End-of-Life Care in the Nursing Home — Is a Good Death Compatible with Regulatory Compliance?

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By using relevant clinical practice guidelines for end-of-life care and by incorporating meaningful quality indicators into an effective continuous quality improvement program, nursing facilities can provide quality end-of-life care for their residents while complying with state and federal regulations.

As a nation and a community, we must all work to maintain the dignity of the 1.6 million citizens residing in nursing homes. Moreover, since one in every five deaths in the United States occurs in a nursing facility, and 30 to 50 percent of people admitted to nursing homes die within their first year of residence (Keay et al. 1994; Hing et al. 1989), our commitment includes ensuring a good death for nursing facility residents.

A good death, as described by the Institute of Medicine's Committee on Improving Care at the End of Life, is "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards" (Field and Cassel 1997).

Two forces affecting nursing facilities may influence our ability to provide a good death, the Omnibus Budget Reconciliation Act of 1987 (OBRA '87) and the Health Care Financing Administration's Prospective Payment program for hospitals. These plans encourage the development of postacute medical and rehabilitative services in nursing home facilities. OBRA '87, sometimes called the National Nursing Home Reform Act, attempted to move the focus of nursing facility care from a basic care or maintenance mode to a restorative or rehabilitative mode. This act links participation in Medicare and Medicaid programs to compliance with regulations related to the quality of the resident's care and his or her right to achieve the highest practicable level of function and well-being. Prospective Payment allows many patients needing postacute care of hip fractures, total joint replacements, strokes, or other medical and surgical conditions to be transferred from the hospital setting to nursing facilities (Neu and Harrison 1988 ; Kane et al. 1996).

Health care professionals have found it difficult to strike a balance between working to ensure a good death and complying with regulatory guidelines. A report from the National Hospice Organization (NHO) attributes difficulties in end-of-life care to the complexity of the nursing facility setting and its underlying regulatory apparatus. The latter conflicts with the principles of hospice care and creates an environment in which death is viewed with suspicion or as a failure of care (Schumacher et al. 1998).

According to the NHO report, these unresolved conflicts result in the inadequacies identified by the Institute of Medicine (IOM). The major inadequacies in providing end-of-life care, as defined by the IOM, include

- the over or under utilization of treatment,
- untimely referral to hospice,
- poor technical care in the palliation of symptoms, and

- poor communication about prognoses and treatment preferences (Field and Cassel 1997).

Nursing facilities can, however, overcome these deficiencies and give residents at the end of life and their loved ones the opportunity to experience a good death while remaining in compliance with federal and state regulations. Indeed, each community must work creatively within existing systems and under existing rules and regulations to help its residents achieve a good death, whether or not they are in long-term care.

Distinguishing Avoidable and Unavoidable Decline

Since the Health Care Financing Administration (HCFA) and state agencies that certify and license nursing facilities are obliged to determine whether a resident's decline in function is avoidable or unavoidable, the care of residents at the end of life frequently comes under scrutiny during the survey process (Lawhorne 1999).

Interpretive guidelines instruct surveyors to gather detailed information during a site visit when they discover that a resident has declined (American Association of Homes and Services for the Aging 1998). They make multiple observations; interview direct care staff, the resident, and the family; and review the resident's chart. The survey team specifically wants to know if the facility and its staff have complied with the following measures:

- Have they completed a comprehensive, appropriate, and adequate assessment of the resident, including the identification of any risk factors for decline?
- Have they developed appropriate care plans to address the needs discovered during assessment and to modify risk factors if possible?
- Have they provided individualized care and services for each resident continually and consistently?
- Have they conducted ongoing evaluations of outcomes of care?

A decline is considered avoidable when (1) assessments are incomplete, inaccurate, or not ongoing or individualized, (2) interventions are not completely implemented, ongoing, and consistent with accepted standards of care, or (3) evaluations of response to interventions are not ongoing and do not prompt reassessment of resident status and consideration of additional options (American Association of Homes and Services for the Aging 1998). If the facility has not attempted and exhausted all reasonable options, the survey team is likely to cite the facility for an avoidable decline.

The issue of avoidable deaths has recently surfaced. A government report on California nursing homes raised concerns that sixty-two residents who died were determined by chart review to have received care that was unacceptable. However, "in the absence of autopsy information that establishes the cause of death, we cannot be conclusive about the extent to which this unacceptable care may have contributed directly to individual deaths" (U.S. General Accounting Office 1998). This report to the United States Senate criticized both providers of care and the federal and state oversight processes which either missed problems or failed to take appropriate actions when problems were identified. Subsequent and continuing deliberations by the Special Committee on Aging will place additional pressure on surveyors to determine if nursing facility deaths are avoidable.

Surveyors determine that a decline is unavoidable when progression of underlying disease, aging, or other factors contribute to the decline and all appropriate interventions have been implemented aggressively but to no avail; or when the resident refuses care despite ongoing efforts to counsel the resident and offer alternative treatments (American Association of Homes and Services for the Aging 1998).

Here lies the dilemma. Conflict may arise when surveyors and providers disagree about whether all appropriate interventions have been implemented and whether the implementation was sufficiently aggressive (Lawhorne 1999). Thus, the

facility may be caught between allowing a resident to experience a good and natural death and risking the surveyors' asserting that the dying resident's decline is avoidable because all possible interventions are not being aggressively implemented.

Two case reports presented informally at state chapter meetings of the American Medical Directors Association illustrate the conundrum.

Case 1

A resident who was dying slowly of congestive heart failure developed apathy in addition to dyspnea, profound fatigue, and loss of appetite. The nursing facility staff and attending physician believed that they had addressed the dyspnea and fatigue and surveyors agreed, but they disagreed about how the facility had managed the apathy and loss of appetite which resulted in a decline in activities of daily living and weight loss. The facility attributed these symptoms to a natural end-of-life disengagement, but the surveyors argued that the comprehensive assessment failed to address the possibility of depression and that the care plan failed to offer treatment for it. The resident's decline was considered avoidable and the facility was cited.

Under such circumstances, it is extremely difficult to determine whether the survey team or the facility is correct, and further avenues to reconcile the differences are often contentious and nearly always laborious.

Case 2

A resident with advanced dementia and type 2 diabetes mellitus ate only sporadically and had a well-documented advance care directive precluding CPR, tube feeding, and hospitalization. The facility and attending physician stopped all medications, including the oral hypoglycemic agent and stated in the care plan that the new comfort goals regarding type 2 diabetes were to avoid hypoglycemia and symptomatic hyperglycemia. The physician also discontinued routine finger stick glucose determinations because of the discomfort involved in the procedure. A surveyor team cited the facility for poor quality of care because the team was concerned that the facility could not know if the resident had symptomatic hyperglycemia without doing finger stick glucose determinations.

Whose interpretation of this scenario is the correct one? Again, it is a difficult issue to resolve.

The best approach in both cases is determined more by clinical judgment than by evidence-based studies of frail elders residing in a nursing facility. Those who care for residents often feel that they know the residents best, have considered appropriate options and implemented them with compassion and sound judgment. At the same time, state surveyors and HCFA are required by law to assure that these most vulnerable citizens are not harmed and that they have had every opportunity to achieve their highest practicable level of function and well-being.

Until there are better published studies of end-of-life care in the nursing home and until there are better forums for productive resolutions of conflicts arising from differences in clinical judgment, nursing facilities will need to become more skillful in explaining the expected and unavoidable declines that occur during the good and natural death.

Measuring the Good Death in the Nursing Facility

An analysis of information obtained from a focus group composed of people with chronic conditions and those living in long-term care facilities identified five areas of concern (Singer et al. 1999):

- poor pain and symptom management,
- prolongation of the dying process,
- lack or loss of control,
- a sense of burden, and,
- unresolved conflicts with loved ones.

Nursing facilities should attempt to deal with these inadequacies resident by resident, but they must also determine how the nursing facility can deal with end-of-life care more globally. The use of quality indicators is one way nursing facilities can accomplish this.

Quality indicators compiled, analyzed, and distributed by the Center for Health Systems Research and Analysis are now used by HCFA and state surveyors to identify areas where facilities may be providing inadequate care. Of the twenty-nine quality indicators used for this purpose, none address end-of-life issues. Engle (1998) has challenged nursing facilities and policymakers to reconceptualize their approach to residents who are at the end of life.

Traditionally, facilities focus on quality indicators such as mental status, function, and mood or adverse outcome indicators such as pressure ulcers, falls, restraints, and dehydration. Engle suggests using quality indicators such as the number of residents at the end of life who remain in the nursing home to die, have had pain, dyspnea, and fatigue adequately treated, or have had their spiritual and religious needs met. She also focuses on the prevalence of the gentle withdrawal of life-sustaining interventions as requested in residents' advance care directives (Engle 1998).

Keay et al. (1994) also suggest quality indicators for end-of-life care in the nursing facility. After reviewing over 900 articles, books, and abstracts, these authors identified three minimum standards for which 100 percent performance is expected: (1) the presence of an advance care directive or other documentation of the resident's wishes, (2) treatment of pain, and (3) treatment of dyspnea.

And they suggest additional quality indicators:

- documenting the effectiveness of pain treatment,
- address all "uncomfortable symptoms" identified,
- avoid interventions that the resident does not want,
- document and address hygiene needs,
- provide counseling to resident and family, and
- offer follow-up bereavement care.

The Ethics Committee of the American Geriatrics Society published a similar set of quality indicators (AGS Ethics Committee 1995).

The identification, refinement, and use of appropriate quality indicators for end-of-life care marks an important step in improving the care of nursing home residents who are approaching the end of life. Even before these indicators are formally incorporated into the HCFA process, nursing facilities can develop and implement them. Certainly, tracking the prevalence of advance care directives or the prevalence of residents with a surrogate decision maker is useful. In addition, continually monitoring the number of residents who have had specific elements of their advance care directives honored and pain adequately treated can help nursing facilities rate their performance in end-of-life care.

Specific Nursing Facility Approaches to Improving End of Life Care

In-service training and other educational initiatives to improve end-of-life care often fail because of a poorly educated direct care workforce with a high turnover rate. Similarly, clinical practice guidelines are often not implemented because they are more costly than expected or too complex for the facility to maintain (Schnelle 1998). Thus, a different approach is needed.

A better approach is to institute clinical practice guidelines for end-of-life care in a facility that has been prepared for guideline implementation while fostering a culture of continuous quality improvement. The ultimate success of this approach, however, may depend on an additional component: the recruitment and training of skilled certified nursing assistants (CNAs).

At present the high turnover rate among CNAs and other direct care workers makes guideline implementation very difficult. Research suggests that the high turnover rate is driven by injuries received on the job (directly from belligerent residents or heavy lifting), the unaddressed grief CNAs feel when residents die, a feeling that they are not respected or valued, and low pay and benefits (Callahan 1997).

Preparing a facility to implement clinical practice guidelines for end-of-life care requires that the facility's leadership be committed to the process and clearly articulate its support to the staff. A step-by-step implementation guideline has been developed by the American Medical Directors Association; but in general, nursing facilities must address four areas when anticipating guideline implementation (CPG Steering Committee 1998).

First, there must be agreement about what constitutes end-of-life care and which end-of-life symptoms are important to residents, their families, and friends. Once consensus is reached, a search for appropriate clinical practice guidelines for end-of-life care follows. For example, both the American Geriatrics Society and the American Medical Directors Association have published pain management guidelines, and the AMDA's guidelines are specifically tailored for the long-term care setting (AGS Panel on Chronic Pain 1998; CPG Steering Committee 1999).

When choosing relevant clinical practice guidelines, the facility should consider those that are evidence-based. The guidelines should also explicitly identify goals of therapy and outcome measures, and estimate the costs of implementation. The facility can determine the impact of the guidelines on quality of care and forsee the resources needed to sustain the guideline over time (Schnelle et al. 1998; CPG Steering Committee 1998).

Second, the facility must critically appraise its existing care delivery processes and the staff's ability to carry out the functions and tasks described in specific end-of-life guidelines. Essential key processes include the facility's ability to do comprehensive assessments and develop care plans, to manage new problems and complications as they arise, and to continuously monitor the effectiveness of interventions. These key processes require reliable information management systems and good interdisciplinary communication.

Determining the staff's ability to perform the functions and tasks needed to implement end-of-life clinical practice guidelines requires assessing the staff's current level of knowledge and skills and providing technical instruction and mentoring in identified areas of weakness.

Third, an interdisciplinary work group should tailor the particular end-of-life clinical practice guideline for its facility, taking into account its strengths and weaknesses. The work group composition should include direct care staff, management, and professionals skilled in end-of-life care. The goals of the work group are to educate the staff about the importance of end-of-life issues, to build consensus around the clinical practice guideline approach to end-of-life care, and to define the detailed processes, training, and mentoring required to implement the guideline.

Fourth, specific and measurable quality indicators are chosen and monitored. As suggested previously, the literature provides some guidance in these areas, but since there are no HCFA quality indicators at present, facilities should choose quality indicators that are meaningful to them. Specific examples of quality indicators include the number of residents who have

- an advance care directive or documentation of their end-of-life wishes within two weeks of admission,
- documentation that they were asked about pain, dyspnea, fatigue, or other uncomfortable symptoms at least every forty-eight hours,
- pain (or any other end-of-life symptom) for which there is regular documentation that current interventions are assessed for effectiveness at least every forty-eight hours,
- "do not hospitalize" orders on those who are transferred to the hospital,
- "no feeding tube" advance care directives on those who have feeding tubes discontinued, and
- documented access to pastoral counseling or other religious or spiritual support.

After a clinical practice guideline is implemented for end-of-life symptoms and quality

indicators are in place, quality care can be nurtured and enhanced by incorporating end-of-life care into the facility's continuous quality improvement program.

Summary

A good death, as defined by the Institute of Medicine and others, occurs less frequently than desired across all health care settings and the nursing facility is no exception. However, implicating regulatory constraints as the primary obstacle to providing good end-of-life care in the nursing facility is simplistic and probably unfair.

Clearly, there is legitimate concern on the part of caregivers about surveyor interpretations of avoidable functional declines and avoidable deaths, but comprehensive resident assessments; care plans that are individualized, sensitive and sensible; and appropriate monitoring of interventions virtually eliminate this concern.

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