

EDITORIAL COMMENT

Advanced Care Planning Care to Plan in Advance*



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In 1976, California was the first state legally to sanction advance directives (ADs), in the form of living wills. Since that time, judicial and legislative actions have affirmed patients' rights in decision making at the end of life by standing strongly on the ethical tenets of patients' self-determination and autonomy (1). The 1990 Self-Determination Act mandated health care institutions to inform patients of their rights to refuse or discontinue treatment and *required* these institutions to ask patients whether they have ADs and to make those documents available (2).

The envisioned and actual impact of the legislation has been debated (3-5), but consensus grows that conversations and shared decision making between patient and provider are essential to quality care for patients and families (1,5-7). When the signed documents reflect the outcome of targeted communication between providers and families, ADs are associated with less patient anxiety and greater overall satisfaction with provider communication, more use of hospice, and less use of life-prolonging treatment and intensive care unit days at the end of life (4,7-9).

Although the urgency of these discussions is increasingly recognized, the *actual* numbers of sick patients who have any form of written AD (health care proxy [HCP] or living will) in their medical records remain disturbingly low (3,10,11). Studies find that fewer than one-half of all middle-aged or older individuals have any form of AD, even if they have a terminal illness (12,13).

The report by Butler et al. (14), in this issue of *JACC: Cardiovascular Interventions*, indicates that AD gaps may stretch even wider in patients with heart failure. Their timely investigation of more than 24,000 patients hospitalized with heart failure revealed that only 12.7% had documented ADs. To understand current decision processes better, these investigators sought characteristics associated with better response. Although rates were slightly higher in older persons, women, and those of higher socioeconomic status, even these groups still had <20% documentation. Furthermore, the percentage of completed ADs was <30% in patients considered highly likely to face complex decisions, as evidenced by do not resuscitate (DNR) status, palliative care consultation, or discharge to hospice. We echo the summons for action to address ADs in heart failure across all demographics.

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Failure to achieve evidence of substantial self-determination during the past 25 years extends across multiple diseases. The responsibility should ultimately be shouldered by all those who supervise long-term care for patients with chronic disabling illness. However, as the final pathway for many cardiac conditions and the most common cause of Medicare hospitalization, heart failure may serve as the ideal target for system reform, and those who provide care for patients with heart failure may serve as the vanguard for these efforts.

THE HEALTH CARE PROXY IS A PLAYER, NOT A PLAN

It is important to distinguish among multiple components in the process of advanced care planning. Although identifying the HCP is crucial early in advanced care planning, the HCP should perhaps

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stand apart from the other aspects of advanced care planning as being more universally relevant. Assignment of a proxy is a prudent act for anyone receiving medical care, with or without an underlying condition affecting life expectancy, not just for “advanced care.” The requisite information and education acknowledge that we are all at risk for unexpected events that could render us unable to make health care decisions for ourselves. Because there is no individualized medical review involved, instruction on establishing an HCP differs from other steps in advanced care planning not only as a more broadly applicable step, but also as one that can reasonably be performed by an office or hospital employee who does not have medical expertise. The study by Butler et al. (14) showed that even this simple step was uncommonly taken during hospitalization in the population with heart failure.

Even when appropriately completed, the HCP documentation serves only to identify the person who may have to make a plan for someone else. It does not provide any information on how to align that plan with goals and values and preferences held by the patient. Although the existence of an HCP may appear to lighten the burden of decisions for medical providers, those providers should recognize that it only shifts the burden toward the surrogates, sometimes with unbearable weight, if there have been no shared discussions between the patient and family about values, goals, and preferences.

DO WE LEARN ENOUGH FROM THE LIVING WILL?

It is ironic that the most commonly known documents considered to be ADs have become the HCP and the living will, neither of which provides guidance for the majority of decisions by families or providers. The living will does provide general evidence that the patient has considered the possibility of death and has chosen dignity over survival in the case of irreversible lack of meaningful personal participation. However, the situations requiring decisions, particularly in the hospital, are usually much more nuanced. Signing and witnessing the living will may mislead the patient and family into thinking that no further discussions are needed to align the proxy with the decisions that the patient would have made if conscious and competent. Examples of documents that provide more guidance are the Five Wishes, which can be completed by a patient and family, and the MOLST/POLST (Medical/Physician Orders for Life-Sustaining Treatment), which requires physician input and distinguishes between life-sustaining

therapies for a temporary condition and those for an indefinite duration.

DECISION MAKING IS A PROCESS, NOT A POINT

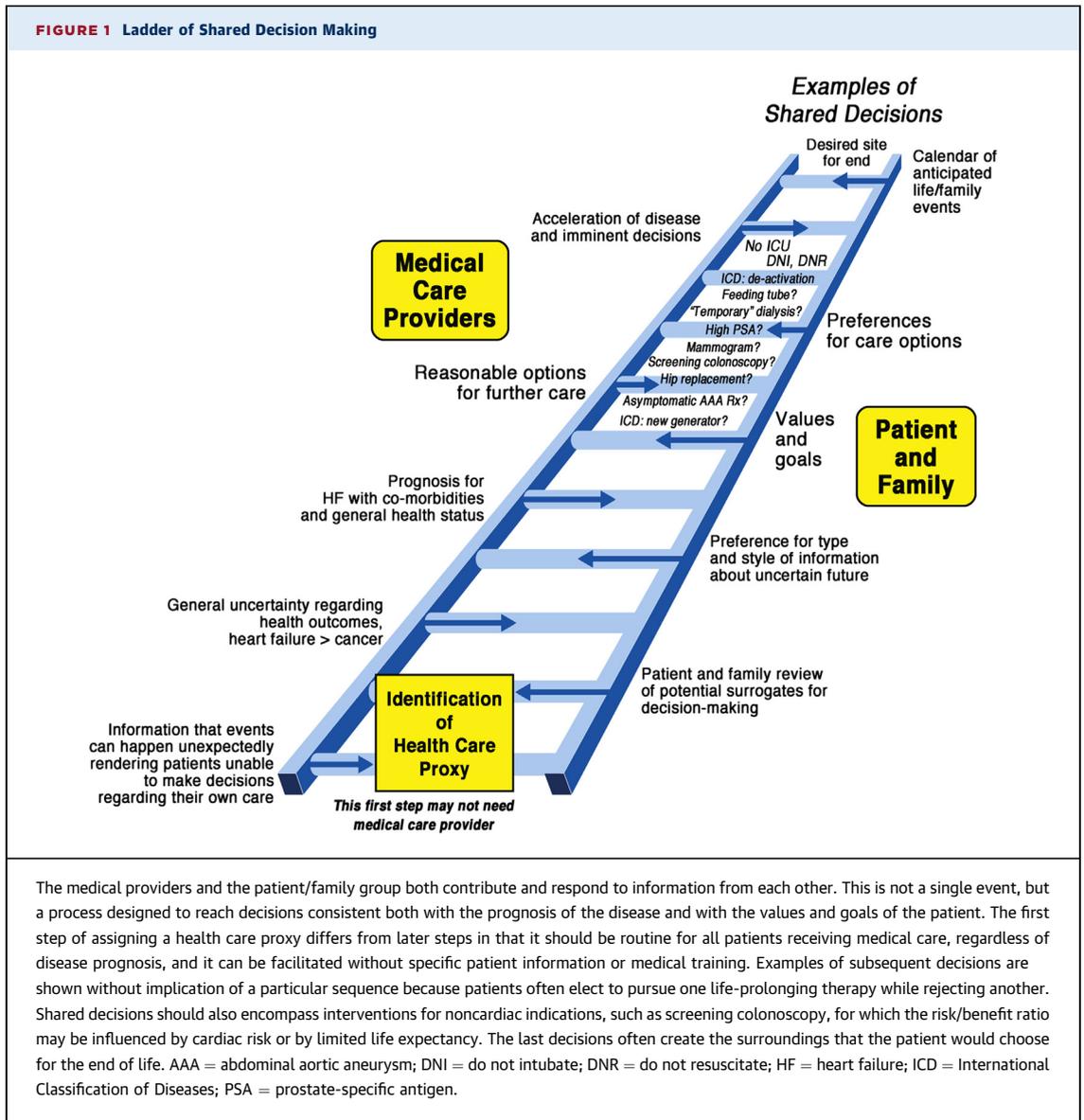
Advanced care planning is most effective as an iterative process that begins with the basic legal document of the HCP and uses this to launch shared decision making based on the goals and values of the patient and family (1,2,6). The cardiologist or, in some cases, the primary care provider supervising the heart failure care aligns to progress with the patient and family up the ladder of shared decisions (Figure 1). At every level, they interact by responding to previous information and adding new information.

STEPS FOR SUCCESSFUL ADVANCED CARE PLANNING

PRESENT INFORMATION ABOUT PROGNOSIS IN THE SETTING OF UNCERTAINTY. The first and foundational component of discussions focuses on a general understanding of disease trajectory and prognosis. Successful conversations begin with understanding how the patient prefers information to be communicated. Doctors should avoid extreme optimism or specific answers to the question “How long do I have to live?” instead offering broad ranges that include both early death and prolonged survival. Uncertainty should be acknowledged but not allowed to deter or deflect consideration of “what if...?” and “what could happen when...?” Despite reticence on behalf of physicians, patients, and families, it is well recognized that “difficult discussions now will simplify difficult decisions later.” Most patients report no added depression or anxiety after discussions of prognosis, and many cite the lack of communication around prognostic information as a complaint in end-of-life care (7,15,16).

ENGAGE THE PATIENT IN A DISCUSSION AROUND VALUES AND GOALS. Elicitation of life values and articulation of the goals and expectations for both life and for medical care are fundamental for effective decision making (1,5,7). Although many physicians feel more comfortable focusing on specific interventions such as cardiopulmonary resuscitation (CPR), conversations evolve to greater relevance when they begin with a discussion of a patient’s hopes and fears around these decisions. Documentation of a patient’s values and what quality of life means to the patient can serve as a foundational piece for a medical team for current and later reference, providing more guidance and power than an HCP without this conversation.

REVIEW AND RECOMMEND REASONABLE OPTIONS FOR FURTHER CARE. The providers should establish



their position as the guide for the discussion and summary of the decisions. Just as they recommend medication options, they should also make recommendations for decisions that will be need to be made presently, and then anticipated at the next level. For instance, “If your kidney function worsens further, we may want to consider whether or not you would want dialysis,” and more commonly, “At some point we will discuss deactivating the shock function of your implantable cardioverter-defibrillator.” Providers should also be candid about well-known therapies that are unlikely to be appropriate, rather than waiting for patients or families to ask. “Although cardiac transplantation is sometimes performed for heart disease like this, you would not have a good outcome

with this because...” However, the medical provider should resist the temptation to think out loud through a confusing catalog of specific interventions that would not likely be recognized by the patient.

Often one decision is linked to another. Selection of an aggressive intervention does not postpone the need to explore the more difficult questions. Consent for cardiac surgery, transcatheter valve replacement, or hip replacement should trigger discussion of the “what ifs” for complications that could threaten survival, independent function, or loss of decision-making capacity. Procedures intended to diagnose or treat silent clinical conditions with future risk, ranging from colonoscopy or surgery for an asymptomatic abdominal aneurysm, should be carefully

weighed against the prognosis of heart failure. The patients and families who are most comfortable with the decision process are those who are helped by providers with whom they have an established continuity relationship. It is unfortunate that many of these discussions are postponed until they have to be initiated by inpatient medical providers with whom patients and families share no history.

TIMING AND SUPPORT FOR DISCUSSIONS. The first discussions should ideally proceed in an outpatient setting during a period of clinical stability. The recent consensus document on decision making in advanced heart failure proposes a routine annual review for patients with advanced disease (1). Trepidation can be minimized if this review is scheduled as a regular event, perhaps linked to the yearly influenza vaccine. The annual review provides an opportunity to summarize not only the status of heart failure, but also the contributions of comorbidities to prognosis and quality of life. For the physician, the annual review also focuses attention on the currently available options for medical or device therapies, for which new recommendations may have emerged.

The current office visit schedules do not routinely allow the time, and sometimes not the space, for detailed discussions with patients and family members. Requiring intense listening and communication skills, and often emotional investment, these discussions also are hindered by strong disincentives in terms of work flow and remuneration. A major revision of coding and reimbursement is required to foster these interactions. This revision should recognize not only the initiation of the conversations, but also that serial discussions of similar length and intensity are usually necessary to move through the steps of advanced care planning, which is indeed a process.

REVISIT AND REVISE. In addition to the annual reviews, decisions may merit revisiting after other milestones, such as recurrent hospitalization, escalation of noncardiac comorbidities that detract from quality and expected length of life, or a move into an extended-care facility. Patients can change their preferences over time based on changes in health status, mobility, and other quality of life indicators (17,18). No assumptions should be made about a linear

hierarchy of decisions. For example, many patients deciding to forego CPR in case of an out-of-hospital cardiac arrest would accept resuscitation during general anesthesia for an orthopedic procedure to improve comfort and mobility. In general, however, patients with heart failure who declare a DNR status also express strong preferences toward quality of survival over length of survival (19).

WALKING THE PATIENT HOME

As medical options diminish, the discussion should focus more narrowly on how to maintain acceptable function and quality of life for individual short-term goals and how to honor a patient's trade-offs between time at home with family and treatment as an inpatient. It is useful to explore the feasibility and preference for death at home, as stated by a majority of patients. Even with the best planning, urgent situations can arise in the hospital that have not been anticipated. The family meeting at this time should minimize focus on interventions deemed medically futile and should establish consensus about the primacy of comfort. Most families wish to be informed and included in decision making, but most do not want to choose which therapies to continue and which to turn off and when. It should be medical care providers who shoulder the primary responsibility for the details of medical decision making at the end of life. To ensure the best outcomes, medical care providers should have previously guided the anticipatory process of advanced care planning and ADs that will ensure the best outcomes. However, it will require concerted effort not only from the medical community, but also from a broader coalition that includes patients, families, and those recognizing their mortality but not yet near it. A shared goal of these constituents is to increase public awareness and acceptance of the vital need for reform of the health care system to support the advanced care planning process.

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