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Hospital Executive Leadership: A Critical Component for Improving Care at the End of Life

JAMES P. COONEY JR., GLENN M. LANDERS, and JULIANNA M. WILLIAMS

Abstract. End-of-life care and its planning by individuals, in concert with their families and professional healthcare givers, pose important social, legal, and ethical issues. The authors evaluate the results of a multiyear (1997–2001) collaborative effort among representatives of Georgia healthcare providers, healthcare payers, and the general public that was designed to (*a*) improve end-of-life care through a community-focused field effort to increase public awareness, execution, and institutional management of advance directives and (*b*) impact institutional and state government systems and policies around end-of-life care. The authors conclude that a proactive presence of senior management is integral in implementing systematic change in hospital-based end-of-life care and offer practical recommendations to hospital leaders to affect real change in their institutions.

Key words: hospital-based end-of-life care, advance directives

Numerous studies focusing on end-of-life care have taken place over the past decade (Pritchard et al. 1998; Steinhauser et al. 2000; Silveira et al. 2000). Through these efforts have come recommendations for functional changes for physicians, nurses, and social workers, primarily—but not institutional leadership. Implicitly, this omission indicates no executive role in the improvement of end-of-life care or, at best, one of indirect support. However, according to a series of recent studies in Georgia (Cooney et al. 2001), a proactive presence of senior management is integral in implementing systematic change in hospital-based end-of-life care.

The majority of us will die from the degenerating consequences of chronic disease (Lynn 2000). This inevitable dying process, by virtue of significant advances in medical technology, can be prolonged. However, the quality of this final phase of life is now a widespread, publicly voiced concern (Steinhauser et al. 2000). End-of-life care and its planning by individuals, in concert with families and professional healthcare givers, is an important social, legal, and ethical issue. In fact, the federal government, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and state laws mandate the patient environment and related community education regarding end-of-life care.

A multiyear collaborative effort among representatives of Georgia healthcare providers, healthcare payers, and the general public was established in the late 1990s to identify opportunities and demonstrate effective options for improving end-of-life care (Landers 2002; Cooney 2002). Our article emerged from an evaluation of a part of that effort: a multiyear public education and systems improvement project involving a dozen communities and more than one hundred institutional healthcare providers.

The most significant and consistent observation

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we gleaned from the evaluation was that a successful end-of-life care improvement initiative requires the proactive involvement of hospital leadership. Such leadership is central to initiating change in the institution's beliefs and practices and charting a clear direction for the hospital's improvement program. Conversely, the absence of institutional leadership leads to weak or failed efforts.

A clear direction does not guarantee success, but its absence almost guarantees failure. Setting specific goals was identified as a minimal precondition for care improvement. Effective leadership, emerging from the hospital and positively influencing a community-developed vision, was found to be present when management exhibited a core understanding of its hospital's end-of-life care environment, including practices, patterns, and attitudes.

The hospital environment is tempered by at least two influences: *(a)* external requirements structuring performance and *(b)* internal, institutional policies and practices developed from the attitudes and perceptions of management and staff.

External Requirements

Federal law. Section 1866(a)(1) of the 1990 Social Security Act (a.k.a. the Patient Self-Determination Act) requires hospitals to maintain written policies and procedures relating to end-of-life care.

Before the Georgia demonstration, Castle observed that the federal law had positively affected patient knowledge (Castle and Mor 1998). However, during the study most hospitals conformed to the letter of the law but not to its intent. Mandated questions regarding advance directives[1] were asked at admission, but seldom was there follow-through, nor were there systems in place to facilitate follow-through. Overall monitoring of compliance and effectiveness by hospital management did not occur, nor were hospitals providing the required community education. As a result, hospitals missed opportunities to provide educational services regarding end-of-life care to their communities, and their own services were, at best, minimal (Tyler and Carone 2000).

After education and training, most hospitals in the study came into conformity with the law's intent and went beyond the minimum requirement for management of advance directive information. Senior management demonstrated active knowledge about the hospital's current level of compliance with the law, and the institution's information management systems also reflected an enhanced ability to manage advance directive information.

On the basis of those findings, the following questions have been developed to assist senior management in reviewing their hospitals' end-of-life care practices as they relate to the federal law:

- What is your hospital's compliance system with regard to the intent of all objectives of the law? For example, where, how, and by whom are patients advised of their rights?
- What are your staff and community education efforts on advance directive issues?
- Do you regularly review aggregate information on patient responses to advance directive questions?
- Have such reviews promoted change?
- How do you structure such regular reviews so that they provide you with strategic information about patients' views of end-of-life care and its impact on hospital policies?

State and local laws. All states recognize advance directives (U.S. Living Will Registry 2001). However, the degree of recognition varies from state to state. In Georgia, institutions with proactive leadership appeared to be knowledgeable about the state's statutes and were able to answer the following questions and take appropriate action as needed:

- What statutes related to end-of-life care currently exist within your state or municipality that affect institutional performance and opportunities for change?
- What policies or systems currently exist within the hospital to support these statutes?
- How is continued institutional compliance with both federal and state requirements measured?

JCAHO guidelines. JCAHO standards RI.1.2.5 and RI.1.2.8 translate the complementary requirements of both federal and state law into performance outcome expectations (JCAHO 2001). Effective managers in the Georgia project knew the JCAHO expectations and developed effective compliance strategy.

Internal Attitudes, Policies, and Practices

One might assume that healthcare professionals are comfortable with the subject of death and proficient in end-of-life care management; however, many are not. This lack was observed in the study and frequently contributed to an end-of-life care improvement program's structural weakness. Leaders gave lip service to the program but did not actively commit their full authority to the position.

This behavior was exhibited by hospital CEOs, physicians, nurses, and members of the clergy. A level of comfort with end-of-life care must be established before improvement efforts can succeed.

Personal and institutional attitudes also color perceptions and influence care practice and strategies for improvement efforts. Managers observed in the Georgia project who successfully identified opportunities for improvement understood their own attitudes and those of their institutions and communities. They had a clear sense of their personal preferences and had executed their own advanced directives. Professionally, they at least encouraged the hospital and medical staffs to do the same.

We found, in practice, the following questions to be relevant in guiding leaders in both personal and institutional assessment of attitudes and beliefs about end-of-life care:

- Have you discussed your end-of-life care wishes with your significant other?
- Have you or your physician initiated such a discussion?
- Are your wishes documented in an advance directive?
- If yes, what have you done to ensure that the directive will be in the right place at the right time?
- Concerning legal and ethical aspects of end-of-life care in your hospital, are you comfortable in your knowledge base and leadership role?
- What steps should you take to become more comfortable?
- What steps can you take to become more proactive?

Physicians and nurses frequently voiced concern about the legal dimensions of their responsibilities. Such uncertainty encompassed individual behavior and institutional expectations. One physician observed, "The legal sands always seem to be shifting, and we don't always know how that affects our end-of-life care practice options from situation to situation."

- How do you continuously ensure that the patient care staff and your administrative team are comfortable in their knowledge base, roles, and authorities?
- Could you hold an in-service education program to educate hospital and medical staffs about advance directives?
- How many of your hospital and medical staff have attended an off-site, end-of-life care continuing education program? Could those numbers be increased?

In the Georgia studies, knowledge of end-of-life care patterns and experiences was instrumental in effectively identifying opportunities for improvement. Initially, administrative and medical staffs at only a few hospitals were knowledgeable about death experiences and patterns of palliative care within the institution. Awareness of individual cases did exist, but there was seldom an ability to evaluate aggregate experiences, and it rarely included any comparative knowledge from other institutions.

To understand the hospital's end-of-life care environment, mortality-related patterns should be selectively reviewed. In addition to the institution's data, information available from other local, state, or national hospital groups has proven to be useful. Such a comparative framework illustrates performance relative to others, provides benchmarks to measure progress, and identifies opportunities for improvement.

We found the following statistics and related questions useful in measuring an institution's current end-of-life care patterns:

Hospital death rates. Most hospitals experience an annual death rate of less than 5 percent (NCHS 1998).

Death rates by cause and age. The majority of community deaths occur from chronic disease at age 45 years and above. These two indicators target subgroups for whom the subject of end-of-life care decisions and actions has immediacy.

End-of-life care education for all ages is important, but all-inclusive targets can prove expensive to reach. In addition, the older populations have greater rates of participation and follow-through (e.g., initiating advanced directives). Targeting specific age groups or those with specific diseases appears to be more cost-effective.

Patients with advance directives. Advance directives—written and legally executed documents—are instrumental in guiding care. However, the process by which such decisions are reached and communicated with family and physicians is most important. It is this discussion process by which physicians and families come to understand the parameters of the patient's wishes. The written document, without such discussion, often falls short of its intentions.

During the study, it was estimated that fewer than 10 percent of hospital patients indicated upon admission that they had a living will or durable power of attorney for healthcare. Of those, only half were accessible during the hospital stay. Few hospitals knew the proportion of patients with advance directives, and fewer still enacted the system changes necessary to realize their full potential.

Interinstitutional transfers. In Georgia, approximately half of all nursing facility admissions over a one-year period were from community hospitals. Fewer than 15 percent of those transferred had any form of advance directive. However, the majority of individuals were elderly and in a very frail health status—30 percent were dead within 90 days of admission. Half would be transferred back to the hospital within six months. Often, the pattern of moving the patients stopped only with the patient's death. Little end-of-life care planning existed, but what plans did exist were seldom written and transferred with the patient (Cooney et al. 2001).

- What leadership steps could you take to improve continuity of care, especially in regard to interinstitutional transfers and end-of-life care planning?
- Regarding palliative care, what information is transferred with the patient to ensure continuity of care?

Interinstitutional transfers resulting in death within 48 hours. A benchmark advocated by the Institute for Healthcare Improvement (IHI) suggests that "Patients who are likely to die within 48 hours should not be inter-institutionally transferred" (Berwick 1998). Almost one-third of the patients studied who were transferred from a nursing facility to a hospital died within 48 hours (Cooney et al. 2001). Few were transferred with advance directives or a care plan designed to ensure continuity.

- Does your hospital's current volume of interinstitutional transfers and transfers resulting in death within 48 hours present opportunities for improvement related to both end-of-life care planning and care continuity?
- Do you have a strategy for evaluating these transfer patterns against the IHI benchmark?

Care-limiting orders. Care-limiting orders can stem from the patient's advance directive(s) and from discussions with the patient's legally recognized proxies and physicians. They are distinct from advance directives in that they are physician-written orders and carry the authority of such. During the study, the presence of care-limiting orders was frequently the only evidence of an end-of-life discussion.

- What proportion of your current patient population has a do-not-resuscitate order?
- Are such written orders kept systematically in an accessible location?
- What steps can be taken to encourage and support medical staff in discussing care-limiting order options with their patients and appropriate family members?

Hospice. In Georgia, it is estimated that only about one-third of the individuals that could benefit from hospice services actually receives them. Many patients are unaware of the services hospice can provide or that they may be eligible for hospice care. Discharge planning presents an excellent opportunity for discussing the hospice option with patients.

- Are there barriers within your institution that inhibit hospice awareness (e.g., a lack of education on the part of physicians and medical directors about hospice; Friedman 2002), and if so, how can they be overcome?

Community education. In addition to patient care services, the traditional role of hospitals has included the provision of educational services to the community. End-of-life care offers an excellent opportunity for hospitals to expand their community service, and as a result of the federal law, hospitals have a legal obligation to provide educational information concerning advance directives to their staff, patients, and the community. It has been observed that a good death is a collaborative effort. The community is a necessary component of this effort.

- Do your mortality statistics indicate opportunities for collaborative efforts with other community healthcare institutions or other community institutions?
- Could existing relationships be used as a basis on which to build collaborative efforts?
- What is the current community education role of your hospital?

A Road Map

Seven steps adapted from the popular FOCUS-PDCA[2] model of quality improvement provide the manager with a road map for improving end-of-life care planning and practices within the hospital environment:

Step 1. Determine where your institution is now, and decide where you might want to be in terms of the your institution's end-of-life care environment.

Step 2. Select specific opportunities for improvement. The identified opportunities will usually be several and, therefore, will present options for implementation in one or more areas. Slow and appropriate change best occurs in simple steps.

Step 3. Determine where you want to be at the end of the implementation period. It takes a long time to change a culture. Nationwide, the healthcare system and our communities are undergoing the early stages of cultural change regarding care at the end of life. Such change is appropriately slow and reasoned. As a consequence, the change process requires a long-term perspective, diligence, and continual attention.

Step 4. Decide your objectives and how you will facilitate their anticipated outcomes. Network with appropriate hospital and community stakeholders.

Step 5. Develop a strategic plan for program implementation and maintenance. The most critical aspect of plan development is "local buy-in". Numerous opportunities to borrow or purchase end-of-life care improvement programs have proven to be successful in hospitals throughout the country. To introduce such programs without local modification and commitment is one of the most effective methods of ensuring program failure. Use a nationally available model as a starting point, but modify it to fit local culture and practice.

Step 6. Implement the plan operationally or as a pilot as appropriate.

Step 7. Periodically evaluate outcomes and adjust the plan as necessary.

Conclusion

It is difficult to effect institutional change under any circumstance, especially with all of the demands placed on hospital managers, and it requires persistent emphasis. Organizational change around end-of-life care is especially challenging considering that deaths in hospitals occur in only 5 percent of discharges, on average. However, when such changes are positively institutionalized, they benefit the entire community. Without hospital leadership, those benefits will be nearly impossible to achieve.

NOTES

1. Advance directives are written instructions about how an individual wants end-of-life care decisions to be made and care to be given.
2. FOCUS-PDCA is an acronym for Find, Organize, Clarify, Uncover, Start—Plan, Do, Check, Act.

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