medical conditions, the need to provide compassionate end-of-life care and make sensitive medical decisions is more compelling than ever. Staffing levels and medical expertise have not kept up with increased complexity and severity of illness and needs of residents. Physician practices and staff training are inadequate to address the changing mission of nursing homes. The following narratives describe how the needs of many dying persons remain unmet. Their stories point the way to policy reforms that must be implemented to improve and ensure quality care at the end of life.
V. FINDINGS AND COMMENTARY

Respondents to the qualitative interview provided rich narratives about the experience of dying in a nursing home. Their stories provide important insights into expectations and concerns, the perceived quality of end-of-life care, communication with nursing home staff and other health professionals, and how the experience could be improved. In-depth, line-by-line analysis of the interview transcripts identified five key themes as well as several related sub-themes. The key themes are discussed in detail in the following sections of this report. Quotations from the narrative interviews illustrate and amplify the identified themes. The following discussion is organized around the central focal areas of the interview; namely, the experience of dying in a nursing home; the experiences of family members of decedents; the professionals who provide care to the dying; the institutions that shape the end-of-life experience; and hospice care in nursing homes.

These findings are the respondents’ perceptions, and the narratives describe what are, in many cases, difficult and emotionally charged experiences. They also reflect events that occurred more than a year before the interviews. In some cases, their reports may be based on mistaken assumptions or a misunderstanding of communications or medical situations. Nonetheless, these vivid stories lend urgency to the need to improve care at the end of life.

<table>
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<th>Key Themes From the Narrative Interviews</th>
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<td>▪ The symptoms, needs, and illness trajectories of dying people are insufficiently recognized, with the result that opportunities for palliative intervention and advance care planning are missed.</td>
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<td>▪ Low expectations of nursing homes and experiences with poor-quality care turn many family members into vigilant advocates for their dying relatives.</td>
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<td>▪ Physicians are viewed as “missing in action” in nursing homes.</td>
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<td>▪ Family members report a need for more and better-trained staff.</td>
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<td>▪ Regulations that reinforce task-focused rather than person-centered care add to the burden borne by residents and families.</td>
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<td>▪ Hospice services in nursing homes often enhance the end-of-life care of dying residents, but respondents report that referral is frequently made late in the illness or not at all, preventing residents from receiving the full benefit of such services. Respondents sometimes report conflicts between hospice and nursing home staff.</td>
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The Experience of Dying in a Nursing Home

The increasing use of nursing homes to provide end-of-life care raises concerns about how well these institutions have evolved to take on this role. As chronic diseases become the most common cause of death, nursing home staff members will need to gain knowledge about disease processes, symptom management, and decision-making processes as residents transition from coping with the symptoms of chronic disease to the dying process at the end of life. The interview narratives provide important perspectives about how disease trajectories and the last stages of dying occur, are recognized, and are managed in the nursing home setting.

Theme 1. The symptoms, needs, and illness trajectories of dying people are insufficiently recognized, with the result that opportunities for palliative intervention and advance care planning are missed.

Quantitative studies have documented the heterogeneity of nursing home populations. Long-stay residents are characterized by declining functional abilities, dementing illness, or other chronic conditions. Shorter-stay residents are admitted for subacute restorative and rehabilitative care. A third category includes residents admitted with terminal illness for end-of-life care. The narrative interviews provide a clear illustration and a deeper understanding of these diverse groups with their implications for care. The following subthemes illustrate the various reasons for entering a nursing home, the different trajectories of illness and death, the difficulties in recognizing when nursing home residents are dying, and the implications of these difficulties for advance care planning, symptom management, and the ability to provide care according to patients’ wishes.

1.a. People enter nursing homes for various reasons, with varying prognoses and functional trajectories. Some residents are terminally ill at the time of admission, with a short life expectancy; others have been in the facility for some time as a result of chronic illness and develop a terminal prognosis while in the facility. For yet others, the terminal phase is indistinguishable from a long, slow decline in function, often from multiple causes. Although terminal illness is commonly understood as proceeding rather quickly from diagnosis to end stage illness, most nursing home residents die after a long period of slow decline, some with fluctuations in functional ability. In the following cases, a long period of decline was followed by a relatively short, clearly defined terminal phase:

She had been in the nursing home because of her first stroke and she wasn't bedfast, but she was in a wheelchair most all the time. But after she had the second stroke, then she never did really regain consciousness at all... it had gone downhill a little ... she wasn't any worse health-wise until she had that second stroke and it was fatal.
—Male cousin of a 74-year-old woman who lived in a nursing home for more than a year after her first stroke
...she was 102, and her physical condition, just got old, just got worse, you know. And her breathing got bad and she had arthritis in both shoulder joints and, and her eyesight got real poor. She couldn't see very good and her hearing was very bad. And, she had a stroke a week before she died.

—Son of a 102-year-old woman with congestive heart failure who lived in the nursing home for 13 years

Such clear trajectories toward death are rare, though, in chronic, progressive illnesses such as dementia. Determining when the person is dying can be especially difficult in such situations and often involves what has been termed a “failure to thrive” or lack of a will to live:

Her only reason she was in a nursing home was [that] physically she couldn’t stay in her house anymore.... [S]he had gradually gone from walking, to the walker, to the wheelchair... somewhere along the way she became very depressed... a couple months before she died... She would cry... She stopped eating almost completely.

—Granddaughter of an 87-year-old woman with dementia and depression who lived in a nursing home for five years

...physically, she was fine... she didn't have the physical problems. It was mental problems... And you just see her gradually go... she talked when she was first in there and then she stopped the talking and she wouldn't eat.

—Daughter of an 84-year-old woman with dementia who lived in a nursing home for several years

Although residents with shorter and more defined courses of illness are a minority of nursing home residents, respondents also described some residents with much shorter courses of illness:

She went very quickly but when they diagnosed her, she was totally devastated by it and ... she wasn't ready to die... she didn't respond well to that treatment... and she had a lot of pain and it became very obvious that she could not care for herself so we had to give up her apartment at the independent living unit and move her into the nursing home ... And she was very comfortable there but she only lasted a few days after she was moved there.

—Niece of an 86-year-old woman whose cancer was diagnosed shortly before she died

1.b. The illness trajectories of terminally ill persons, especially those in nursing homes, vary considerably, are not well understood, and may be difficult to predict. For some trajectories, recognizing that a person has entered a terminal phase may be difficult. Understanding whether a person has begun to die is further complicated when health professionals (1) overlook important changes that may signal the onset of the dying phase and (2) communicate poorly with one another, the resident, and the family about the resident’s health status and care preferences. Physicians and other health providers who fail to determine the resident’s health status and care preferences may order inappropriate and unwanted interventions. Respondents in this study report inadequate communication, inappropriate treatments or transfers, additional caregiver burden, incorrect or late decisions, and unnecessary suffering.
For example, family members sometimes report that they do not understand why the resident was transferred from the nursing home to the hospital:

_She had fallen and hurt her leg and then they put her in bed and she was more or less bedridden and she never really walked again. [S]he just gave up and she wouldn't eat. And ... I don't recall why they put her in the hospital. She never got any better._

—Daughter of a 91-year-old woman with dementia who was hospitalized before she died

Or, family members finally realize that repeated transfers to the hospital are harming the resident:

_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._

—Woman who decided to refuse further hospitalizations or hospital visits for her 89-year-old mother, who suffered from dementia

An unclear prognosis makes decision-making particularly difficult. Ill-informed families often focus on small and fleeting signs of improvement in their loved ones rather than on their overall quality-of-life in the face of imminent death:

...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.

—Daughter of an 84-year-old woman who died of septicemia following intestinal surgery

When imminent death is either not recognized by staff or communicated to the family, medical decisions, particularly those involving a feeding tube, can be excruciatingly difficult:

_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 [who was]... pretty alert ...and by the time we got the tube placement in, she had lapsed into unconsciousness again._

—Daughter of a 76-year-old woman with dementia who was in a nursing home for a week following several falls

Families in these troubling situations have no clear solutions. They often do not realize that their loved one is dying and receive little guidance from nursing home staff members. In other circumstances, family members become aware that the end is near when the patient loses the will to live:

_I took her to a hospital and there was nothing wrong with her. She had just decided not to eat. That was her way of, more or less, of saying I'm ready to go..._

—Grandson of an 89-year-old woman with dementia
Although losing the will to live, refusing to eat, and failing to thrive are common observances, they may not indicate that the resident is approaching death. They may be symptoms of treatable depression or another condition. Moreover, even when these symptoms are associated with the terminal phase, families may not recognize them as such and staff members may not explain their significance. Failing to recognize when symptoms indicate imminent death means that opportunities for conversations about relevant choices are missed and suboptimal care is provided.

1.c. Failing to recognize when nursing home residents are dying prevents appropriate and compassionate end-of-life care for them.

At times, staff members may not realize that a resident is dying. Moreover, staff members and other health providers may not take the opportunity to anticipate the resident’s needs over time or evaluate the resident for palliative care. Staff members who do not recognize when the resident has transitioned into a more active dying process miss the opportunity to focus on the resident’s goals and palliative needs rather than on restorative and rehabilitative services.

*I had mentioned it to the doctor, ‘Did they tell you what was going on with my dad?’ ‘Oh, who’s your dad?’ And I said ‘That man that is sitting there, HANGING there.’ And I said, ‘Would you please have them at least put him to bed? ...The man is in a coma... Isn’t there something you can do to make him more comfortable? ...He is NOT going to run away from anybody right now.’*

—Daughter of a 77-year-old man with dementia who was restrained in a chair and whose comatose state went undetected until she alerted staff

Regulatory pressures to improve function and prevent decline are appropriate for many nursing home residents, but nursing home staff may misinterpret those requirements and provide inappropriate treatments and services. These interventions may result in unnecessary suffering for residents in the last stages of dying and distress for the family:

...they [were] giving her care and physical therapy but she really didn't want the treatments. She didn't want to go. We had to kind of force her sometimes.

—Daughter of a 91-year-old woman with dementia who was given rehabilitative treatments in the weeks before death

*The day before, while he was in a coma, they were so pleased...to tell me that they had given him a whirlpool bath. And he was bruised from head to toe. I mean, his arms were bruised, his legs were bruised, he was bruised all over, you know...very time we sort of tried to hold him or make him comfortable, he grimaced like he was in pain. Somehow or other, I felt that something was hurting him from his whirlpool bath the day before because of all of his bruises. But they were so PROUD that they had given him a whirlpool bath. They must have struggled to hold this man up.*

—Daughter of a 77-year-old man with dementia in coma
Failure to recognize that the resident is dying results in what appears to the family to be inappropriate care. Rather than shift from “cure” to “care” by providing therapies to ease a resident into death, dying residents are treated as if they are stable or might still improve. Too often, staff do not discuss whether residents may be approaching death and, if so, how best to treat them. Respondents express distress about seemingly unnecessary interventions, highlighting the importance of setting clear care goals and providing care consistent with those goals.

1.d. Some residents find that their pain is insufficiently recognized and treated, their dyspnea (difficulty breathing) is poorly managed, and their emotional suffering is not addressed.

When nursing home staff do not recognize imminent death, opportunities for palliative care, including appropriate symptom management, are missed. Respondents are particularly distressed when reporting problems with managing residents’ pain and emotional suffering. Families repeatedly express frustration when staff members overlook basic necessities of care and symptom relief for their loved ones:

And my mom began to struggle with the pain. It was coming onto a dosage time and the nurse at the assisted living facility really was like, well, it's not 8 o'clock yet, blah, blah, blah. ...[s]he died at 8:57[and] the dosage was given at a point where my mom couldn't really take it, and it dribbled out of her mouth a little bit. I don't know if she died in pain or not.
—Daughter of a 71-year-old woman who lived in assisted living following a stroke and then developed lung cancer

She was in the nursing home. The last week, she was very ill. She was lucid. But, she was cross at times because she was SO uncomfortable. They did NOT give her enough medication to ease her pain, which they should have ... if you rang the bell for medication, if she were in pain or something like that, they probably didn't come, and if we weren't there, very frequently, we had to go GET somebody.
—Niece of a 76-year-old woman with lung cancer whose pain was not relieved until her last day, when she was given morphine injections

Although less frequently reported, problems were also noted with managing dyspnea:

He had to have one of those [oxygen concentrators] on him all the time.... And they weren't too good about making sure it ran. I went up there one time, and the thing was completely off. Nobody was around, you know. And those things irritate you, especially when Pop can't get any wind.
—Son of an 86-year-old man with emphysema

Emotional suffering is also a concern for family members. Although they may be aware of acute suffering, they may not always understand the source of that suffering and may not be told what to expect in end-of-life situations. They remain troubled by the experience long after their loved one’s death:
He looked afraid. I just know him. He, I could tell he was afraid, and the TV being on all night and eyes open and just to sleep a little bit during the day— it's almost like you're fighting death.
—Daughter of a 70-year-old man diagnosed with cancer two weeks before his death

However, appropriate treatment of these symptoms can provide substantial relief, as the previous narrator points out:

I had worked for hospice for a year [previously], most of those patients get an anti-anxiety medication. ... when people are terminal, they are anxious and worked-up about it. So, what they gave him [her father the medicine], I was familiar with it from.. working there [where] they use it quite a bit. ...Of course, once they get ALL this medication into their system, they sleep because of the medicine. And they usually never wake up. So I was a step ahead because I knew some of these things. But of course, knowing it and going through it yourself are two different things...The hospice care could have been better, so...The nurse from hospice and the medication could have been more efficient.

1.e. Although most nursing home residents have advance directives, they often are not used to guide important decisions at the end of life, and occasionally they are not followed.

Since the implementation of the Patient Self-Determination Act in 1991, hospitals, nursing homes, and other health care facilities have made substantial efforts to inform patients and residents of their right to execute advance directives. Most of our respondents indicated that the decedents had previously executed advance directives. However, most did not cite these directives as important factors in end-of-life decisions. When health care professionals do not notice that a person has begun dying, they are unlikely to refer to advance directives. When advance directives are discussed among the family, the provider, and the dying person, they do help guide difficult decisions about end-of-life care. For example, advance directives can be useful in reconciling family disagreements:

And one of my brothers was getting upset with the doctor. Okay, why can't you guys take her to the hospital? ...[The doctor] pulled out her chart. ‘This is the reason why: We're going by what she wanted.’ And I felt the same way: If she didn't want to be taken to the hospital and ... I make them take her to the hospital, I probably would have been upset with myself for a long period of time. And I just didn't want to go against her wishes.
—Granddaughter of an 85-year-old woman who was on dialysis until she went into a coma the day before she died

They also help clarify the limits of health care interventions:

And [the doctor] explained ... it was metastasized. ... there wasn't much point in giving him chemotherapy. And he said, ‘Does he have a living will?’ and I said, ‘Yes, he does, and he does not want extra attention like that.’
—Wife of a 79-year-old man diagnosed with melanoma
... I sat down the first day that she was there and talked with the hospice people and she made the decision as to what she wanted, you know, if she wanted oxygen... she made all those decisions herself. And I mean I sat there with her and explained it to her, and as far as no resuscitation and no code and all that stuff, we sat down and discussed it and she made the decision and she signed it and I signed it as her witness and all of it was her decision.

—Friend who refers to herself as the “niece” of an 80-year-old woman with terminal cancer

However, the presence of an advance directive or other advance care instruction (e.g., a DNR order) does not guarantee that the resident’s wishes will be followed if the documentation is not transported with the person to the hospital:

[The living will] was in her file, in the hospital file. BUT...the people who took her to the hospital [for a chest x-ray] did not take that living will physically in hand with her. So, when she choked, she was a Code Blue. So the doctor did his thing, brought her back, busted her ribs, but nevertheless, he saved her. Now he saved a lady that wanted to die!

—Daughter of an 85-year-old woman with asthma who lived in a nursing home for three years

...the girl said to me, "I've saved your husband's life," which told me that she did not follow instructions because I had a DNR ...What are you going to do? You just live with it.

—Wife of an 84-year-old man with dementia

Although these quotations are compelling, comments such as these occur relatively infrequently in the narratives. The sources of dissatisfaction are more likely to be associated with the quality of ongoing care, the lack of communication about the resident’s condition and prognosis, and the staff’s failure to respond to the resident’s changing needs and preferences.

1.f. Some are satisfied with end-of-life care in nursing home settings, and respondents attribute some of this satisfaction to clear communication about what to expect and assistance in planning treatments.

Despite their dissatisfaction, some respondents report appreciation for staff attention and acts of kindness and express satisfaction with care. The longer-term nature of nursing home care can provide staff members with the opportunity to get to know residents well, recognize trajectories of illness, and provide timely and appropriate transitions from cure to care modalities. The longer-term relationship can mean that residents can die with supportive nursing home caregivers assisting them and their families. Respondents were particularly satisfied with health professionals who explained what to expect in the illness trajectory and process of dying. Information provided to respondents in a timely and appropriate manner was perceived as helpful and supportive:

I mean they would tell you in a soft gentle way versus, well, your pop's gonna die, you know. We knew the same conclusion but there's a way to say it and a way to not say it...But when these people, hospice come on, we knew, and especially when we decided or they
told us that it was time that we needed to have 24-hour care we knew that it was imminent. They know, they can tell...We just knew. It was just in a soft, gentle way that the time is near.

—Son of an 86-year-old man with arterial sclerotic heart disease

...we had a good relationship with her and she answered all of our questions and we were very clear from August on, exactly every step that would be taken because we asked her questions and she answered them. You know, we've been there before ...with other relatives so she was very straightforward, this is what will happen, this is what we need to do so.

—Niece of a 91-year-old woman with cerebrovascular disease

Well, they had made me aware that his system was slowing down. I don't know that those were the exact words, "shutting down" is the expression they used. And I was, I was aware having been with my great-grandmother and my grandmother, so, and my mother. I was with her when she died. And I was aware of what happens.

—Wife of a 79-year-old man with melanoma

Family members for whom death was a new experience reported that getting information about the particulars of the dying process helped make the experience easier to understand:

... they was very good as far as talking. I talked to...several nurses, the ones that took care of her, and then I talked to the head nurse and they [were] all... real informative and... I was very happy with the way they took care of her.

—Brother of an 82-year-old woman with chronic ischemic heart disease

I think we got pretty much adequate information from the nursing home staff, 'cause we would ask questions. We would ask a lot of questions, as far as what was going on and what's going to happen and what the prognosis was and everything...We would always get what I considered an honest, thorough response to, to whatever our questions were.

—Son of a 72-year-old man with dementia

Respondents wanted to be told what to expect as death occurred, and some reported that this knowledge eased their experience of the dying process. The information that staff members provided helped family members prepare emotionally for their loved ones’ death, defined the dying process, and provided considerable relief to the families’ suffering:

...the hospice people did tell me a lot about what to expect and what not to do and what to be concerned about doing. So, they were helpful so they said if she had a temperature, not to worry about that and different things of that type that she really wouldn't know ...

—Nephew of a woman (age unknown) with atherosclerotic heart disease and bladder cancer

Talking with staff members about what to expect also seemed to provide the family members with emotional support. Respondents indicated that they felt comforted by such interactions:
We even had one little nurse from Sweden [who] just slipped in real quiet one night and anointed her.... And she was SO sweet, and she would just talk to us and tell us now that when every little change she had in her breathing or anything, she would tell us, ‘Now, this is normal. This is the way it goes.’ Actually, she was a nurse's aide, I believe. She hadn't worked there very long.

—Son of a 102-year-old woman with cardiac arrhythmia

... they were a good sounding board and they gave us stuff to read and they talked with us and they were well aware of our situation. They really helped us through the stages and how, as her life was ending, what to expect. And they were very helpful.

—Son of a 78-year-old woman with multiple myeloma

...and then they told me how it would work. She said, ‘There's a little darkness to the feet, a little darkness to the knee,’ she said, ‘And then it's over.’ And I did notice that. That's how it happened.

—Wife of an 84-year-old man with Alzheimer’s disease

In addition to providing family members with information about what to expect, these conversations helped guide the families into less aggressive, more palliative treatment options as their loved ones’ condition declined:

What they told me is that I was to just keep him comfortable. And, so that did not cause a problem. Yeah, and they said that was simply, that was not prolonging life. That was simply making him comfortable. Same thing with the morphine they had to use right at the end.

—Daughter of an 85-year-old man with prostate cancer

Families also gave examples of individual staff members who extended themselves beyond the call of duty. Knowing how exacting the staff routines in the nursing home can be, family members appreciated the symbolic importance of such behaviors:

The nurse... left the Alzheimer's unit in the charge of her assistants and went and sat with him that whole time till he breathed his last breath. Then she cleaned him up so that we could go over there. And that whole last week, they were just so good to us... they kind of rolled out the red carpet when we showed up. They just praised us for the love and the care that we showed toward our Daddy ... They treated him like he was a person, a human, and they showed love and affection for him... he would go down to [the nurse’s station] and she would just pull him up a chair and let him sit there. And he was very content just to be with her.

—Daughter of an 81-year-old man with Alzheimer’s disease in the nursing home for four years

Family members were often touched by gestures of human compassion and professional concern that lessened their burden:
...they were always very compassionate and caring towards us. I think they had the experience to deal with families as well as the patients. ...that experience was pretty invaluable ... I know the family did feel that the nursing home also was concerned about us and how we felt.
—Son of a 72-year-old man with dementia in the nursing home for three years

Sometimes staff members found inventive ways to treat dying residents in special ways, and families cherished these efforts:

_and... the man in charge of the kitchen should get a gold crown, because he would come visit her and just ask her what she would eat. And he would fix it. If she wanted bacon and eggs 3 times a day, [the cook] would go in the kitchen himself and cook it if that's what she wanted so they were wonderful._
—Niece of a 91-year-old woman who refused treatment for a possible malignancy

Nursing home staff members are in an ideal position to provide individualized, resident-centered care because they have the opportunity to get to know the resident well, develop a trusting relationship over time, and provide care consistent with the resident’s needs and preferences. Staff members who have developed good relationships with family members are also able to help them prepare for and anticipate contingencies that may arise in the end stages of life.

**The Experience of Family Members**

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<th>Theme 2. Low expectations of nursing homes and experiences with poor-quality care turn many family members into vigilant advocates for their dying relatives.</th>
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The negative reputation of nursing homes has been documented in numerous opinion polls and surveys (John Hancock Mutual Life Insurance Company and National Council on the Aging, 1996; *The NewsHour With Jim Lehrer*/Kaiser Family Foundation/Harvard School of Public Health, 2001). Respondents in this study reported low expectations for quality care, and many were frankly concerned for the well-being of their loved ones. Too often, experiences in the nursing home reinforced these negative expectations.

2.a. Families have low expectations for nursing home care and do not consistently trust the staff to provide dying residents with competent and compassionate care.

_It's just reality, that you don’t go into a nursing home expecting to be staying at the Hilton... They could have communicated with him a lot better and just checked on him a lot more. Even in the bad shape he was in, I think he learned to live with it. When he entered the nursing home, he just lowered his expectations... Everything he had heard about a nursing home, about the bad horror stories became true, you know...I think he just lowered his expectations._
—Son of a 75-year-old man with congestive heart failure who was in and out of nursing homes and hospitals in the last years of his life
Several respondents described their resignation about nursing homes in general. They were careful not to expect too much from them:

I think that nursing homes today are a way of life. I'm not a spring chicken myself. I'm 74 years old but I can remember when there were no nursing homes. The onset of Medicare and Medicaid and everything prompted this. Years ago, someone was ill, they were cared for by their family at home. Okay? And now, it's big business. Because I wrote out a lot of checks and I know it's big business... You could stay at the finest penthouse hotel for what they charge you and then when you relate the charges to what you get, it ain't that much.... Well, I mean they, they, they don't fall all over them. I mean they feed them, they give them medication, they get them up in the morning. They keep them clean, they put them to bed, etcetera, etcetera, you know. That's why I say it's like a big warehouse operation.
—Brother of a 78-year-old woman with cerebrovascular disease

2.b. Nursing homes are perceived as understaffed and lacking in resources.

One factor in these low expectations concerns the perceived inadequacy of nursing home staff and resources. Although respondents were sympathetic to the staff and the problems nursing homes face, they were anxious about the safety and well being of their loved ones. Respondents worried that staffing levels in nursing homes were too low to provide their loved ones with adequate care and supervision. Nursing home residents who are dying require ongoing supervision and thoughtful caregiving as they approach death. Although family members sometimes expressed sympathy for staff members working under the stressful conditions of the nursing home, they were also critical and related their concern.

I don't know what the rule is...but I think it was 17 or 20 patients to one aide, and ... my mother ... was just unable to care for herself. ...And I just have always felt that this law needed to be changed [so] the ratio of patient to aide should be made smaller ... they took care of her the best they could. They were very kind to me, and they assisted me...
—Daughter of a 97-year-old woman with cancer

Respondents often referred to difficulties caused by insufficient staffing, particularly necessary for the tasks of caring for needy and frail individuals. Toileting concerns figured prominently in their accounts of sub-optimal care that resulted from staffing shortages.

I'm not very happy about, you know, nursing homes. But like I say... you're not paid attention to, there's not enough people to keep people, to take them to the toilet, for a simple thing, you know. It's really, REALLY is degrading. There were a lot of people sitting in chairs, and they would call out, they have to go to the bathroom, and I'd be sitting there with my dad. And then they would ask to go to the bathroom over and over. And I would finally get up and I'd say to one of the girls, ‘The lady has to go to the bathroom.’ ‘Yeah, yeah, we’ll get to her.’ Well, finally you see this puddle on the floor underneath the wheelchair, and nothing gets done about it. And then, the food trays come. They take the lady in the wheelchair and wheel her, without changing her, there[?] in front of her food. And what does she do? She sits there and eats, and then somebody comes
along with a mop and mops up the floor, you know, where the puddle is but she's still wet, eating her dinner. I mean, it's disgusting!
—Daughter of a 77-year-old man with dementia

Sometimes when she did mess on herself, they didn't, they wouldn't really clean her, you know. And, it depended what shift it was, and then there's some, there's some staff members that really did their job, like, I would imagine they really LIKED their job, that they really, you know, took their job to another level. And, then there's some like, they didn't really want to fool with it, okay?
—Son of a 58-year-old woman with renal failure

Respondents in these narratives also report insufficient supplies, reflecting the lack of resources in some nursing homes. These respondents expended considerable effort to supplement the nursing home’s resources.

... the nursing home did not provide disposable diapers.... If you wanted your family to have the disposable diapers, you had to buy them yourself. So I did buy them myself and at times I would come in, and I would think, gosh, they're going through the diapers fast. The lady that was in the room with me told me that they used the diapers for other patients. So I started putting her name on all of them [laughs] for the diapers just to have it, you know, to conserve them...
—Niece of an 83-year-old woman with dementia

Respondents were also troubled by inattention to maintenance in the facility. They noted occasional problems with the equipment:

My mom had to be on oxygen all the time, and they had oxygen piped into her room but it was not working. So they had her on the portable, on a portable oxygen tank. And it had run out, and they hadn't even come in to CHANGE it. And, I changed it when I got there. And, so I had a conversation with them about that. And they got the maintenance man down there and he said that Mom had already reported it to them, and they knew. But they had not gotten anyone there from maintenance there to repair it until I went in and complained about it, you know. Then they got a maintenance man there and he got it repaired, so she could go back on the piped-in oxygen instead of the portable tank.
—Daughter of an 89-year-old woman with chronic obstructive heart disease

Problems with cleanliness disturbed some respondents and added to their mistrust of the facility. Family members reported that basic personal care of their loved ones was inadequate, and the unsavory environmental conditions of the nursing home increased their discomfort. Concerns about staffing levels, supplies, and associated problems with cleanliness and assistance with toileting combined to give many respondents an overall negative impression:

He was not kept, his bed was not clean. I had even offered to change the sheets myself if they would give me a set of sheets. Things were not done timely. HE was not kept as clean. They didn't help him bathe. 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... And they wouldn't
answer when you called...promptly. I think, it seemed to me they were TERRIBLY understaffed. The people that I did see there seemed to be very busy but things weren’t getting done, so I don’t know WHY that is, but he was very unhappy there. And I was unhappy that he was dirty, his bed was dirty, you know, they weren’t helping him bathe and that sort of thing.
—Niece of a 95-year-old man with cancer of the colon

...it was just nobody wanted to go visit her because it stunk... it did smell, and stuff. But they all came to visit. It was just not a comfortable place to be.
—Daughter of an 84-year-old woman with neurological disease

2.c. Family members see themselves as advocates for their loved ones in preventing harm and ensuring basic care.

Because they distrust the quality of care offered in nursing homes, family members report the need for sustained vigilance, intensified involvement, and direct advocacy for the dying person.

And I don't think that my husband would have gotten the care that he GOT if it wouldn't have been for my being there and checking it out all the time.
—Wife of a 76-year-old man in a nursing home following radiation for kidney cancer

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.
—Daughter of an 89-year-old woman with dementia

Family members are often attuned to changes in their loved ones, and when they notice problems that staff members miss or do not respond to, their trust in the facility and the health care providers is undermined:

[The aide] said, ‘You know, she kept holding her mouth.’ Well, when I found out, I asked the doctor, and sure enough, she was running a temperature and she had an abscessed tooth. I would think you would look for the physical things first, you know.
—Sister of a 69-year-old woman with dementia and progressive aphasia

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.
—Woman who alerted facility staff to pneumonia in her 99-year-old uncle

Some family members insist that health care professionals consider the family’s knowledge of their relatives:

We went through the emergency room, and each time she looked like she had been hit by a Mack truck, because they took blood and they didn't listen to us that if you touch her like
that, she's going to be black and blue, her skin’s going to tear.... they just don't believe that family know as much about a person as we knew about her.
—Niece of a 91-year-old woman who refused treatment for a possible malignancy

The nursing home experience convinces some that maintaining an adversarial and constantly vigilant attitude is necessary to prevent neglect and mistreatment of their relatives:

And, I honestly believe in a facility, if there isn't someone watching out for them, they'll just sit there and be drugged and be a zombie and that's it.
—Daughter of an 84-year-old woman with dementia

And, she wasn't the only one that didn't get fed either. [If w]e didn't go 3 times a day, she didn't get fed.
—Daughter of a 94-year-old woman with dementia whose family reported her nursing home to state authorities

Family members recognize that their presence makes a difference to the nursing home staff, and they know that residents without family members or other advocates may be significantly disadvantaged compared with those who have family members involved in their care:

...there were certain shift members that we knew that they really took their job seriously and there was some that were, were... I don't know. I don't know if it had to do with us being there, you know, it makes a difference because I do think that, from my understanding, the more that family goes to a nursing home, you know, I guess they're not going to be neglected because they see that, that their family members, they care. ...There are some elderly people that do not get any visitors, stuck with it. You know, they probably say, ‘Nobody cares so why should we care about them, too?’ I don't know; that's just my opinion.
—Son of a 58-year-old woman with renal failure

2.d. Family members expend great effort and shoulder significant burdens to provide their relatives with care and advocacy.

Caregiving involves many activities, including performing tasks in the nursing home, managing finances, and even taking home laundry. Many respondents admitted that these tasks caused them to neglect their personal and professional obligations. One frequently mentioned burden is traveling significant distances to visit the resident, sometimes over extended periods of time:

I was 240 miles from her and ... the others [family members] were a little bit closer but they work....I was more flexible than most of them, but ... the ones who worked took a turn on the weekends and those of us who did not have a regular job, we did the week stuff. So she was well cared for but NOT because the facility gave it to her.
—Niece of a 76-year-old woman with cancer, with hospice in the nursing home

She was about 2½ hours away, yeah. I got there at least every other day. And my sister who lived a half- hour away was there probably almost every day. My brother who lived
about an hour away was there probably almost every day. I mean, two or three of us were there every day.
—Daughter of an 84-year-old woman who went to the nursing home following complications from intestinal surgery

Sometimes family members performed housekeeping duties:

They were trying to see that my wishes were taken care of for her. But I would have to go out there because ...they couldn't give Mom one-on-one care, which basically she needed a lot of... I bathed her and I changed her bed... I took her linen home ... The people that were working, they did it, but, they couldn't be there and a lot of times, she NEEDED them there.
—Daughter of a 97-year-old woman with cancer whose daughter thinks the state should require stiffer staffing requirements for nursing homes

Respondents related the considerable time and effort devoted to financial and administrative tasks:

I had to apply for Medicaid, which is something I thought once you did, it was over with. Well, I didn't know you had to apply for it every year. What a pain! They treat you like they're giving you gold... I mean, my sister tried to help, but she was working and it was hard for her ... there was just so much and I had do it all... it was just VERY time consuming and it was very, very difficult.
—Daughter of an 84-year-old woman with dementia

So I was trying to get his financial stuff in order, trying to get her to a lawyer, trying to get them to make out a living will, and all this other stuff, you know. And that was almost an impossibility, and then trying to get the nursing home stuff filled out and trying to get her to tell me what your financial circumstances are. I had never done this. You know, you don't want to get into your parents’ financial stuff. That was always their private thing, you know. And then at this stage when they’re both a mental wreck...Because everybody wants to know how much you could PAY.
—Daughter of a 77-year-old man with dementia

I kind of had to learn the hard way about the Medicare and Medicaid and what was paid for and how many days was allowed, and the hospital, and just a whole lot of things I didn't know until I got a bill for something that wasn't paid for...
—Niece of an 83-year-old woman with Alzheimer’s disease

A few family members reported that they placed their caregiving duties ahead of their job and family responsibilities:
I practically spent the last few weeks entirely dedicated to her care ... I'm self-employed, so I abandoned my job and pretty much my family and everything although other family members rallied around to help. And so it was tough.
—Niece of an 86-year-old woman with cancer who died after complications from palliative surgery

Occasionally, the financial burdens are crushing:

All three years, I paid my own way. Medicare only costs the first how many days or something. After that, I have [to] pay 100 percent myself. I spent almost my savings. Yeah, I don't have any other income.
—Husband of a woman (age unknown) with stomach cancer

2.e. Family members remain highly involved in end-of-life care, decision-making, and advocating, both for the resident’s preferences and for what they viewed as the resident’s best interest.

In addition to providing direct caregiving and surveillance, family members are also involved in decisions about care. Some families placed great importance on teaching staff members about their relative’s wishes and needs.

...it was a training process [for staff]...You need to understand we know her body very well. We’ve spent a long time with her, and that she’s going to eat what she’s going to eat ... we went through several activity directors while we were there...it was a learning curve for everybody...
—Niece of a 91-year-old woman who refused treatment for a possible malignancy

At times they reported their conversations with the dying person about end-of-life preferences:

She did initially [want a feeding tube], yes. ... I just kept talking to her about it...I was afraid if we put that feeding tube in she would live in a terrible way for a long time. And I didn’t want that to happen to her. I mean, I worked in nursing homes. I’ve seen people live on feeding tubes for years... She didn’t really didn’t know what it meant so I went into graphic detail of where the tube will go, how she will be fed, how you have to take care of everything, and you know. And then she said, ‘No, I don’t want that. Don’t do that.’
—Granddaughter of an 87-year-old woman with dementia and depression

2.f. Despite considerable burden, many report feeling gratified for the care and supervision they provided.

This sense of gratification may be attributed to having “done the right thing,” having met obligations to friends or family, or fulfilling a sense of reciprocity.

Respondent: ... we chose to do his washing and we had him a chest of drawers up there with his clean clothes. And we would clean his blue jeans. ...And I paid special attention to his teeth and his hearing aid and all that kind of stuff, because momma had threw hers
away in the nursing home. That's what we chose to do. [He’d] say, 'Bubba, go get me this, go get that or do this or do that,' and I'd go do it.

**Interviewer:** Did you feel burdened by that?

**Respondent:** Nah, heck no.

—Son of an 86-year-old man with arterial sclerotic heart disease

This section described respondents’ feelings about the quality of nursing home care and their need to be advocates for their loved ones. This perceived need for advocacy also relates to respondents’ concerns about the health care professionals who care for their loved ones.

### Professionals Who Care for Dying People

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<th>Theme 3. Physicians are viewed as “missing in action” in nursing homes.</th>
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Respondents noted that they communicated infrequently with physicians, rarely saw physicians in the nursing home, and were often dissatisfied with the level of attention and care they provided. Because nursing homes are considered to be health care facilities, respondents expected physicians to be accessible and available to address their loved ones’ health concerns.

Some family members never met their relative’s doctor, and they reported wanting more information and communication about the resident’s condition:

...*and the doctor was supposed to have been in every day. We never saw him.*

—Daughter of an 84-year-old woman in the nursing home with complications from intestinal surgery

*I never saw the doctor. I don't even know his name! [T]hey had a list of names. I picked one out of the hat. I never heard of him, never knew him. And, apparently, he used to visit her once in awhile cause she spoke about it. When she passed away, I didn't see a doctor.*

—97-year-old husband of a woman who died of a heart attack

Problems with contacting the doctor were a source of frustration for some respondents:

...*you have to realize that I'm a retired physician, and I was, in a way, participating in her medical care.... I had to go and contact the physician who was difficult to contact, even though he was a friend of mine. 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.*

—Male relative of a 93-year-old woman with chronic obstructive pulmonary disease

Some respondents reported feeling dissatisfied with the quality of the doctor-patient interaction:
The doctor would only come in randomly... All he would do is sit on the bed and ask how are you feeling, listen to their heart, listen to their lungs, and charge 75 dollars, you know.
—Daughter of a 91-year-old woman who stopped eating after she fell

Increasingly, nurse practitioners and physician assistants are used as “physician extenders” in nursing homes. This respondent was not happy about the quality of the intermediaries taking the place of the physician:

I mostly spoke to his nurse practitioner. So I really don't feel like it was a patient-doctor conversation in that it felt very uncaring. I felt like I was really interrupting her in her busy day because the doc was not available.
—Daughter of a 71-year-old woman with lung cancer who had hospice services

### Theme 4. Family members report a need for more and better-trained staff. Nursing home staff members are often perceived as overworked and lacking the training and time needed for compassionate care.

Although respondents are sympathetic to the problems nursing home staff members face, they also worry about the safety and well being of loved ones. Because many residents have stays lasting many years, staff turnover can be upsetting and disorienting. Because some nursing home tasks, like feeding, are so labor-intensive, additional staffing is necessary for patients to receive adequate nourishment.

... 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. ... they were very inadequately staffed for the kind of patients they had.
—Woman who thought her 83-year-old aunt, who suffered from heart disease and dementia, died from aspirating food when she was fed too fast

Family members understand that difficult working conditions contribute to high turnover rates among staff members, but they are dismayed at the negative effect turnover has on their loved ones:

I think there were three [different] head nurses while I was there ... And I can understand why. I mean, it's very taxing, and it's very an emotional job but... sometimes that makes it hard because then they don't know you and you have to clue them in.
—Daughter of an 84-year-old woman with dementia

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.... Well, she'd get used, she'd get attached to the nurses that were good to her. And then when they left...that bothered her quite a bit. ...it's hard to find help for a nursing home, why, a lot of people don't like to work there.
—Son of a 102-year-old woman who lived in a nursing home for 13 years
Institutions That Shape the End-of-Life Experience

Nursing homes are evolving institutions that are taking on new roles in an atmosphere of substantial regulation, resource constraints, and a resident population that is increasingly diverse, frail, and disabled. Respondents provided important observations about the end of life in such institutions.

Theme 5. Regulations that reinforce task-focused rather than person-centered care add to the burden of residents and families.

In an effort to protect residents and improve nursing homes, regulations and guidelines tend to focus on specific tasks, safety, and documentation. This “task-focused” emphasis addresses restorative and rehabilitative services, which may not be the most salient focus for people nearing the end of life. In contrast, “person-centered” care addresses the individual resident, determining individual preferences and goals and providing care consonant with those goals at each stage of a resident’s illness. Person-centered care respects individual differences, preserves the resident’s dignity, and shapes care decisions that reduce the distress and burdens experienced by residents and their families.

5.a. Task-focused (regulation-based) rather than person-centered care is too often the rule.

Some respondents were concerned that filling out charts and following rules detract staff from providing residents with compassionate care:

“These people, they send out [the message that] they have a job to do and they don’t care about the patient. It seems like they want to get this job done... ‘Do that lady and do it now,’ that kind of stuff. And finally I told them to stay away. ...They knew they weren't helping her. 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. Here I am and torn. Is this doing her good or isn't doing her good?"
—Husband of an 82-year-old woman with brain cancer

Sometimes respondents believed that staff members misinterpret the rules and unnecessarily restrict the autonomy of nursing home residents:

“You know, my mother, there's nothing wrong with her mind. She can administer her eye drops.... She is in MISERY without them...So, they called her doctor and...he TOLD them to let her go ahead and have her eye drops.... But then this other nurse said, ‘Oh no, she can't because that's not the same doctor.’"
—Daughter of an 89-year-old woman with chronic obstructive pulmonary disease and emphysema
5.b. Respondents attribute some problems to state and federal mandates, nursing home rules, and management constraints that discourage individualized and palliative care for the dying.

Facilities sometimes do not adjust internal rules to better serve the changing conditions of the dying person. In the following example, the nursing home was concerned with a potential fall. In compliance with restraint reduction guidelines, the staff moved the dying resident’s mattress to the floor despite the family’s considerable distress:

Well, I complained about her mattress on the floor. And then they said they had to do that. And I really felt bad about it, but on the other hand, I could see their point too... But 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.
—Daughter of an 89-year-old woman with dementia who was in the nursing home for three years

...because his mattress was sort of down on the floor, I said, “And could you also PLEASE get him a normal bed? Because I don’t want to be looking down at my dad when he’s dying!
—Daughter of a 77-year-old man with Alzheimer’s disease and Parkinson’s disease

Sometimes nursing home staff members adhere to nonexistent rules:

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.
—Woman with power of attorney for her aunt, an 83-year-old with dementia

So they told me that he would last less than 21 days or whatever the maximum for hospice is. ...[After 21 days passed, the hospital staff said] he’d either have to be moved on or die, one or the other. I mean, they were very blunt about this thing...they couldn't keep him [in the hospital] any longer. ...I think this is absolutely the pits, but it seemed to be what Medicare insists upon. ... We couldn't have hospice any more, and we had to move out.
—Wife of a 79-year-old man with melanoma who died two days after being transferred to a nursing home

5.c. Some respondents reported unwanted transfers that were based not on the preferences of the dying person or their family members but rather on facility limitations.

Respondents noted the limitations of assisted care facilities:
The first one [assisted living], at first it was good and then his condition got worse ... They weren’t up to the challenge....It was always a lot of smiles and “We're going to do better...then towards the end they finally said, ‘We can't, we're just not equipped to handle this.’ We did ultimately move him to another facility.
—Son of an 80-year-old man with dementia

The following family had to give up a familiar facility for one that could provide needed services but was less compatible:

There was a dispute. He had a decubitus on his backside. And it wasn't healing properly. So they moved him to the medical nursing home, and then the doctor there did not want to send him back to the other one, even though the guardian felt that that was better for him to go back with the other folks. The doctor said no, and that's why they kept him at the medical place.
—Granddaughter of a 94-year-old man with diabetes and dementia

These transfers were viewed by family members as burdensome to the dying person. The following person experienced a considerable delay in receiving his pain medication because his discharge from the hospital to the nursing home was not properly coordinated:

Well, when we got [to the nursing home], it was almost time for his medication again. And, well, no, they didn't have that medication. They had something, a substitute or something.... But I don't know how it, how it worked on him.
—Wife of a 79-year-old man with melanoma who was moved from a hospital to a nursing home for the last two days of his life

Hospital trips from the nursing home are often difficult for the dying person and family members alike:

In the hospital it was just basically sitting there waiting until someone came to look at him. And they would either suture him up or do an X-ray or CAT scan and send him back.
—Daughter of a 77-year-old man with Alzheimer’s disease who experienced long delays in the hospital emergency room

...even when I told them no more hospital visits, they still wanted to take her to the hospital. They wanted to take her, I believe they wanted to take her the last week of her life, and I said no. They'd call me and, ‘Well, she's not doing so good... take her to the hospital, do you want us?’ And I said, ‘No. You're not going to take her anywhere.’
—Daughter of an 89-year-old woman with dementia who said that she counted 11 unnecessary hospital visits before making her decision

Occasionally, people who are dying endure multiple transfers to various facilities:
He was in and out of nursing homes, maybe three or four times the last year, year and a half. And each one was traumatic for various reasons.... as far as incompetent help...the hospitals in general were pretty good. He was hospitalized about four or five times, I'm not sure, in the past couple of years. I think [the hospital] generally was okay, but the nursing home experiences were not the best.
—Son of a 75-year-old man with congestive heart failure

5.d. Respondents recognize the difficult situation of many nursing home staff members, and they appreciate their expressions of concern, demonstrations of caring, and sensitivity to the unique needs and wishes of the resident.

Respondents expressed appreciation for staff members and facilities that stretched their resources to provide care despite facility limitations and that adjusted the rules to focus on residents and their needs. Sometimes respondents realize how difficult their family relative is to manage:

He was well taken care of, and I would drop in without letting him know. And he always looked clean and shaven, and they took real good care of him. But I know he was quite a problem. They were just real patient. So, they would put up with him as long as they could. Because, as I said, he was a boxer in the service and he could really swing!
—Wife of a 75-year-old man with dementia who lived in several different nursing homes

Respondents expressed particular appreciation for staff members who go beyond their assigned duties to acknowledge the resident as a person and show respect for his or her life.

...one of them had the habit of singing to Mom ... when she got off her shift. They were just good to her. And they were good to us—I think two of them came to the funeral. Even the secretary.... That showed a lot of respect to Mom, I thought. They took [it] as hard as if it was their mother. They really did.
—Son of a 102-year-old woman with heart disease who lived in a nursing home for 13 years

Some residents and family members even reported declining hospice care services in the nursing home, because they considered the nursing home care to be so good. However, as the next section illustrates, hospice care was highly valued by many respondents.

Hospice Care in Nursing Homes

<table>
<thead>
<tr>
<th>Theme 6. Hospice services often enhance the end-of-life care of dying residents but respondents report that referral is frequently made late in the illness or not at all, preventing residents from receiving the full benefit from such services. Furthermore, respondents sometimes report conflicts between hospice and facility staff.</th>
</tr>
</thead>
</table>

33
The Medicare Hospice Benefit has increased the use of hospice services by nursing home residents. Hospice care in nursing homes offers nursing homes the opportunity to provide intensive palliative services to dying residents without increasing the facilities’ staffing levels. Respondents talked about their own and their loved ones’ experiences with hospice services.

6.a. Respondents reported that hospice care often helps nursing homes provide better quality care to dying people.

Several narratives noted that symptom management and other end-of-life treatment issues improved when hospice services became involved. Many reported that the simple presence of hospice care enhanced the caregiving:

_They had counselors in talking with her every day. Her doctor was there a lot! I mean, he was right there. Hospice was there. The social worker was there. The counselors were there. There was a tremendous amount of support available for both her and I._

—Niece of an 86-year-old woman with pancreatic cancer

Respondents reported that hospice workers provided good symptom relief and lent support to both the dying person and loved ones.

_...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, which was their job, but that was also their action, if you know what I mean. They spoke to my mom in kind, positive ways. They allowed her to be who she was, which was a quiet reserved person who did not share a lot of feelings. Towards the end, when she was really, really ill—it was probably the last day of her life—they wet her mouth, and they tried to give her food until she was not able to eat anymore, and they tried to give her liquids until she was not able to take liquid anymore._

—Daughter of a 71-year-old woman with lung cancer

_They were there every however often 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. I think it was every four hours or three hours or whatever, they would be there to clean her up and turn her over and make sure she was clean, and that was good._

—Daughter of an 84-year-old woman with an unspecified degenerative disease of the nervous system

Some respondents felt satisfied with the quality of the death they had witnessed:

_...we felt like her passing was a gentle passing, and that’s what I wish for anybody, any of our loved ones was that it was a gentle passing so that, we did feel very supportive, very supported and... The people we had were great. I just think that people were wired together to be hospice people when they were born..._

—Niece of a 91-year-old woman who refused treatment for a possible malignancy
... They brought in hospice. ... they were great. They really were. And we were all sitting around talking to her one afternoon and all of a sudden, one of the other ladies said, ‘I don't think Aunt's breathing.’ ... I mean, it was just so simple, so easy, she just went to sleep. And like I said, the nursing home was wonderful.

—Friend who refers to herself as the “niece” of an 80-year-old woman who was diagnosed with terminal cancer six weeks before she died

Despite these positive reports, respondents also expressed some concerns:

6.b. Misunderstandings and conflicts about the role, scope, and regulations governing hospice care were reported as being common among nursing home staff.

Respondents were disappointed with the care that was provided and reported disagreements between hospice and nursing home staff about care provision. It is not always clear what palliative measures hospice care will allow.

And then the oncologist recommended hospice care, ... they had recommended radiation for her just to open up the airway, not for curative, and so as long as she took radiation, the hospice would not be involved, and so the day that she had the last radiation, they did become involved. But it was not wonderful.

—Niece of a 76-year-old woman with lung cancer

Some respondents were concerned when hospice and other facility staff members did not collaborate well. They welcomed the more person-centered mode of care and treatment for their loved one:

And in conversation, it just seemed to be like... different philosophies, because the nurse ... is really practicing. I don't know another way to express it, except ‘cover your ass,’ and the hospice people are more like, they have a different philosophy. Their philosophy is...is leaving this world in the most dignified, respectful, and painless way.

—Daughter of a 71-year-old woman with lung cancer

6.c. Some family members misunderstood what hospice care in the nursing home would involve.

Some respondents reported being disappointed with the volume of services provided by hospice care in the nursing home. Perhaps because families have heard positive reports about hospice care but are not sufficiently informed about the Medicare hospice benefit, they often think that hospice care in nursing homes is more extensive than is typically possible:

Actually, 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. .... Once I got involved with hospice, just like most anything else, 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...

—Niece of a 76-year-old woman with lung cancer
Some respondents expected hospice to be present more often:

_They moved her [in the nursing home] ‘cause they wanted to get hospice involved, and my impression of hospice was that someone would be there. Well, it was only like a couple hours, not even a couple hours a day. It was only a couple hours a week or so...._  
—Daughter of an 84-year-old woman with dementia

Some respondents were disappointed with the amount of face-to-face contact with hospice workers. The timing of hospice referral was another source of disappointment.

**6.d. Referrals to hospice for nursing home residents frequently are not made or are made too late to be useful.**

Several factors contribute to referrals that occur late in the dying process:

... _they were trying to get hospice, and we did the paperwork, and the nurse from hospice came Saturday morning just right after he died._  
—Daughter of an 81-year-old man with dementia

_We had met with hospice. We were going to begin hospice that week she died. My brother and me had met with the nursing home, and we were going to have them start coming in._  
—Daughter of a 91-year-old woman who died before hospice care was set up

Difficulties in acknowledging that a person is dying also contribute to late hospice referral:

_They didn't sign up with hospice until like the last week of their loved one's life. You know, hospice is a wonderful thing, but it's just hard to admit. They're saying this is the end of life._  
—A chaplain and niece of a woman who received hospice services, describing the reluctance her congregants feel in deciding to opt for hospice services for their loved ones

**6.e. Respondents report that hospice care was not an option at the facilities in which their loved ones lived.**

_They were going to provide hospice if she was going back home or if she was going to stay with anybody._  
—Niece of a 93-year-old woman who had a stroke who thought her nursing home care was excellent

_He wanted her to stay there. She couldn’t have gotten any better care in hospice, you know, ’cause he didn’t want her moved from there, yeah, and he wanted her right there._  
—Cousin of an 84-year-old woman with dementia
Many respondents perceive hospice services in nursing homes as a source of considerable satisfaction, but frequent difficulties with getting timely referrals as well as flawed nursing home/hospice collaborations detract from the positive potential of hospice care.

Summary of Narratives

These valuable insights into the experiences of dying in nursing homes provide important information about end-of-life care. Family members recognize the limitations of nursing homes, and many respond by becoming vigilant advocates. They have concerns about the amount and quality of nursing care and resident monitoring, as well as about the training of staff. But the respondents also express deep appreciation for staff members who have gone out of their way to provide compassionate care to their dying relatives.

Many respondents report inadequate management of pain and other symptoms at the end of life. They voice substantial dissatisfaction with physician services, most notably the paucity of physicians in nursing homes, the infrequency of physician visits to the institution, and the lack of communication between physicians and family members. This communication failure is particularly acute as it relates to stage of illness, prognosis, and advance care planning for patients in the terminal period. Many families are confused about the dying experience and treatment options and do not know what to expect. This lack of communication may result in unwanted transfers to hospitals and other undesired interventions as well as referrals to hospice care that are late or do not occur. These areas of concern can be translated into potential policy reform and training initiatives.

VI. TRAINING AND POLICY CONSIDERATIONS AND RECOMMENDATIONS

The previous sections described the experiences of dying nursing home residents and their family members. Although these vivid accounts note instances of appropriate—at times excellent—care, general improvements to end-of-life care in the nursing home setting are urgently needed. This report’s examples of good care as well as the problems that compromise humane caregiving for people who die in nursing homes point the way to necessary remedies.

**Overarching Recommendation:** A sustained effort on many fronts, including increased funding for training and staffing, is needed to improve end-of-life care in nursing homes.

The following recommendations address many of the initiatives required to sustain this effort.

**Educating Health Professionals**

Several recommendations address enhancing education of physicians and other health professionals to improve end-of-life care. These include recommendations on content of education and training, incentives to provide such education, and advocacy for funding for education regarding end-of-life care.

1. Improve career education and continuing training of health professionals in the following areas:
the care of dying patients, including managing their physical symptoms (e.g., pain and dyspnea) and emotional distress;
- knowledge of illness trajectories and physical function to make more accurate prognoses; and
- communication with dying patients and their families about their individual preferences and expectations, and improved advance care planning consistent with these preferences.

2. Advocate for federal funding to support career education and continuing training of health professionals in end-of-life care.

Training Physicians in End-of-Life Care

3. Use incentives under general medical education (GME) funding to improve physician training in end-of-life care. Such training might include:
   - requiring that internal medicine, family practice, pediatric, and obstetrics and gynecology residents follow a panel of patients, including terminally ill people, throughout their residency;
   - requiring that physician residents follow individual patients as they leave the hospital to enter a nursing home; and
   - providing GME funding to support training in palliative care and geriatric fellowships.

Training Nursing Home Staff and Administrators

4. Provide education and mid-career training for nursing home staff, such as the End-of-Life Nursing Education Consortium (ELNEC) Project and the National Board for Certification of Hospice and Palliative Nurses, and develop career tracks in palliative care for nursing assistants to improve the following:
   - management of symptoms associated with dying;
   - communication with residents and family members clarifying individual preferences and describing what to expect in the dying process;
   - identification of decision points in the dying process; and
   - focus on resident-centered care.

5. Train and educate nursing home administrators to:
   - improve their understanding of quality assurance in end-of-life care;
   - clarify regulations and guidelines for covering and implementing the Medicare hospice benefit in nursing homes;
   - enhance strategies for responding appropriately to family advocates;
   - encourage best practices in staff training, oversight, and retention, including career-track incentives for certified nursing assistants in end-of-life care; and
   - ensure that Nursing Home Administrator certification includes adequate content on end-of-life-care.

Informing the Public About End-of-Life Care
The public would benefit from information about end-of-life care options as well as information about what they might expect over the course of a terminal illness.

6. Develop a public information campaign with educational materials targeted to nursing home residents experiencing a terminal illness and their families. The information provided would include:
   - how to be an effective advocate for dying nursing home residents;
   - what end-of-life care in nursing homes entails;
   - what to expect when people in nursing homes die;
   - why one should consider the availability of hospice care when selecting a nursing home;
   - how Medicare hospices provide care and what the Medicare/Medicaid hospice benefit pays for;
   - strategies for communicating effectively with doctors and other health care professionals; and
   - educational resources for learning more about the end of life in nursing homes.

**Developing New Knowledge and Improved Practices**

Although much is known about how to improve care, much more must be learned. Active support of research on how to improve care, enhance the use of current resources, and use future resources appropriately is key to improving the experiences of dying people.

15. Develop and support centers of excellence for end-of-life care.
   - Use private/public partnerships to develop research and educational centers focused on improving symptom management and developing innovative models for caring for dying people.
   - Advocate for federal funding to support such centers

**Policy Issues**

Current federal and state policies create disincentives to providing the most appropriate care for dying people. Moreover, more attention needs to be paid to the quality of care and its monitoring. Specific recommendations follow.

7. Create incentives (and address disincentives) for physicians to regularly visit and care for dying patients in nursing homes.

8. Increase reimbursements to nursing homes to enhance staffing and resources, improve quality of care, and avoid unnecessary hospitalizations.

9. Examine the quality of end-of-life care to:
   - improve strategies and methods for monitoring quality;
   - understand the unintended consequences of quality assurance strategies and measures;
   - encourage quality improvement organizations (QIO) to conduct quality improvement projects related to end-of-life care;
   - train surveyors to address the quality of symptom control and end-of-life care; and
resolve potential conflicts between the goals of rehabilitation and maintaining function and the goals of palliative care at the end of life.

10. Study the viability of using the Medicare skilled care benefit to address the end-of-life palliative care needs of nursing home residents.

11. Provide incentives (and remove fiscal disincentives) for nursing homes to contract with Medicare-certified hospices, and hold nursing homes accountable for achieving high-quality outcomes specific to end-of-life care regardless of whether they contract with or fully use hospice or palliative care services.

12. Identify and disseminate best practices, policies, and procedures to enhance collaboration between nursing homes and hospice providers.

13. Include the right to hospice care in the Patients’ Bill of Rights.


VII. CONCLUSION

As increasing numbers of Americans spend their final hours in nursing homes, much more must be done to ensure appropriate and compassionate care, improve the caregiving workforce, and reform policies and regulations that guide care in institutional settings. A sustained effort on many fronts, including increased funding for training and adequate staffing, is needed to improve end-of-life care in nursing homes.
REFERENCES


Brown University, Center for Gerontology and Health Care Research, 2004, Facts on Dying, [www.cher.brown.edu/dying/factsondying.htm](http://www.cher.brown.edu/dying/factsondying.htm)


Appendix A
Quantitative Survey Methodology

Sampling Design
A mortality followback survey methodology was used to identify decedents. Death certificates from 47 states and the District of Columbia were sampled to arrive at national estimates of the dying experience. (South Dakota, Wisconsin, and New Mexico were excluded from the sample because these states do not release death certificate information.) Two strata were created based on the 1998 mortality data. Eight states that accounted for nearly one-half of the nursing home deaths in the United States were purposely selected, and 14 of the 39 remaining states and the District of Columbia were randomly selected. Of the selected states, only one (Georgia) declined to participate. The research team sought approval of the research protocol from institutional review boards (IRBs) at Brown University, each participating state, and New York City, which maintains its own Vital Records Office. Five IRBs placed additional restrictions (either requiring that the research team obtain written informed consent or requiring that the state deliver the interview request). New York City’s IRB required that potential study participants mail their written informed consent to the IRB before having any contact with the research team. Because of concerns about whether participants could comply with these requirements in a timely fashion, New York City was dropped from the sampling scheme.

To understand better the effect of high-intensity service areas, the research team oversampled cases in hospital service areas with the highest and lowest deciles of intensive care unit utilization in the last six months of life. This ranking was based on the 1996 Dartmouth Atlas of Health Care. Information from death certificates about the cause of death was used to exclude traumatic deaths (e.g., homicide and motor vehicle accident victims) to focus on decedents likely to have received end-of-life care over some period of time. In the analysis, data were weighted to accommodate this complex sampling design and provide a national estimate of the dying experience in the United States. A total of 1,578 interviews were completed, representing 1.97 million deaths when extrapolated back to the population.

Data Collection
The information collected from the death certificates included the date of death, cause of death, name of the deceased, name of the informant, and address of the deceased. Using this information, the research team developed a sampling frame of individual respondents. Trained interviewers collected data for the quantitative survey using a computer-assisted telephone interview system and a highly structured questionnaire.

For the selected states, the person listed on the death certificate as the informant, usually a close family member, was asked whether he or she was the person most familiar with the decedent’s circumstances in the last month of life. If the informants answered no, they were asked whether they knew the person who was most familiar with the decedent at the end of life. In that event, the person most familiar with the decedent was interviewed. The cooperation rate from respondents was estimated to be 65 percent.
Measures
The quantitative study used informant reports to measure the perceived quality of end-of-life care. The respondents were asked about quality of care at the last two places the patient spent two or more days in the last month of life. The main outcome measures were based on a conceptual model of patient-focused, family-centered medical care. This model examines whether the informant believed that health care providers and institutions (1) provided the desired level of physical comfort and emotional support, as measured by pain control, shortness of breath, and emotional distress; (2) supported shared decision-making, as measured by communication with physicians and other health care providers; (3) treated the patient with respect and dignity; (4) kept the family informed about what to expect and provided emotional support; and (5) coordinated care among providers and settings.
Appendix B
Qualitative Study Methodology

Collection and Analysis of Interviews
The qualitative portion of this study compiled information from 54 in-depth telephone interviews of relatives of people who spent some time in a nursing home during the last month of their lives. The decedents died in 2000, and the qualitative interviews took place one to two years later, between November 2001 and October 2002. The interviews followed up a large, nationally representative survey in which telephone interviewers collected a range of quantitative data about the end-of-life care experiences of decedents from the point of view of a key informant, usually a family member. The interview sample was drawn from throughout the nation and included people of various races, ethnicities, and religions from urban, rural, and suburban areas. Some respondents were sophisticated about medical care, and others were not; some had few financial concerns, and others had exhausted their life savings.

Table 1 compares information about the decedents in both the quantitative survey and qualitative interviews, and Table 3 provides a similar comparison of respondents to the quantitative survey and qualitative interviews. The quantitative survey involved 1,578 respondents, of whom 587 (37.2 percent) were very familiar with the circumstances of a person who had spent at least 48 hours in a nursing home during the last month of life. From these 587, 54 respondents were selected for qualitative interviews. Potential respondents were selected with deliberate oversampling for decedents who had received hospice services in the nursing home.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Quantitative Survey</th>
<th>Qualitative Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedents ((n))</td>
<td>1,578</td>
<td>54</td>
</tr>
<tr>
<td>Spent at least 48 hours in a nursing home in the last month of life ((n))</td>
<td>587</td>
<td>54</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>83.2</td>
<td>83.9</td>
</tr>
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<td>70.4</td>
</tr>
<tr>
<td>Race (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
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<td>77.4</td>
</tr>
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</tr>
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<td>Asian</td>
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<td>Marital status (%)</td>
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<td>qualitative</td>
</tr>
<tr>
<td>--------------------</td>
<td>--------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Married</td>
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</tr>
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<table>
<thead>
<tr>
<th>Education (%)</th>
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<tr>
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<td>47.2</td>
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<tr>
<td>Some college</td>
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<tr>
<td>College graduate</td>
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<tr>
<td>Post-college</td>
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<td>7.6</td>
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<tr>
<th>Cause of death (%)</th>
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</thead>
<tbody>
<tr>
<td>Stroke</td>
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<td>1.1</td>
</tr>
<tr>
<td>Cancer</td>
<td>15.8</td>
<td>22.2</td>
</tr>
<tr>
<td>Heart disease</td>
<td>46.5</td>
<td>22.2 *</td>
</tr>
<tr>
<td>Dementia</td>
<td>12.8</td>
<td>27.8 *</td>
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<table>
<thead>
<tr>
<th>End of Life Decisions</th>
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<tbody>
<tr>
<td>Advance directive (% yes)</td>
<td>82.2</td>
<td>81.1</td>
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<tr>
<td>Hospice involvement (% yes)</td>
<td>23.6</td>
<td>42.6 *</td>
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</table>

Note: Percentages may not total 100 because of rounding.

*\( p = <.05 \)

Among the decedents who spent at least 48 hours in a nursing home in the last month of life, most (67.2 percent of the quantitative survey group and 70.4 percent of the qualitative survey group) were female. The two groups of decedents had similar racial distributions and educational status. The qualitative survey group was 70.4 percent non-Hispanic white, 11.3 percent black, 7.6 percent Hispanic, 1.9 percent Asian, and 1.9 percent American Indian/Alaskan native. Most
of the decedents in both groups were widowed (60 percent). The average age was 83.9 years at death.

As Table 2 indicates, the duration of the nursing home stay among decedents was quite wide, with two decedents having spent more than 10 years in a nursing home and 8 having spent less than one month. A number of factors make it difficult to provide a precise measure of the amount of time decedents spent in nursing homes prior to death—especially, frequent transfers among some decedents to and from home, hospitals, or assisted living facilities. In the format of the qualitative interview, respondents were not directly asked about the precise amount of time the decedent spent in a nursing home, or the exact date of admissions, transfers and discharges. We estimate that the median time spent in the nursing home by decedents was six months to one year.

<table>
<thead>
<tr>
<th>Duration</th>
<th>Number of Decedents</th>
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<tr>
<td>Less than one month</td>
<td>8</td>
</tr>
<tr>
<td>1-6 months</td>
<td>16</td>
</tr>
<tr>
<td>6 months to one year</td>
<td>9</td>
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<tr>
<td>1-2 years</td>
<td>6</td>
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<tr>
<td>3-10 years</td>
<td>12</td>
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<tr>
<td>10-13 years</td>
<td>2</td>
</tr>
<tr>
<td>Unable to determine</td>
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</table>

Hospice services were received by 42.6 percent of the decedents in the qualitative survey group compared with 23.6 percent of the quantitative survey group. This difference is due to deliberate oversampling for hospice services. Four out of five decedents in each group had advance directives.

Some differences in cause of death were observed between the qualitative interview group and the quantitative survey group. More members of the qualitative interview group died of dementia-related causes than in the quantitative group (27.8 percent versus 12.8 percent), and fewer died of heart disease (22.2 percent versus 46.5 percent). These differences are consistent with the oversampling for hospice care recipients in the quantitative group. Although it does not reach statistical significance, a trend toward more cancer-related deaths in the qualitative interview group (22.2 percent versus 15.8 percent in the quantitative group) is also consistent with oversampling for hospice service recipients.

Respondents to the qualitative survey were more likely to be female (64.8 percent; see table 2). The most common relationship to the decedent was that of daughter/son or daughter-in-law/son-in-law (40.7 percent), followed by spouse or partner (14.8 percent), sibling (5.5 percent), and parent (3.7 percent). Others included nieces, nephews, aunts, uncles, grandchildren, and other family or friends (35.3 percent). The finding that most key informants were not spouses is not surprising, because the spouses themselves may be suffering from debilitating conditions or deceased. Moreover, nursing home residents are less likely to have close family members than
are people who remain in the community. Respondents tended to be well educated, with more than 90 percent having a high school diploma and more than 30 percent having a college degree.

Table 3. Characteristics of Respondents to the Qualitative and Quantitative Surveys

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Quantitative Survey (%)</th>
<th>Qualitative Study (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to decedent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>14.0</td>
<td>14.8</td>
</tr>
<tr>
<td>Son/daughter (or son-in-law/daughter-in-law)</td>
<td>43.0</td>
<td>40.7</td>
</tr>
<tr>
<td>Parent</td>
<td>9.5</td>
<td>3.7</td>
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<tr>
<td>Sibling</td>
<td>6.3</td>
<td>5.5</td>
</tr>
<tr>
<td>Other</td>
<td>27.2</td>
<td>35.3</td>
</tr>
<tr>
<td>Sex (female)</td>
<td>68.9</td>
<td>64.8</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school graduate</td>
<td>8.5</td>
<td>3.7</td>
</tr>
<tr>
<td>High school graduate</td>
<td>27.0</td>
<td>24.1</td>
</tr>
<tr>
<td>Some college</td>
<td>32.6</td>
<td>33.3</td>
</tr>
<tr>
<td>College graduate</td>
<td>14.7</td>
<td>22.2</td>
</tr>
<tr>
<td>Post-college</td>
<td>17.8</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Note: Percentages may not total 100 because of rounding.

* $p = <.05$

Survey instruments and structured questionnaires have well-known limitations (Ajzen, 1988, 1991), especially regarding subjects with emotional and value-laden content. Qualitative research has important strengths that quantitative research lacks. A priori assumptions inherent in the structure and content of survey instruments fundamentally limit the subject’s response. In contrast, qualitative methodologies temporarily suspend the generation of hypotheses and the premature identification and definition of categories to consider the subject first from the respondent's point of view.

Reports by surrogate respondents cannot be considered wholly reliable (George, 2002), but family members are often highly involved in their loved one’s deaths and can provide vital information and important continuity between the quantitative and qualitative studies. The
subjects these respondents discuss in their narratives, the words and cadences they use, and what they consider to be important to the story reveal domains the researcher would not otherwise have discovered. In-depth, qualitative research allows the breadth of a subject to be explored, stimulates fresh questions, identifies new concepts, and permits a complex appreciation of the subject. Individual case narratives illuminate the intricacy of relationships, values, dilemmas, and other important features of human experience (Kaufman 2002, Clark 2002).

The combination of quantitative and qualitative methodologies can “provide a richer understanding” and yield “insights...used to develop additional research questions” (Galanos and Moore, 2002). Using quantitative and qualitative methodologies together provides a powerful way to appreciate how dying persons and their families experience their situation. Whereas quantitative methods help define the scope and magnitude of a subject, qualitative methods provide trustworthy results through detailed description and prolonged immersion (Inui, 1996). Satisfying experiences as well as horror stories contain important information about the values, assumptions, and expectations of family members as well as those of health care providers. They help explain “the ‘structure’ of a system: how interdependent individuals, groups, and institutional components function (or fail to function) together” (Berkwits and Inui, 1998). The combination of methodologies thus offers an overall picture of the state of end-of-life care as well as a richer understanding of the important issues involved (Buston et al., 1998; Curry et al., 2000; Murray, 1996; Pope and Mays, 1995).

The research team consisted of a physician/researcher specializing in end-of-life care, a health policy/health services researcher, an anthropologist experienced in qualitative nursing home research, a health services researcher with expertise in hospice care, an epidemiologist with qualitative training, and a doctoral candidate in sociology experienced in qualitative methods.

Interviews were semi-structured and open-ended, lasting 35 to 90 minutes each depending on how much detail each respondent wanted to provide. Interviewers followed a script that first requested respondents to describe the decedent’s last year and last week of life, which allowed respondents to identify themes that were important to them. Follow-up questions focused on pain management, 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.

After transcribing the interviews, the research team generated a coding system through an intensive and iterative series of steps. To prevent prejudging the material, each team member read the same transcript without an a priori list of labels and then created descriptive labels, called codes, to fit the transcript. The team members then gathered for a line-by-line reading of the transcript in which they discussed the suggested codes. Each meeting generated discussion, debate, disagreement, and reconciliation—always grounded in the words of the respondents— that led to the creation of mutually agreed-on codes. Team members designed codes that reflected what they believed each respondent meant. The way respondents used words, added emphasis, interjected sarcasm, had difficulty remembering, held back tears, recalled touching moments, returned to important themes, and qualified their opinions revealed complex meanings that the team tried to capture in the evolving coding system. Team members considered context, repetition, sequence, and trajectory of the story as significant qualities of each transcript. Codes
were applied to fragments of sentences as well as to longer quotations. As the process repeated itself, each transcript generated new sets of codes for new situations. After extensive coding sessions in which agreement about coding became more efficient and reliable, the team designated two members to code the remaining transcripts and enter the codes into the ethnographic coding software, Atlas.ti. Other members of the team then read the coded transcripts as an additional validation check. Each interview was also summarized to clarify the trajectory and specific issues embodied in each story.

Team discussions generated tentative hypotheses to help explain the material in the transcripts. In analyzing subsequent transcripts, these ideas were challenged and fine-tuned, leading to a fuller understanding of the complex situations described. Specific issues raised in each case were considered separately and compared across interviews, allowing the team to array the codes and themes in various clusters and discuss how they connected with more generalized macro-level themes. The sample size of 54 interviews provided reiteration of major themes as well as examples of a range of specific circumstances and conditions. Understanding the smaller components and how they affect the larger components helps explain the different ways in which they affect care. The way these elements contribute to both the positive and problematic features of end-of-life care in nursing home settings suggests policy actions and educational initiatives for improvement.