

Response to Morrison, Advance Directives/Care Planning: Clear, Simple, and Wrong (DOI: 10.1089/jpm.2020.0272)

Carole Montgomery, MD,¹ Susan E. Hickman, PhD,² Christine Wilkins, PhD, LCSW,³
Erik K. Fromme, MD,⁴ and Stephanie Anderson, DNP¹

Dear Editor:

IN HIS RECENT NOTES from the editor, Dr. Morrison takes aim at advance care planning (ACP), comparing it with his family's old Ford Pinto and borrowing a phrase from H.L. Mencken dubbing it "clear, simple, and wrong." Although we are at least as disappointed as Dr. Morrison at the state of the science on ACP, we believe his conclusions to be as faulty as his family's volatile lemon of a car. Far from clear, simple, and wrong, ACP is unclear, complex, and...right?

Existing research does not support the notion that ACP is clear or simple. The Overview of Systematic Reviews of Advance Care Planning¹ referenced by Dr. Morrison identified tremendous heterogeneity because researchers used many different definitions of ACP, in many different settings, with many different outcomes, making it difficult to compare studies and draw any conclusions. However, that heterogeneity reflects significant progress in understanding what ACP is, what it can and cannot accomplish, and how to study it. There is now expert consensus around both a definition of ACP² and outcomes³ that promise the next 30 years of research will bear more fruit. Further work is needed to develop evidence-based conceptual models, robust outcome assessments, and systematic uptake of implementation research findings.

We absolutely agree with Dr. Morrison's point that individuals make different choices when they are well or in response to hypothetical scenarios, that some patients do not want to talk about their wishes, and that conducting high-quality ACP conversations is a skill that requires training as well as practice. But it is also true that there are many things patients and families can do to prepare themselves, like identifying a health care agent for future decision making or completing an advance directive. The impact of these early ACP activities may not be easily measured years down the road, but do we really want to say that those efforts are a waste of time? Some patients and families arrive at critical moments well prepared to make difficult decisions and others arrive confused and conflicted. We in health care are seldom privy to the actions that result in a family being "well-prepared"—but we

clearly see the benefits when they are. Learning more about what matters most to their loved one, what acceptable and unacceptable outcomes may look like for them, and an understanding of their loved ones' decision-making paradigm can help patients and families prepare for these difficult times.

Two wrongs do not make a right. ACP is right, but for seriously ill patients, the health care system is all wrong. Everyone in palliative care knows that the exquisite advance care plan you put in place today can be undone tomorrow in an instant if the patient ends up in an emergency room or hospital where the standard approach is to treat until treatment options are exhausted. One reason there are so many negative ACP studies is that they are conducted within health care systems oriented toward treatment (and often paid more for more treatment or penalized when patients die).

ACP is right for patients and clinicians, but health systems have to do their part for it to have real impact. Health care systems need to develop a system-wide infrastructure that promotes quality ACP for all individuals as a standard of care. Such an infrastructure includes a process for proactively addressing ACP with patients and their families, reviewing earlier conversations to provide coordinated care, and ensuring an efficient and effective medical record that makes it easy to document and access prior discussions and decisions. Even the best ACP conversations will not result in goal-concordant care in a system that is ill equipped to honor patient preferences. This need cannot be met through specialty palliative care alone or by relying solely on physicians. These goals are lofty and challenging in our complex chaotic health care system. This does not make them wrong.

We appreciate Dr. Morrison's provocation encouraging researchers and funders to "find something new" and the opportunity to debate the state of the field. However, we are not waiting for ACP to work. With the critical support of federal grants and foundations, we are actively innovating, implementing, and studying to build the science of ACP. As Dr. Morrison notes, "goal-concordant care is the

¹Respecting Choices, a Division of C-TAC Innovations, Washington, DC, USA.

²Indiana University Center for Aging Research, Regenstrief Institute, Indianapolis, Indiana, USA.

³Advance Care Planning Program, NYU Langone Health, New York, New York, USA.

⁴Serious Illness Care Program, Ariadne Labs and Dana-Farber Cancer Institute, Boston, Massachusetts, USA.

foundation of palliative care, indeed of all health care.” On this, we completely agree.

References

1. Jimenez G, Tan WS, Virk AK, et al.: Overview of systematic reviews of advance care planning: Summary of evidence and global lessons. *J Pain Symptom Manage* 2018;56:436–459.
2. Sudore RL, Lum HD, You JJ, et al.: Defining advance care planning for adults: A consensus definition from a Multidisciplinary Delphi Panel. *J Pain Symptom Manage* 2017;53: 821–832.
3. Sudore RL, Heyland DK, Lum HD, et al.: Outcomes that define successful advance care planning: A Delphi Panel Consensus. *J Pain Symptom Manage* 2018;55:245–255.

Address correspondence to:
Carole Montgomery, MD
Respecting Choices
900 16th Street NW
Suite 400
Washington, DC 20006-2426
USA

E-mail: cmontgomery@respectingchoices.org