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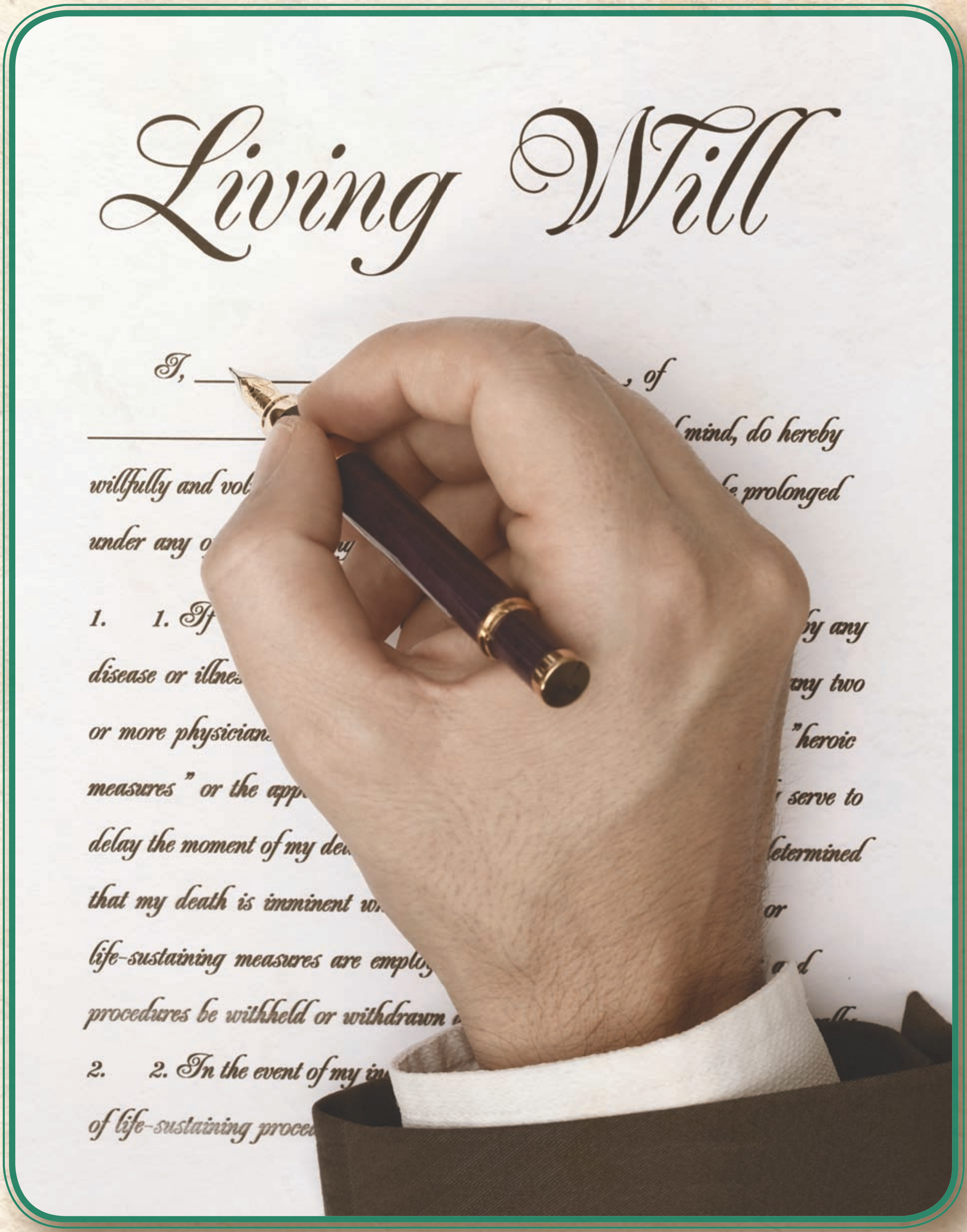

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Advance directives

Empowering patients at the end of life

***Abstract:* Advance directives were conceived as a prospective means of empowering patients to direct their own end-of-life care. Unfortunately, these directives have been inadequately incorporated into healthcare decisions due to less-than-optimal execution and implementation. The authors explore challenges to implementing advance directives and propose potential solutions.**

By Joan M. Nelson, DNP, ANP-BC and Tessa C. Nelson, BA

Advance directives (ADs) are written documents that allow an individual to express his or her wishes regarding the extent of healthcare intervention he or she consents to in the event of losing the capacity to express these wishes. Based on the ethical principles of autonomy and self-determination, which value an individual's right to make informed choices about his or her own care, ADs honor the right of a competent person at present to refuse potentially life-saving future medical treatment. The courts have upheld the rights of a competent adult to accept or refuse medical treatment based on the doctrine of informed consent.[1] Instructive directives include living wills, which describe the patient's goals and wishes for artificial nutrition, hydration, intubation, and other end-of-life care in the event of a terminal condition and the patient's inability to speak for him- or herself. Proxy directives are used to appoint a surrogate decision maker who is charged with understanding and expressing the wishes of the represented patient and acting in the patient's best interest.[1]

ED providers generally consult with patients and families about ADs when an acute change in patient condition requires an intervention that will have an uncertain effect on quality of life. Examples of these situations include decisions related to treatment of pneumonia in a patient with end-stage dementia, ventilator care for a patient with an exacerbation of chronic obstructive pulmonary disease (COPD), or an anoxic brain injury. An AD can help the surrogate and healthcare providers in the decision-making process in the event of persistent vegetative states in which the cortex, midbrain, and brain stem are not communicating and the patient is unable to perceive or communicate with his/her environment.[2]

Patients who have completed an AD and discussed this directive with their healthcare providers and family members express less anxiety and more empowerment concerning the end of life. Advance-care planning, in which a patient's values, goals of care, and understanding of current health condition are discussed, have been shown to increase surrogate decision maker confidence in his or her ability to represent the patient in end-of-life decision making.[3,4] Additionally, in an analysis of survey data of 3,746 subjects from the Health and Retirement Study, Silveira, Kim, and Langa found that patients with ADs were likely to receive care that was consistent with their preferences.[5]

The living will was first proposed in 1969 by Luis Kutner.[6] The Patient Self-Determination Act of 1990 was then crafted to ensure that patients have the right to participate in and direct their own healthcare decisions. It requires any healthcare institution that receives Medicare or Medicaid funding to inform patients of their rights to state their wishes for end-of-life care in a living will and to appoint a surrogate decision maker (medical power of attorney). Many believe that only the terminally ill or those who have chronic illnesses need advance-care planning, but the well-publicized cases of Nancy Cruzan, Karen Quinlan, and Terri Schiavo put the importance of advance-care planning, even for the young and healthy, on the national stage.

Keywords: advance-care planning, advance directives, end of life, living will, Patient Self-Determination Act

Barriers related to ADs

In practice, of the approximately 30% of older adults who will lack the capacity to make their own contemporaneous end-of-life choices, only two out of three will have ADs indicating personal preferences or naming a surrogate decision maker.[5] When younger adults are included in the sample, only 18% to 36% of U.S. adults have ADs, and only one out of three of this population's primary care providers (PCPs) were aware that such a directive existed.[7] Fewer still receive input from their healthcare providers when creating their ADs.[3] According to the 2010 U.S. Census Report, 28% of the population is not part of the White majority group.[8] Ethnic minorities are less apt to complete ADs due to cultural differences in ideas about death and end-of-life communication and mistrust of the healthcare system.[3,9,10]

Healthcare system barriers. PCPs are encouraged to complete ADs with patients and are evaluated based on quality standards from the Agency for Healthcare Research and Quality (AHRQ), in part, based on the percentage of patients in their practice over 65 who complete ADs.[11-13] Proponents of this approach stress the importance of the ongoing relationship between the PCP and patient. In reality, however, hospitalists are generally the end-of-life caregivers, and the PCP is often unaware of scenarios unfolding in the hospital. Effective communication between providers working in inpatient and outpatient settings is currently lacking, and PCPs are often unaware even of patients' admissions to emergency or inpatient facilities. Annual visits to a PCP currently provide the only financial structure based on Medicare payment codes in which healthcare providers can discuss ADs, but there are many competing goals for this limited-time visit: providers must discuss and order routine screening exams; they must provide health maintenance and health promotion services; and they must educate. In short, PCPs are increasingly pressed for time as they try to balance their patients' access to services and constant fiscal pressures.

The American Hospital Association encourages completion of AD in the event of hospital admission; the hospital collects an AD which, because it is more current than an extant document on file at the PCP office, takes priority. Most hospitals not only collect pre-existing documents but will encourage completion of a document if the patient does not have one. The prioritization of the newer AD creates questions of propriety: on one hand, given that the hospital-based AD is collected at a time of great personal and family stress, it may reflect a spontaneous emotional response to an emergency that fails to reflect the deep-seated values of the patient; on the other hand, the AD collected in the PCP setting is created soberly and reasonably, but is it realistic to believe that exigent decisions should be guided only by cognitive reasoning, devoid of the emotional realism that accompanies the hospitalization? After all, theory without corresponding experience is mere intellectual play, and any general form created in the comfort of a PCP office applies to myriad of situations rather than being tailored to the single, actual, pertinent one.[14]

Provider-level barriers. These general ADs are often poorly implemented by healthcare providers due to a lack of adequate specificity.[15,16] However, the document cannot feasibly be reviewed by providers in a healthcare emergency when detailed goals are outlined in a living will. Additionally, AD documents are often unavailable to healthcare providers and family members because patients store them in a "safe" place without providing access to, or information about, the location of the documents.[12]

The timing of putting an AD into practice is complicated as well. ADs often stipulate that they are to be implemented in the event of "irreversible" condition, which is not always predictable during the emergency. Most AD laws allow withdrawal or withholding of life support in cases of "terminal" illness, defined as a life expectancy of less than 1 year, but accurate prediction of life expectancy is difficult, and interpretation of "terminal" falls to the individual provider (with a second medical opinion).[1] Physicians inconsistently honored the patients' ADs when provided with several scenarios in which patients with ADs encountered medical crises.[17] The perceived reversibility of the medical condition and the amount of time since the AD was made were important factors in the decision to disregard the AD.[17]

Medical decision making by healthcare providers is often influenced not only by patient preferences but also by social details surrounding the medical crisis (for example, family preferences, fear of litigation, financial constraints, and the healthcare provider's own values).[18] Qureshi et al. discovered that ADs did not significantly influence providers' provision or withholding of most treatments in a study of physician treatment decision making for patients with acute stroke.[16] Though most healthcare providers support the use of ADs, implementation may be complicated for providers grappling with ethical principles, such as paternalism (the idea that the provider knows best), beneficence (the promotion of well-being), and nonmaleficence (the avoidance of harm)—all of which may be perceived as conflicting with the patient's right to autonomy.[19] Of course, it is the PCPs' professional responsibility to use their advanced healthcare knowledge to counsel their patients. The problem comes in separating advanced healthcare knowledge from personal values, which could limit patient autonomy. This ability to separate patient from provider values becomes overly complicated when, due to illness, the only access to patients' wishes is through a written document that must be interpreted. The Agency for Healthcare Research and Quality studies have found that physicians are poor predictors of patient values, often erring on the side of undertreatment.[3]

Surrogate-level barriers. Due to the unpredictability of end-of-life circumstances, some authors have argued for the importance of surrogate decision makers.[20] However, in contrast with healthcare providers, surrogate decision makers often choose more aggressive treatments than the patient would.[21] This is not surprising, since the proxy is generally charged with making any and all end-of-life decisions although ADs and prior discussions are most often limited solely to life support. Furthermore, surrogate decision makers may be too emotionally distressed to provide adequate direction or guidance, and they too are influenced by their own values and beliefs. Multiple studies have documented the lack of success of programs designed to improve congruence of surrogate and patient decision making despite a wide variety of interventions intended to improve substituted judgment (for example, scenarios, value-based forms, and surrogate-patient communication).[22] In sum, completing ADs does not effectively reduce surrogate decision maker stress or enhance communication between patients and surrogates.[23,24]

Patients may struggle to understand their own goals and values related to end-of-life care. It is not unusual for patients to hold seemingly contradictory values and wishes related to medical treatments. Ohnsorge, Keller, Widdershoven, and Rehmann-Sutter argue that ambiguity is understandable when negotiating complex, multidimensional experiences.[25] Perspective dictates verdict when addressing a faceted situation: looking at alleviation of family members' caregiving responsibilities or at avoidance of pain will generate one set of end-of-life decisions; looking at commitments to loved ones or maximizing/relishing remaining moments will yield quite another set. Eliciting blanket "preferences" for end-of-life care can obviate the nuanced understanding of patients' true goals and values.

Patient-level barriers. ADs assume that patients can predict their goals and values attached to a future end-of-life time. This assumes that these goals will remain constant. Does the "self" remain constant over the course of a lifetime? Significant life events change an individual's thoughts about specific issues. Learning, growth, regression, change: all of these are part of the human condition. Several studies have demonstrated that, even without a change in condition, a significant number of patients changed their decisions about life-sustaining treatments over a period of 18 months to 2 years.[26,27]

Whether or not an AD can capture a person's end-of-life wishes with fidelity hinges on whether surface changes have the ability to change the core of one's being or if there is something constant about one's beliefs that could be accessed by and preserved in a meaningful AD. A change in thought and values need not be the same. For example, the patient is more likely to recognize that quality of life and functional deficits can coexist, concomitantly tending to desire more life-prolonging measures than previously anticipated as functional status declines.[28,29] The patient has not changed his or her values in this example; rather, the patient simply has realized that his or her understanding of functional deficit had been incomplete, and subsequently, having experienced the deficit, has realized that quality of life had not been altered as profoundly as had once been predicted. Therefore, while the patient in this case altered the AD, the nature of the patient's "self" had not changed. Additional experiential data had recalibrated patient cognition. However, the question of whether or not the "self" changes with altering circumstances is at its most complicated when dealing with issues such as dementia. If the mind itself changes, is the person who made the AD in the past the same person to whom the AD is now being applied? How could nondementia-experiencing individuals access or understand a demented individual's "self" in order to make decisions for him or her? Some ethicists and healthcare professionals argue that the "self" changes so sufficiently as to make ADs inapplicable to the changed person.[30]

Summary of barriers

Criticism pertaining to ADs ranges from the somewhat clerical (for example, where to store the AD so it can be found in case of emergency) to the truly philosophic. Since the directive is made in advance of actual medical crisis, it has been argued that patients are acting without the benefit of informed consent.[30] Decisions are made without knowledge or understanding of the underlying social, physical, or emotional conditions that may influence the decision making at the time it is required (see *Barriers related to ADs*). Whether such an understanding is possible or how it may be most approximately reached is the aim of this inquiry.

Proposed solutions

Many of the complications regarding ADs and end-of-life decision making could be resolved with a cultural shift toward approaching and discussing death more openly. It is likely patients would have clearer ideas about their beliefs and a better understanding of the actualities people face when dealing with death and dying if death were a more common topic of conversation. Interventions within cultural centers and churches in order to facilitate culturally-sensitive dialog about end-of-life issues may help people overcome cultural and racial barriers. Of course, this kind of shift in custom is only partially the responsibility of medical providers; the larger burden is on culture as a whole. There are, however, medical community actions that would alleviate some of the difficulties in end-of-life decision making.

Logistics of advance-care planning. It was previously stated that there were complications regarding whether the AD should be completed in an emergency scenario or with the

PCP; neither of these is ideal as a stand-alone option. There is evidence to support the efficacy of a nonprimary care-based approach to discussing ADs. Nurses and allied health workers in an inpatient facility who had been trained in advance-care planning were effective in securing advance-care plans, in helping to appoint surrogate decision makers, and in respecting care wishes at the end of life.[4] These authors describe a program in which advance-care planning was discussed with patients and families with healthcare provider consult during hospital stays in Melbourne, Australia. A successful acute care program such as this would require a hospital stay long enough to allow for the advance-care discussion. Average hospital lengths of stay are slightly longer in Australia than in the United States (6 days compared with 4.8 days).[31] Better coordination between acute and primary care settings could permit similar timely discussions, either before or after a hospitalization, when treatment choices are known to the patient, but the stress associated with the immediacy of the procedure is absent.

Barriers related to ADs

Patient-level barriers

- AD not completed
- AD not accessible to family and provider when it is needed
- Wishes change over time
- AD created at time of either significant stress or no experience with condition
- Lack of clarity about one's own wishes
- Change in "self" with conditions such as dementia

Provider-level barriers

- Lack of time and reimbursement for regular AD discussions
- Lack of access to or knowledge of AD
- Lack of specificity of AD
- Unknown nature of disease trajectories
- Fear of litigation
- Value conflict

Surrogate-level barriers

- Conflict between values of patient and surrogate
- Unknown situations arise for which there is little guidance by AD or prior conversations with patient
- Generally favors more aggressive treatment than patient would choose
- Emotional distress due to surrogate need to make weighty decisions in time of emotional stress

System-level barriers

- Poor communication between primary care and acute care settings
- AD not translatable into medical orders
- AD discussions not reimbursable
- ADs for all patients over 65 not appropriate as quality indicator

Table created by authors.

Timing of AD discussions is likely the key to meaningful completion of documents. Discussions shortly after a hospitalization that resulted from complications of a chronic condition will likely be fruitful because the patient fully understands the risks and benefits of hospital treatment, having just experienced it. Though the courses of many chronic illnesses are predictable, it is not until the patient has experienced some of these predictable sequelae that he/she can fully engage in making decisions about these disease complications. A documentation mechanism that translates these wishes effectively into orders is imperative when patients are truly able to engage in meaningful discussions.

The POLST: translating goals into medical orders. The Physician Orders for Life-Sustaining Treatment (POLST) is a mechanism that healthcare providers can use to document patient end-of-life wishes and that has been implemented in most states. Despite the misleading name of the POLST, nurse practitioners are able to sign these forms in most states.[32] The POLST contains information about patient wishes for the level of desired medical intervention, including hospitalization, resuscitation, ventilation, artificial nutrition/hydration, intubation, and antibiotics. It should be reviewed whenever the patient has a change in condition, is transferred to another care facility, changes healthcare provider, or wishes to amend previous treatment decisions. The wishes detailed in this document are more easily converted to medical orders than are traditional living-will documents and; have therefore, been shown to result in better correlation between medical care and patient wishes at the end of life.[15] The document, unlike most hospitals' do-not-resuscitate orders, extends beyond a single hospital admission or care setting and is valid in both hospital and community settings. While healthcare providers consider the POLST to be a successful AD, it is currently used only with patients who have a life expectancy of less than 1 year due to either chronic illness or advanced age.

The demographic it serves is the most important factor in the POLST's success. Chronically ill patients who have suffered near-death experiences or who have a basis for predicting likely scenarios surrounding their deaths—as opposed to patients whose deaths are unable to be corralled into any kind of statistically probable bracket—have a more complete idea of both their emotional and rational responses to the prospect of death. Persons with this integral experience are obviously better able to make competent, illness-related decisions. A patient, for example, who has end-stage COPD and who has had multiple pneumonia-related hospital admissions requiring mechanical ventilation can understand the risks and benefits of this treatment and make pragmatic decisions about his or her wishes for continuing this form of treatment in the future. All patients with potentially terminal illnesses should have the opportunity to have these discussions with providers and surrogate decision makers and be encouraged to complete the POLST.

Avoiding futile care. The 1983 case of young Nancy Cruzan was the impetus for ADs. Cruzan was in a persistent vegetative state due to a motor-vehicle accident—a person who, clearly, would not be permitted to file a POLST.[27] This case and those following it have led to a shift toward promoting ADs, regardless of age or medical history.

Systemic changes can rectify AD-centered problems by ridding families and surrogates of the decision-making burden in cases where poor patient outcomes are practically inevitable. There are end-of-life situations when a healthcare provider uses medical judgment to cease life-saving efforts, regardless of the AD. For example, the provider makes a medical decision to stop resuscitation after a given duration of providing CPR without a response. The 1980 Uniform Determination of Death Act defined death as the cessation of circulatory and respiratory functions or irreversible cessation of brain function.[6] In the case of brain death—an irreversible, complete loss of brain function—most healthcare organizations have policies wherein organ-sustaining support measures are withdrawn within 48 hours.[2]

Often, end-of-life decisions involve extremely high treatment cost and extremely limited quantity-of-life or quality-of-life benefit. For example, the chance of regaining consciousness is only 6% if a patient is in a persistent vegetative state for 3 months after an anoxic event; this chance for recovery drops to 1% after 6 months of a lack of consciousness.[2] Aggressive treatment for patients with nonsmall-cell lung cancer, compared to palliative care alone, is associated not only with diminished quality of life and greater expense but also with decreased life expectancy.[33]

AD policy discussions are highly controversial despite the poor outcomes pursuant to aggressive end-of-life care and the fact that a quarter of the Medicare budget is directed toward care of patients in their last year of life.[10]

Implementing and sustaining treatments with little known benefit are inconsistent with current healthcare practice. Healthcare providers are educated generally to provide care that is supported by evidence. Medical and surgical treatments that have not demonstrated efficacy are generally neither utilized nor reimbursed. If this principle was applied to forms of end-of-life care with clearly minimal treatment benefits, providers and organizations could adopt policies prospectively, as they do in the case of brain death, and eliminate the need for last minute, stressful decision making. Of course, there are situations in which these risks and benefits are subjective and dependent on patient values.

Unique issues with dementia population. The population experiencing dementia is yet another group for whom ADs are important but problematic. Although the disease trajectory is fairly predictable in most types of dementia, the newly diagnosed person will have insufficient experience on which to base reasoned decisions and will be different from the person for whom the directives will ultimately be implemented. Entrusting these decisions to a surrogate is also problematic, as discussed earlier. Value-oriented discussions between surrogate and patient over the course of a lengthy relationship will likely position the surrogate as the best proxy decision maker. Involvement with the Alzheimer's Association and community groups could familiarize patients with all stages of dementia along with impending future decisions, allowing for more pointed dialog about real choices that may eventually be encountered. The surrogate needs to constantly assess quality of life in order to make decisions that comport with patient values during the end stages of dementia.

Having a voice

Patient-centered care compels healthcare providers to seek understanding of patients' values and wishes and to honor those values and wishes. ADs are an attempt to ensure that patients have a voice in their end-of-life care, but they are fraught with operational and theoretical problems. The ability to engage in meaningful AD discussions depends upon prior experience with situations similar to those in which decisions are to be made. Evidence supports the conclusion that the current system of obtaining and implementing ADs is inadequate, but suggestions for alternative approaches are lacking. The authors have suggested different strategies for end-of-life/AD discussions for patients with dementia, for those with advanced chronic illnesses, and for those who have experienced unexpected traumatic events. The discussion is based on existing scientific evidence and an exploration of historic philosophical literature, and it is intended to serve as a springboard for more discussion and idea-generation. These discussions and ideas should then entail tests aimed at developing a workable, evidence-based process for end-of-life discussions and ADs.

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