

Advance Directives and Advancing Age

The major challenge to his proposal was possibly not evident to Louis Kutner when he first proposed the notion of a “living will” nearly 30 years ago.¹ The idea of planning ahead for medical decisions in the event of illness that entails decisional incapacity must have seemed a solid one, being analogous to the well-accepted practice of making an estate will, but the challenge turned out to be a debilitating one. Based on the premise that people and their views change, it asserted that unstable advance preferences are not authentic in eventual situations. Supporters of advance directives pointed out that advance wishes are at least as authentic as anything else available when the patient cannot speak for him or herself. In this issue of the *Journal of the American Geriatrics Society*, Straton et al. extend existing knowledge to an aging population showing how declining physical function predicts a trend toward increased interest in life-sustaining treatment in an advance care planning scenario.² This correlation is stronger in subjects who also report having some depression.³ Which side of the debate does this lend itself to? Arguably, neither. Instead, it helps to resolve the debate.

THE DEBATE

The living will movement enjoyed popular and legal support. By 1990, the Federal Patient Self Determination Act had been passed, requiring that patients be asked at the time of enrollment in or admission to a healthcare service entity whether they had advance care plans.⁴ Today, all states and the District of Columbia have statutes that support designation of a proxy decision-maker or use of written instructions.⁵ Furthermore, the Supreme Court has endorsed the protection under common law of personal statements about wishes for care in the event of decision-making incapacity and the right to receive palliative care.⁶ Case law has underscored the possibility that care may err toward excessive or insufficient intervention, and generally makes the patient's wishes the main standard of appropriate care.^{7,8}

Nevertheless, patients and families find it hard to imagine ahead and clinicians find it difficult to feel bound by prior decisions that might have changed.⁹ Philosophers provided the scholarly counterpart to this experience; they could not fully justify precommitment when real-time autonomy was the overriding goal.¹⁰ A related, compelling, and repeated observation from the disability community found that subjective appreciation of their own quality of life does not decline with level of disability as much as nondisabled observers tend to assume.¹¹ I recall the late 1980s, when doctors working in emergency wards, performing resuscitations on people with little hope of survival, found the process

unsettling and used to joke that to avoid such a fate they wanted a “do not resuscitate” or “comfort care only” order stamped on their own body. Some of those doctors are close in age to the peer group that Straton et al. studied. If extrapolation of these findings holds, it would seem that when we face declining physical function ourselves, life-sustaining interventionist approaches do not look so bad. Although Odysseus may have been right to ask that he be bound to the mast of his ship to prevent himself from succumbing to the Sirens' temptations,¹² we regular, aging mortals may have less to resist than Odysseus had and more reason to change our minds in favor of life-sustaining interventions. It should be no surprise that people can adjust to disabled states, find gratification and quality in those states, and do not lose the will to live even (or especially) when mildly depressed.

Siding with the law, other commentators pointed out that we bind ourselves to a chosen future in many ways (e.g., engaging in a business contract, getting married).⁸ That these commitments can be renegotiated or rescinded does not differentiate them from advance care plans. Advance care plans can be revised until the last moment of decision-making capacity too. And designation of a proxy can, in many predrafted forms or by adding a personal statement, include a directive that the proxy can make revisions after the patient's capacity is lost.¹³ Further guidance for their use, to enhance the chance of valid expressions that are as durable as possible, makes advance care plans even more reasonable.^{14,15}

One investigator has argued that advance directives should be valid but only within constraints set by general standards for care of decisionally incapacitated patients.¹⁰ Others have argued, for the most part compatibly, that advance directives should provide a portrait of values, goals, and preferences that can be used as one source of information among others to guide substituted judgment decisions (decisions the patient would have made had he or she been able to). Similarly, commentators have argued that advance directives will work best if they are more advisory than binding. In this vision, advance care plans should emerge out of discussions that happen periodically over the course of an illness—or even a lifetime—between the patient and family. Healthcare providers should provide consultation so that, when it comes to implementation, the directives make medical sense and are acceptable within norms of medical practice.¹⁴

A PRACTICAL APPROACH

The studies by Straton et al. have brought practical wisdom—which seems appropriate given that they

population they studied is one of elders—to the situation. The practical wisdom is this: confidence that the patient's preferences are stable will rise if sources of instability are addressed. By providing more data to predict what may lead a person to change his or her advance care planning preferences, two approaches become possible: identifying when to review advance care plans and identifying populations for whom stability of preference may be difficult to achieve or may predictably lean in one direction.

Straton et al.'s findings indicate that elderly patients with loss of function since their last advance care planning may benefit from a review and update of their preferences. They also reveal that, if a patient has had loss of function, perhaps with some mild resulting depression, it is reasonable to think that his or her prior preferences may have become more interventionist had they been updated.

Extrapolation and interpretation rather than direct simplistic application of prior preferences to real-time decisions is always necessary. The predictors of change that Straton et al. have confirmed in an aging population can make this extrapolation and interpretation more formulaic, and probably therefore more reliable, and can enhance existing formulaic approaches.^{2,16,17} Commentators have suggested other predictors of change or stability: life circumstance changes such as marriage, bereavement, or childbirth or existential changes such as growth in spirituality or conversion experiences. Some evidence exists that review of decisions makes them more stable, whereas recent hospitalization may add instability.¹⁸ To establish whether these or others are indeed predictors of preference change, further research is needed.

The role of depression, both mild and severe degree, in preference stability and validity needs more research. Significant depression is generally understood to limit autonomous decision-making authority. The subjects in Straton et al.'s study, being competent to be study subjects, must have been largely decisionally competent. They can be reasonably understood to have been reporting what was likely mild depression, being triggered perhaps by loss of physical functioning or perhaps by age-related declining social role. Whether mild depression limits preference authenticity or represents only a source of normal-range preference instability can be discerned in the clinical patient care setting by treating the depression and following the standard criteria for decision-making competence. If a patient was competent at the time to complete the advance care planning, then the preference statement is valid, and any vacillation is just one more factor to consider in the overall process of applying advance planning preferences to a real-time situation.

Another aspect of preference stability relates to preferences for goals of care, rather than treatment-specific decisions. Although we know that goals of care can predict specific treatment choices reasonably well,¹⁹ we do not know whether goals are more or less stable over time than specific treatment choices. This question is important for the palliative and hospice care movement more generally because it believes that, when the care goals (which can range from cure through prolongation of life to comfort only) are clear and shared by all parties, the specific decisions usually fall into place coherently and comfortably. Although this is common sense, and clinical experience seems to support it, research that evaluates these assump-

tions and provides guidance on how to ascertain and use goals for care is still largely uncharted territory.

In sum, Straton et al. have taken another step toward resolving one of the major challenges to advance care planning; they have provided practical insight into how predictable care preference change can be used to improve the authenticity and efficacy of the process. Other challenges remain for the optimal use of advance care planning, but this approach to assisting in care decisions for the event of incapacity will probably remain for the indefinite future. It is time to shift from debating advance care planning's merits toward serious research that will help patients, their families, and clinicians to use the process optimally.

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