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End of Life in Nursing Homes: Experiences and Policy Recommendations

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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.