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Notes from the Editor

Advance Directives/Care Planning: Clear, Simple, and Wrong

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> ''For every complex problem there is an answer that is clear, simple, and wrong.''
> —H.L. Mencken

I HAVE BEEN THINKING a lot recently about the eerily prophetic words of the early 20th century journalist and satirist, H.L. Mencken, in the midst of New York's COVID-19 pandemic.[1] As I read Waller and colleagues article ''Impact of Advance Directives on Outcomes and Charges in Elderly Trauma Patients'' in this issue of *Journal of Palliative Medicine*, I could not help but think of Mencken's biting satire again—quoted at the top of my editorial. Yet again, 30 years after the Patient Self-Determination Act of 1991, we have a report that documents that the vast majority of adults (this time trauma patients 55 years and older) have not completed an advance directive, and for those who did, the advance directive had no discernable influence on the care received. As of May 2018, 80 *systematic reviews* of advance care planning covering >1660 research studies had been published[2] and the National Institutes of Health and the Patient-Centered Outcomes Research Institute had funded >750 research studies at a cost of >$300 million in taxpayer money (an average of $1 million/year). Foundations have spent untold millions. What evidence has all of this research and money wrought? The >1660 studies and 80 systematic reviews on advance directives/care planning have produced only limited and low-quality evidence that advance directives/care planning can actually result in changes in patient, family, clinical, utilization, or financial outcomes.[2] Like the study published in this month's journal, the majority of high-quality research has failed to find a strong link between advance directives/care planning and outcomes of importance. Similarly, despite 30 years of diverse interventions and programs, two-thirds of adults do not have an advance directive (an imperfect yet reasonable surrogate for occurrence of an advance care planning discussion).[3]

Goal-concordant care is the foundation of palliative care, indeed of all health care. All of us in health care try to help our patients achieve the goals that are of importance to them. Occurrence of unwanted treatments (such as tube feeding or cardiopulmonary resuscitation) near the end-of-life in the 1970s led to a neat solution: advance directives/care planning. The concept behind advance care planning is simple and straightforward. If patients can articulate their values and goals, identify what treatments would align or not align with those goals, and those wishes could be documented or shared with a trusted surrogate decision maker, clinicians would honor these preferences and patients would avoid unwanted treatments. The problem, however, is that decisions near end of life are not simple, not logical, and not linear. They are complex, uncertain, emotionally laden, and can change rapidly with changes in clinical conditions. The history of advance directives/care planning reminds me of my family's 1975 Ford Pinto—a car with a fundamentally flawed design yet one whose every broken part we dutifully repaired for five years until it was finally and mercifully sold for parts. Why do we keep waiting for advance directives/care planning to work?

Over the past >30 years, since the creation of the first living will, our research has identified multiple flaws with advance directives/advance care planning and made multiple repairs. Not all clinical situations or patient conditions can be envisioned in advance—enter the health care proxy to supplement the living will. Patients do not communicate with their health care proxies, inform them that they are proxies, or know what to tell their proxies—enter nonphysician or lay advance care planning programs (Respecting Choices, ''Death over Dinner,'' ''The Conversation Project,'' ''Go Wish''). Existing preferences are not acted upon—enter medical orders for life-sustaining treatments (MOLST). Advance directives are inaccessible when needed—enter Electronic Medical Orders for Life-Sustaining Treatment (e-MOLST). Preferences may change over time—enter longitudinal advance care planning. Doctors do not have time to discuss end-of-life wishes with patients—enter billing codes for advance care planning. Doctors do not know how to have these conversations—enter serious illness conversation guides. Each of these ''repairs'' has yet to consistently or measurably improve goal-concordant care.[2–6]

Advance directives/care planning is unlikely to ever achieve reliable occurrence of goal-concordant care. First,

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goals of care conversations require sophisticated knowledge of prognosis, disease and associated comorbidities, and treatment outcomes—knowledge that most patients, families, and advance care planning counselors do not have. Second, preferences that patients express when they are well or in hypothetical scenarios typically do not reflect the complexity, emotion, or interpersonal elements of real-time decision making. Adaptation to physical (and cognitive) disability, desire to live to see a future event (e.g., a wedding, bar mitzvah), or fear of death when the hypothetical becomes real, all can influence real-time decision making in a way that cannot be accounted for in advance. Third, patients often do not want to talk about their wishes for fear that talking about bad outcomes will make them happen, desires to avoid distress associated with envisioning adverse outcomes, concerns that they will be ''written off'' as not worthy of intervention if they have an advance directive (e.g., DNR = do not treat), or because they really do not know or cannot anticipate what their wishes will be in some unknown and unfathomable future. My 84-year-old father refused to engage in any advance care planning discussions before his nephrectomy for kidney cancer because it ''wasn't necessary'' despite the fact that two of his children were physicians, one of whom had spent a decade conducting advance directive/care planning research. Fourth, conducting good serious illness conversations is not simple. Like learning a surgical procedure, it requires specialized knowledge and skills, training with feedback from experts, and ongoing practice.[7] Finally, and perhaps most importantly, goal-concordant care will not be achieved until health care is not overwhelming driven by the profit motive and financial incentives do not influence decision making so strongly.

Some of my colleagues and fellow researchers have suggested that we are making progress, that the search for the holy grail of goal-concordant care is within our grasp, and that we just need more research and a slightly different intervention. Others suggest that advance directives/care planning is inherently good and that we just have not chosen the right outcomes to measure or those outcomes are simply not measurable. Perhaps this is true. Certainly, there are some populations in which advance directives play important roles such as for nursing home residents with advanced dementia or frail older adults living in New York City during the COVID-19 pandemic surge. Yet, I cannot help but wonder where we would be now if only half of the research money spent on advance directives/care planning had been spent on breathlessness research, on developing models of community or rural palliative care, on improving dementia care, on reducing disparities, on enhancing access to palliative care, or training health care workers in core communication knowledge and skills. Given the evidence gaps in our field, is it fair to patients and families to continue to focus our limited research workforce, finite effort, journal space, and scarce research, and clinical operational dollars on advance care planning while ignoring other needs? Isn't it time to finally acknowledge that advance directives/care planning is ''an answer that is clear, simple, and wrong?''

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