REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 4-I-10

Subject: Advance Care Planning

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Referred to: Reference Committee on Amendments to Constitution and Bylaws (Daniel B. Kimball, Jr., MD, Chair)

Advance care planning is the process of helping patients articulate what personal values and goals of care should influence treatment decisions in the event that they become unable to make their own choices and of assisting patients to identify who will be their decision maker under these circumstances. By encouraging patients to anticipate what they would want and the difficult questions that may arise, advance care planning helps ensure that the individual's own goals will guide medical care.[1,2] Giving patients this opportunity to express their values and expectations about care under various medical circumstances and to identify who should make decisions for them when they cannot do so themselves supports patient self-determination, facilitates decision making in difficult situations, and promotes better care at the end of life.

ENGAGING PATIENTS IN ADVANCE CARE PLANNING

All physicians have a responsibility to engage their patients in advance care planning, even though the degree of responsibility may weigh differently on different specialties. Patients themselves may be too shy or fearful to broach the subject of advance care planning. In fact, studies have shown that patients want the physician to initiate the process.[1,3,4] Specifically, physicians should encourage all their patients to reflect on and express their values and their vision of what is acceptable quality of life, regardless of age or health status—unexpected illness or injury can affect people of all ages. The ideal time for physicians to begin such discussions is prior to hospitalization, when the patient is relatively healthy, has decision-making capacity, and is able to engage these questions without the distractions of the difficult emotions, discomforts, and potential effects of treatment that are associated with critical illness or injury.[3] Physicians should be available to help patients complete formal advance directives and name health care proxies, or to refer them to other resources.[5]

Physicians should review goals for care and treatment preferences with the patient periodically and whenever there have been significant changes in the individual's personal or health status to ensure ongoing mutual understanding, and should urge the patient to communicate any changes to his or her surrogate and other intimates. Reaffirming the patient's goals of care will help ensure that any treatment decisions will be aligned with their values. If the patient has executed a written advance

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directive and/or formally designated a health care proxy (for example, through a Durable Power of Attorney for Health Care), these documents should be updated accordingly.

Physicians should be prepared to address patient concerns, expectations, and misunderstandings. Asking about previous experiences—in their own care or that of a family member or other intimate—may help patients put their feelings into words.[6] Physicians should assure themselves that they understand what a patient is saying—for example, by reflecting back to patients how the physician interprets what the individual has said.[6] Physicians may also work with palliative care specialists, social workers, or other similarly trained professionals to provide additional resources to their patients for advance care planning.

IMPORTANCE OF A SURROGATE DECISION MAKER

Physicians should encourage patients to identify whom they would want to have make decisions on their behalf and, ideally, to formally name that individual as their health care proxy. Physicians should also urge patients to include family members or other intimates in conversations about advance care planning, or at least to communicate their goals and preferences.

Engaging the patient's intimates can benefit all parties. Individuals who are close to the patient best understand the patient's values and are best able to make choices that reflect those values, benefitting the patient. Knowing the patient's goals and preferences makes it easier to choose among treatment options and helps reduce anxiety and fear in what are often difficult circumstances, benefitting the patient's surrogate.[1] Data indicate that decision makers who participated with patients in advance care planning better understood the patient's situation, were more comfortable, and were more confident in their ability to predict the patient's preferences.[7]

Bringing the patient's surrogate and other intimates into the process of advance care planning can improve the process of decision making later by making it easier for caregivers to communicate with the physician when decisions must be made. Studies have shown that caregivers refrain from asking questions not because they are unwilling to participate in decision making, but because they do not know what to ask or perceive the physician as unable or unwilling to discuss their concerns.[8,9] Finally, being aware of caregivers' concerns enables physicians to better prepare them for the death of their loved one.[9]

ADVANCE CARE PLANNING AND THE SPECIALTY PHYSICIAN

While all physicians should be available to support their patients in advance care planning, not all have the same degree of responsibility to engage directly with their patients in this area. Physicians who see their patients infrequently or on an episodic, non-life-threatening basis and who are aware that the patient has a primary care physician should confirm that the patient and his or her primary care physician, or other physician the patient sees more frequently, have addressed goals and preferences for future care. If the patient has not addressed advance care planning with another physician, the specialist should at least provide relevant educational materials and offer to follow up, whether by working directly with the patient or referring the individual to a social worker or other professional who could assist. In contrast, specialists who have close or long-standing relationships with patients, especially patients nearing the end of life, arguably have a stronger ethical responsibility and may be better positioned to guide patients through the process of advance care planning than even the individual's primary care physician.

Despite wide recognition that outcomes in end of life care are strongly related to advance care planning, and more particularly, the quality of communication between clinicians and patients, many physicians are still uncomfortable initiating or engaging in these discussions.[4] Any physician who is not experienced in advance care planning should take advantage of the variety of resources available.[10]

Advance care planning supports physicians in fulfilling their ethical responsibility to respect patients' right to participate in decisions regarding their care even when the patient lacks decision-making capacity[1]; it also eases the burdens on surrogate decision makers. Most importantly, advance care planning supports truly patient-centered care, helping to ensure that patients neither receive care that they do not desire nor are denied medically appropriate care they would want at the end of life.

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and that the remainder of this report be filed:

The process of advance care planning is widely recognized as a way to support patient self-determination, facilitate decision making, and promote better care at the end of life. Although often thought of primarily for terminally ill patients or those with chronic medical conditions, advance care planning is valuable for everyone, regardless of age or current health status. Planning in advance for decisions about care in the event of a life-threatening illness or injury gives individuals the opportunity to reflect on and express the values they want to have govern their care, to articulate the factors that are important to them for quality of life, and to make clear any preferences they have with respect to specific interventions. Importantly, these discussions also give individuals the opportunity to identify who they would want to make decisions for them should they not have decision-making capacity.

Proactively discussing with patients what they would or would not want if recovery from illness or injury is improbable also gives physicians opportunity to address patients' concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions. Encouraging patients to share their views with their families or other intimates and record them in advance directives, and to name a surrogate decision maker, helps to ensure that patients' own values, goals, and preferences will inform care decisions even when they cannot speak for themselves.

Physicians should routinely engage their patients in advance care planning in keeping with the following guidelines:

(a) Regularly encourage all patients, regardless of age or health status to:

i. Think about their values and perspectives on quality of life and articulate what goals they would have for care if they faced a life-threatening illness or injury, including any preferences they may have about specific medical interventions (such as pain management, medically administered nutrition and hydration, mechanical ventilation, use of antibiotics, dialysis, or cardiopulmonary resuscitation);

ii. Identify someone they would want to have make decisions on their behalf if they did not have decision-making capacity;

iii. Make their views known to their designated surrogate and to (other) family members or intimates.

(b) Be prepared to answer questions about advance care planning, to help patients formulate their views, and to help them articulate their preferences for care (including their wishes regarding time-limited trials of interventions and surrogate decision maker). Physicians should also be prepared to refer patients to additional resources for further information and guidance if appropriate.

(c) Explain how advance directives, as written articulations of their preferences, are used as tools to help guide treatment decisions in collaboration with patients themselves when they have decision-making capacity, or with surrogates when they do not, and explain the surrogate's responsibilities in decision making. Involve the patient's surrogate in this conversation whenever possible.

(d) Incorporate notes from the advance care planning discussion in the medical record. Patient values, preferences for treatment, and designation of surrogate decision maker should be included in the notes to be used as guidance when the patient is unable to express his or her own decisions. If the patient has an advance directive document or written designation of proxy, include a copy (or note the existence of the directive) in the medical record and encourage the patient to give a copy to his or her surrogate and others to help ensure it will be available when needed.

(e) Periodically review with the patient his or her goals, preferences and chosen decision maker, which often change over time or with changes in health status. Update the patient's medical records accordingly when preferences have changed to ensure that these continue to reflect the individual's current wishes. If applicable, assist the patient with updating his or her advance directive or designation of proxy forms. Involve the patient's surrogate in these reviews whenever possible.

(New HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than $500 to implement.

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