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Making Room for Dying: *End of Life Care in Nursing Homes*

by SANDRA H. JOHNSON

People are dying in nursing homes. This may sound like a clarion call for a new wave of nursing home policing; instead it is a statement of a simple fact that we must embrace. Over 20 percent of older Americans meet their deaths in a nursing home, and 30 percent of all persons dying in hospitals have been transferred there from nursing homes just a few days earlier.

Understanding that people die in nursing homes—and *should* die in nursing homes, just as they should be able to die at home—ought to drive us to improve their care. The literature is already rich with case studies and demonstration projects undertaken by nursing homes to improve care of the dying. Broader change requires a shift in culture and a reframing of the issues. Contemporary standards for nursing home quality and the accepted framework for end of life decision-making have inadvertently placed obstacles in the path of good care for the significant proportion of older people who will spend their final days in a nursing home.

Enriching the Ideal for Nursing Home Care

The cornerstone of contemporary nursing home quality standards has been the unequivocal repudiation of the related beliefs that nursing homes are way stations for the dying elderly and that decline is inevitable for nursing home residents. Instead of being resigned to inevitable decline, regulators and professionals are commit-

ted to maintaining, if not improving, the physical, mental, and social health of nursing home residents. This hard-won expectation of active support for maintenance and growth rather than mere caretaking has directed nursing homes toward a more engaged and less fatalistic care model. This change is good, in part because the nursing home industry, regulators, and caregivers have become alert to substandard care that had once hidden behind routine acceptance of physical and mental decline.

These rehabilitative, health-promoting expectations, however, may have unintentionally produced a death-denying culture within the nursing home. Regulations impose standards that assume that physical, mental, and emotional decline are signals of deficiencies in care unless demonstrated to be otherwise. Physical changes commonly associated with dying, such as weight loss, have thus become signs of failure, rather than a normal part of dying, and so trigger requirements that the facility justify its care. Because nursing home administrators are highly sensitive to regulatory risk and avoid situations that may attract the attention of regulators, the regulatory emphasis on positive indicators of health can discourage them from providing good care to a dying resident. This dynamic is revealed, for example, by the fact that imminently dying residents are often transferred to hospitals so their deaths will not occur in the nursing home and require that care be defended. Failure to accept the indicators of decline that naturally occur in dying may also be reflected in the emphasis on tube feeding for nursing home residents. Thus, the rehabilitative expectations, captured and reinforced in regulation, skew nursing home care models away from care of the dying.

Sandra H. Johnson, "Making Room for Dying: End of Life Care in Nursing Homes," *Improving End of Life Care: Why Has It Been So Difficult?* Hastings Center Report Special Report 35, no. 6 (2005): S37-S41.

Before nursing homes can improve end of life care, dying will have to find its place in the nursing home culture. For nursing homes, a shift in culture necessarily involves paying attention to regulation and to the providers' reactions to regulation as well as to other behaviors that create and maintain a culture. Culture and regulation go hand in hand in the nursing home environment because of the pervasive scope of nursing home regulation, the enforcement orientation of regulators, and the intense risk aversion of nursing home administrators. Efforts to make room for the dying patient require a review of standards and adoption of changes to facilitate the appropriate level and type of care for them. Some have argued, for example, that changes in the mandatory Resident Assessment Index could more readily encourage nursing homes to provide better palliative care. Such efforts should not require nursing homes to abandon their mission of health promotion, however. Palliative care models view support of the dying as active, positive, and promoting of health and human values, even as aggressive medical interventions aimed at cure are relinquished. In addition, both hospices and nursing homes engage in the most intimate forms of care, and this shared experience can form a meeting ground between what are now often viewed as separate approaches to care.

The challenge is to encourage the regulatory system to accept the process of dying, with its accompanying physical and mental deterioration; to exercise restraint in the use of interventions, including inquiries, that would otherwise be pursued; and to do so without creating a shield for neglect. Nursing homes are plagued by a reputation for neglect and abuse, but gearing the entire system to account for the bad apples can inadvertently have the effect that all homes provide less than optimal care for the dying. Unintentional adverse effects are a problem for any health care regulatory system, of course. They can occur whenever health care professionals make decisions in patient care that are motivated not by the best interests of the patient, but by the provider's fear of litigation or scrutiny by a regulator. Nursing home administrators often try intensely hard to avoid doing things that would trigger regulatory scrutiny because part of their professional obligation is to manage legal risks. This has a very deep effect on patient care because the administrator has a profound influence on patient care in the nursing home (as compared to other health care settings). Such decisions therefore raise ethical issues concerning the duties of health care providers, including administrators, to patients, not only to the facility. While administrators have a professional obligation to protect the facility, ethical duties to residents' well-being supersede their management responsibility. Because of their influence on care, administrators cannot defer that ethical obligation to professional caregivers.

Of course, the nursing home culture consists of more than the regulatory environment. If the nursing home culture is to make room for dying, the incremental patterns that maintain that culture will have to be addressed. Publicly marking the death of a resident by more than redistributing clothing or reassigning the "bed," expressions of sympathy to other residents and to family, and bereavement support for staff can be significant in creating a culture that responds to the reality of death. Paying attention to culture also broadens the focus to include the community of caregivers in the nursing home. Often, direct caregivers and residents in a nursing home differ in terms of race and ethnicity, socioeconomic class, and culture. If culture is taken seriously, the clashes in expectations and values that occur between residents and caregivers—and often between the professional and nonprofessional staff—can be addressed as larger questions rather than as individual conflicts with uncooperative caregivers.

Adjusting the Framework for End of Life Care

Improving the quality of care for the dying in nursing homes is not solely a matter of nursing home culture and regulation, however. It also requires adjusting the general framework for end of life decision-making to better account for the nursing home context.

One important characteristic of the dominant legal and ethical framework for end of life care is the drive to the crucible—a concentration on the cases that place fundamental values in stark contrast and thus highlight intractable moral conflict. The paradigm case in the end of life debate—whether nutrition and hydration should be provided for a person in a persistent vegetative state—has persisted as *the* test case for the moral and legal questions for decades. But testing principles and decisions against this paradigm can thwart progress in improving care for the dying. By focusing squarely on issues that are more commonplace, both in terms of incidence and in the sense of shared values, nursing homes can improve the lives of those who will die in their facilities. Rosalie Kane argued that long-term care should emphasize what she termed "everyday ethics"; similarly, the well-being of individuals living and dying in the care of nursing homes is better served if we focus on the routine rather than the extreme.

If nursing homes have a distinctive case in which key ethical issues are embedded, it is the decision whether to transfer the dying resident to a hospital. Unnecessary hospitalization of nursing home residents when death appears imminent is both a symptom of, and scaffolding for, the culture that denies death and thus impedes the most appropriate end of life care.

Studies indicate that hospitalization when death is imminent does not provide the resident with better treat-

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ment. Rather, such transfers can impair good care because the hand-off to a new care team can result in absent or unclear transfer orders for pain and symptom management, disruption of care plans developed with the resident or the family, and the disturbance of moving to an unfamiliar location. Reducing the incidence of unnecessary hospitalizations can improve care of the dying significantly in the nursing home without facing a stalemate over the moral values of human life and human caring.

A second “common” issue is improvement in pain and symptom management. Unrelenting pain can interfere so completely with thought, self-awareness, emotional engagement, and social relationships that it can rob the individual of the experience of being human. But pain is badly undertreated in nursing homes; studies report that 30 to 80 percent of residents receive inadequate pain management. Pain management may be undercut by regulations intended to avoid excessive use of pharmaceuticals, especially those that affect awareness. Efforts to improve pain management confront a tendency on the part of health care providers and family members to underestimate pain in the elderly, as well as the tendency of the elderly to underreport pain for fear of being a burden. Assessing pain in people with cognitive impairment requires intense effort. Improving pain management will not grab the headlines or fuel the debates that withdrawal of nutrition and hydration does, but it is the foundation for compassionate care for the dying.

Food and water—including medically provided nutrition and hydration—carry symbolic weight, but especially in the nursing home setting. Nutrition and hydration, and the nutritional status of the resident, are a core measure of adequate or deficient care. Deficiencies in diet and hydration are commonly viewed as the root cause of substantial physical and mental impairments and of injuries ranging from bedsores to mental confusion. Poor food service and inattention to encouraging fluid intake are, in fact, key indicators of poor nursing home care.

Nutrition and hydration in the nursing home are also icons of the ethic of care. The better nursing homes, for example, understand the social and emotional power of eating. Despite the focus on health promotion, sometimes the primary goals of nursing home care, especially for the

families, are to keep this person safe, to keep her warm, and to keep her fed.

Tube feeding is not the same as eating, however. Its sole justification is that it maintains the physical health of the patient. When tube feeding does maintain physical health, there can be a battle over whether continuing or stopping is moral or immoral. Increasingly, however, evidence indicates that a common intervention for tube feeding in nursing homes—percutaneous endoscopic gastrostomy (PEG)—does not reduce the risk of pneumonia or infection and may not reduce the risk of bedsores. This new knowledge presents a challenge, or opportunity, analogous to earlier efforts to reduce the use of physical restraints in nursing homes. The two developments are similar in that the common practice was supported by a “common knowledge”—restraints keep residents safe and PEGs keep them healthy—that has proven mistaken. As with restraints, new knowledge about the negative effects of medically provided nutrition and hydration should reduce recourse to tube feeding, even when the nutritional intake of patients appears inadequate, while strengthening rather than rejecting the values that support feeding.

The battleground of medically provided nutrition and hydration for the PVS patient is fought ferociously because there is disagreement over the meaning of life and the meaning of care. In contrast, the most significant nutrition and hydration issue in the nursing home for end of life care may now present a question of fact rather than contested value. Unless this common practice is uncoupled from its association with the crucible of the provision of nutrition and hydration to the patient in PVS, the shared values that support its reduction in use will not be recognized.

Questioning the Assumptions

Different states have varying normative and legal frameworks for decisions concerning medical care at the end of life. Furthermore, actual practice often differs significantly from the principles established in the law and in the ethics literature. In practice, for example, health care professionals, families, and patients may bring more nuance to the situation than either the law or the ethics literature can encompass.

Listening, by Robert Pope

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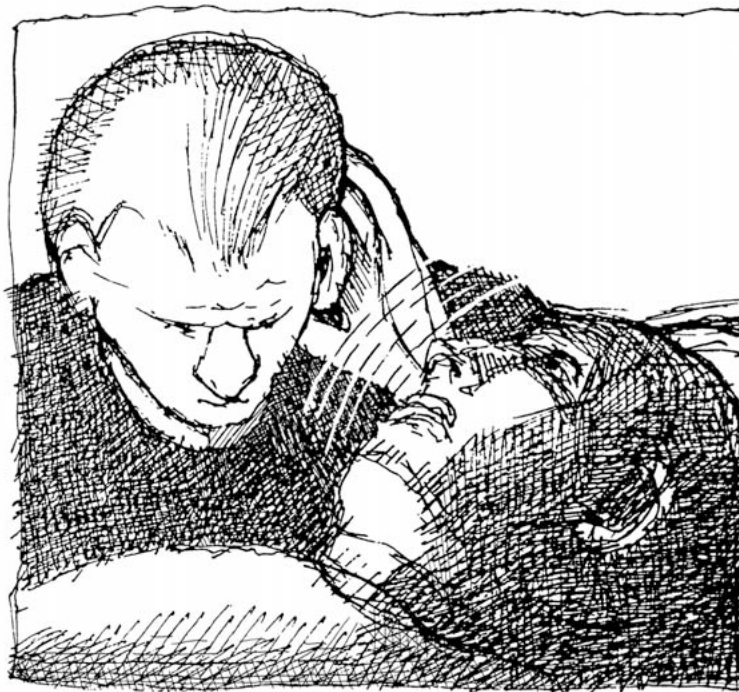
Three fundamental assumptions in the current structure for end of life decision-making are particularly ill-suited to the nursing home environment. These are the concepts that “end of life care” is synonymous with “care for the dying,” that the patient is the only person whose autonomy or well-being has moral significance, and that there should be a presumption in favor of life-sustaining treatment.

Legal, ethical, and clinical decision-making at the end of life still bear the mark of their original emphasis on the significance of terminal illness. The moral and legal distinction between terminally ill individuals and others certainly has been modified somewhat; however, the status of “dying” still has significant connotations. More important, it assumes a recognizable process with a beginning that is as clearly defined as its end.

For nursing home residents, the dying process is often subtle and incremental. Is *this* pneumonia or *this* infection the one that signals imminent dying, or will treatment restore the patient to her previous health status? The problem of recognizing the onset of dying may be an even more serious problem among patients with dementia, who constitute a significant population in nursing homes. According to one study, only 1.1 percent of residents with advanced dementia were identified by clinicians as having a life expectancy of less than six months, while 71 percent of those same patients actually died within that time-frame.

The problem of identifying the beginning of the dying process or categorizing a patient as “dying” is not only one of medical uncertainty. It is, rather, evidence of a lack of language and even a lack of concepts for this stage of human life, even though it is a stage typical of so many nursing home residents. The problem of defining when someone can be labeled as “dying” is also a manifestation of the denial of death and the fear that accepting a broader “end time” will cause individuals to be neglected and devalued. Unfortunately, when aggressive interventions are pursued or when palliative care is withheld until one is labeled as “dying,” individuals and their families do not receive optimal care and support.

The dominant structure for decisions at the end of life, however we define that period, single-mindedly focuses on the well-being and autonomy of the patient, but this too is a mistake; family members are not merely adjuncts to the patient. Family members bear significant burdens



in the long-term care of an individual, even when that individual is housed in an institution. These family members can experience significant physical, emotional, and financial stress at levels that adversely affect their own health, especially when they are older or are physically vulnerable themselves. Their concerns and well-being should be recognized as morally significant. Requiring that families be singular and unflinching in their devotion to the patient's best interest not only demands the humanly impossible but provides an insufficient moral accounting of the situation.

The moral status of paid caregivers in a nursing home, professional and nonprofessional alike, should not be denied. Their voice also belongs at the table for what they can contribute to understanding appropriate care for a particular resident. Researchers have found that nursing home staff use family terms to describe their relationship with residents and view themselves as protective and caring and intimate with the residents—sometimes more so than actual family. Compensated paraprofessional caregivers engage in the most intimate care of the resident over weeks, months, or years. Even though they are often paid less than people working at other, less demanding positions, their commitment to caring is evident on a daily basis.

The autonomy and well-being of family members who bear the burden in the care of a dying person are morally significant, despite cases in which family members are callous, distant, and opportunistic. Similarly, compensated caregivers should be recognized as moral agents and their voices should be considered in decision-making about in-

Allowing individuals to choose life-sustaining treatments over those that relieve pain or promote function, but putting the burden on them to do so, would show respect for pluralism, freedom, and individuality without imposing excessive burdens on individuals or their families.

dividual patients even though there may be conflicts in values and culture, and even though there are cases where compensated caregivers are neglectful or abusive. Such is life; although the “exceptions define the rule,” general practice should not be determined by the worst cases. Bringing the conflicts and differences to the table may enrich our understanding of the best way to care.

Finally, the legal structure currently defers to individual choice regarding life-sustaining treatment. Legal standards defer to individual choice out of respect for the pluralism and freedom that lead us to disagree on the “one right thing” to do and out of fear that any diminution in the commitment to prolong life would result in a devaluation of human life, or that any community effort to identify appropriate care would destroy personal liberty. Deference to individual choice places confidence in the inherent value of individuation even though identifying the choices of incompetent individuals presents serious and familiar difficulties. It is also a deference that weights the scale significantly in favor of medical intervention. Thus the medical intervention holds a favored position, not the individual’s life history and values or the more complex goals of care.

With advances in palliative care as a discipline and with increasing expertise in relieving suffering, it is time to consider whether the presumption in favor of life-sustaining treatment should be changed to a presumption in favor of care that provides comfort, relieves suffering, or promotes activities of daily living. Stating the presumption in that fashion would bring the goals of palliative care to the forefront and put life-sustaining medical interventions in proper perspective. People do vary in their preferences and convictions. Allowing individuals to choose treatments that do not relieve pain or promote function but putting the burden on them to do so would support respect for

pluralism, freedom, and individuality without imposing excessive burdens on individuals or their families when the choice is merely unclear.

This essay necessarily speaks about nursing homes and nursing home residents in general terms. Not all nursing home residents are alike, however; and not all nursing homes are the same. Some nursing home residents are alert and engaged; others are in various stages of dementia; some are insensate. Obviously, the goals of care for dying nursing home residents and the expectations for nursing homes will have to account for these variations. The term “nursing home” itself is a catch-all phrase sometimes used indiscriminately for many different levels of long-term care. Even among skilled nursing facilities there is significant disparity in how ill and disabled residents are, and this, too, will influence appropriate care models.

The quality of nursing homes also varies considerably. This essay leaves the problem of policing the bad apples largely on the shelf. Although it is a significant problem, the design and implementation of a regulatory system has to follow the identification of appropriate goals and standards for quality of care rather than the goals and standards developed for purposes of enforcement. At the very least, these two perspectives need to be in dialogue and perhaps in tension; one arm of the effort should not exclude the other.

Advocates for nursing home residents and those nursing homes in the leadership of best practices have worked hard to dismantle the stereotype of the nursing home as a warehouse for those who are declining into death. This work needs to be protected. However, once dying is recognized as an undeniable part of living—including living in a nursing home—it is clear that the ideal of health promotion will have to embrace care for the dying.