



American Academy of Nursing

Policy Brief

Advance Care Planning as an Urgent Public Health Concern

Submitted by the AAN Task Force on End-of-Life Conversations

The American Academy of Nursing endorses end-of-life conversations as essential for the care of patients with life-limiting conditions so that patients' values and preferences for their care and treatment are honored. These conversations, formally known as advance care planning, should rightfully occur between health professionals, patients, and patients' families.

With the aging of the American population and the resulting growth in the number of individuals facing the end of life, advance care planning has become an urgent public health concern requiring the attention of policy makers. This **Policy Brief** provides background and recommendations to the Board of Directors of the American Academy of Nursing from the Academy's Task Force on End-of-Life Care Conversations.

Background

During the 2009-2010 national debates on health care reform, conversations about medical care at the end-of-life became highly politicized. At the heart of the controversy was a proposal in the U.S. House of Representatives' version of the reform bill that would reimburse physicians for time spent in counseling patients about end-of-life treatment decisions. Interpretations of this provision portrayed it as an effort to save costs by encouraging patients nearing death to forego life-extending treatments. This misunderstanding highlights the urgent need to clarify the purpose and intent of advance care planning related to treatment decisions for patients with life-limiting conditions.

The federal Patient Self-Determination Act of 1991 codified patients' right to determine the medical care they receive. The law requires hospitals to provide information about advance directives to adult patients upon admission for any condition. Specifically, patients have the right to specify their future treatment by means of an advance directive or power of attorney for health care. In operation, the letter of the law is met in a vast majority of hospitals by admitting personnel who distribute advance directive forms. Thus, while the law set an important legal

precedent, it has had little effect on encouraging real advance care planning or on the completion rate of advance directives by the public.

Health professionals widely endorse the ethical premise that patients' values and preferences should be the driving factor in treatment decisions about end-of-life care. When patients are no longer able to speak for themselves, families are generally accepted as proxies of the patient. Ideally, advance care planning between clinicians, patients, and patients' families has occurred over time, and patients have expressed and clarified their preferences verbally and in writing. "Over time" connotes the evolving needs and preferences of patients and families and recognizes the complex, competing, and shifting priorities in goals of care as the medical condition changes. Such optimal advance care planning should be initiated by health care professionals, preferably well ahead of a patient's terminal phase and any resulting cognitive incapacity.

Despite wide acceptance of this premise and comprehensive national guidelines on palliative care and advance care planning,^{1,2} along with long-standing advocacy by many national organizations,³ advance care planning remains problematic. Numerous issues add to the urgency of better policies that will facilitate advance care planning. For example, often advance care planning has not been initiated prior to a patient's terminal phase. Even when advance care planning has been initiated and documents such as advance directives have been completed, such documents may be out of date, not readily available (especially during transitions in care settings), or not considered by clinicians. As a result, too much unwanted aggressive and futile treatment may occur that is not in synch with patient preference. Studies show that costly life-extending treatments that are not aligned with patient preferences result in patient and family dissatisfaction with care.⁴

Further, good advance care planning requires substantial clinician time that typically is not reimbursed. If conflicts over treatment decisions occur, consultation by hospital ethics committees can be very helpful but also are not typically reimbursed. In general, current payment methods for medical care pay more for aggressive treatments, even when they are not medically indicated or wanted by the patient, than they do for advance care planning and ethics consultation. The latter, while uncompensated, result in higher patient and family satisfaction and less wasteful treatment.

Therefore, the Task Force presents to the Academy Board of Directors the following recommendations for the improvement of policies related to advance care planning.

Recommendations

1. The time invested in advance care planning by qualified health professionals for patients with life-limiting illness should be reimbursed by all payers. In addition, ethics consult time invested in facilitating family-clinician meetings and conferences surrounding treatment decisions for patients at end-of-life also should be reimbursed.
2. Health information technology, such as the electronic medical record (EMR), offers promise for documenting advance directive care planning and making such information more readily available within and between patient care settings. Further, the EMR offers

a central repository for recording revisions to the plan as the patient's condition and preferences evolve. As EMRs are developed, the approach to documenting advance care planning and advance directives must be built into electronic systems so that this information is prominent and readily available for use in care decisions.

3. The 1991 Patient-Self Determination Act should be updated and expanded beyond the clerical function of providing advance directive forms to patients on hospital admission. Expanded requirements upon hospital admission should facilitate the components of advance care planning, to include initiating conversations, providing information and assistance to patients, facilitating patients' determination of their preferences, making sure patients' advance directives are properly stored and readily available once they are completed, and encouraging clinicians to follow advance directives.
4. Health professions education and training are critical to the knowledge, skills, and attitudes that future clinicians bring to the clinical care of patients with life-limiting conditions. Health professions education programs must include content on advance care planning. In addition, interprofessional training exercises should be required for students on conversations about treatment decisions, eliciting patient preferences and values, and working with families when patients are facing end-of-life care. Academic program accrediting bodies and health professions licensing bodies should expect and test for this content, including tests on clinical skills exams.

The Academy's Task Force on End-of-Life Conversations would be pleased to discuss these recommendations with the Board, or to provide expanded information at the Board's request.

Respectfully Submitted,

The American Academy of Nursing Task Force on End-of-Life Conversations

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¹National Consensus Project for Quality Palliative Care (2009). *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*. <http://www.nationalconsensusproject.org>

²National Quality Forum (2006). *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*. http://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

³ For example, the Hospice and Palliative Nurses Association, the National Hospice and Palliative Care Organization, the American Academy of Hospice and Palliative Medicine, and the Center to Advance Palliative Care.

⁴Teno, J.M., Mor, V., Ward, N., Roy, J., Clarridge, B., Wennberg, J., et al. (2005). Bereaved family member perceptions of quality of end-of-life care in U.S. regions with high and low usage of intensive care unit care. *Journal of the American Geriatrics Society*, 53, 1905-1911.

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