

UCSF

UC San Francisco Previously Published Works

Title

"Advance" Care Planning Reenvisioned

Permalink

<https://escholarship.org/uc/item/60g7h85m>

Journal

Journal of the American Geriatrics Society, 69(2)

ISSN

0002-8614

Author

Moody, Sandra Y

Publication Date

2021-02-01

DOI

10.1111/jgs.16903

Peer reviewed

“Advance” Care Planning Reenvisioned

INTRODUCTION

Advance care planning (ACP) has become a necessary part of modern medicine because of the multitude of choices brought about by technological advances that sustain life while prolonging dying (Figure 1). These advances, albeit welcomed, have made treatment decisions, especially in the context of serious or advanced illness, more nuanced and complex. The number of choices is often overwhelming. Asking patients to make decisions about treatment or interventions in advance of illness further complicates the process. ACP requires individuals to imagine choices they would make when facing a future health crisis, without knowing how they would actually feel or what would be important to them in that future moment.^{1,2}

Shifts in the course of disease require patients and clinicians to be willing, flexible, and prepared to pivot when prognostic or other disease-related news is surprising or devastating. Even when decisions are made in advance, what ultimately matters most are decisions made in the moment(s) in response to unfolding clinical events.^{3,4} Despite substantial efforts to encourage ACP, it has long been recognized that many patients continue to receive “expensive, burdensome treatments that do not align with [their] values and preferences.”⁵

I am confronted with this dilemma regularly as a geriatrician and palliative care physician. Yet, the personal experiences of losing two friends in 2019 brought the problem into better focus for me. Their clinical trajectory and decision-making processes prompted me to reconsider whether current approaches to ACP are realistic for most individuals. In life, it is rare for people to make decisions far in advance of an event, yet in medicine, we ask patients to do just that.² Perhaps, the mere phrase “*advance* care planning” needs to be reenvisioned to reflect the dynamic nature of decision-making that occurs along the continuum of serious or life-threatening illness.

Two Friends, Two Terminal Illnesses

A friend from medical school noticed a lump in her breast after showering. It struck her as odd, as she had just had a normal screening mammogram about 6 months before. Indeed, a diagnostic mammogram revealed a large mass in her right breast. Biopsy revealed infiltrating lobular carcinoma in situ, thought to be local. She was referred to

surgery by her oncologist within the week of her diagnosis. She underwent chest computed tomography, and to her surprise, the surgeon announced metastasis to the rib cage. She told me, “Sandra, my rib cage lit up.” Within a week, she was catapulted from thinking she had local, likely curable cancer, to learning that she had stage IV metastatic lobular carcinoma. She was devastated as she started chemotherapy with surgery postponed, but her oncologist told her that this would likely be a chronic disease.⁶ The surgery never happened because her disease progressed.

Another friend, on his way to his teaching job, ran into a friend on the street who noticed he looked yellow and said so. With no pain and no other symptoms, he learned he had a small mass at the head of the pancreas. He was diagnosed with pancreatic cancer, which had caused obstruction of the common bile duct and led to jaundice. He had a Whipple procedure and subsequently chemotherapy. He underwent the surgery performed in hope of a cure, and three to four cycles of chemotherapy before he was faced with the news that he was going to die.

From diagnosis to death, I witnessed their decision-making processes. For one, I was physically distant but in close communication (annual visits, monthly videocalls, and frequent e-mails), serving as supporter and sounding board. For the other, I was directly involved in decision-making, joining him for physicians’ appointments, helping him process medical information, and providing space for thinking out loud while he tried to make the best choices along the way.

ACP Reenvisioned

It was a far greater challenge to be present for my friends as they underwent their journeys, as I tried to straddle objectivity and intimacy, encouraging choices and reconciling the setbacks, and hoping for cure despite the evidence otherwise.

It was necessary for both friends to have honest conversations, to clearly understand what to expect. The skill of the physician, in guiding those conversations, was essential. At the beginning of their journeys, decisions were not about advance directives, code status, or comfort care. Rather, decisions stressed what choices would yield the best opportunity for survival as long as possible. The focus was not on the “what ifs,” but on the “what is.” They made decisions over many individual moments in response to the most recent blood test and imaging results, and they carried hope that each time they opted for care that would take them in

DOI: 10.1111/jgs.16903

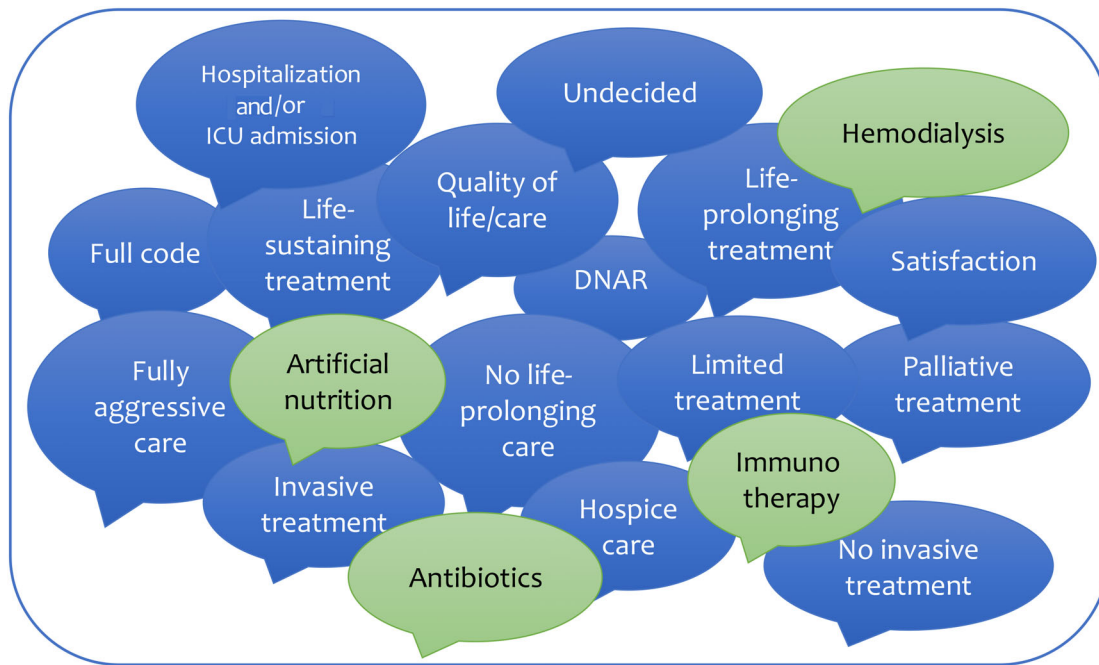


Figure 1. Medical decision-making entails a multitude of options. DNAR, do not attempt resuscitation; ICU, intensive care unit.

one direction rather than another, it would change the course of things for the better.

I observed each of them moving toward acknowledging and accepting the fact that cure was not possible. Each came to the point where the focus became “comfort,” “hospice,” “supportive” care. Deciding what they wanted done “in the future” was too out of reach, too far away. It was clear that treatment decisions made in response to the information at hand were tangible and thus more accessible to them, easier to consider and choose. These decisions represented the limit of what they could consider and choose—it was all they could handle at the moment. Anything beyond that was too much to ask.

This experience made me ask whether ACP, as we know it, is the right concept. How can we support a process of decision-making in response to a diagnosis or prognosis, a test result, or a change in clinical condition that allows patients to decide what is important at that particular time or in the reasonable “near” future? I propose that we think of this process as “*adaptive*,” where decisions are responsive, adaptive to the situation; where there are the multiple moments to decide about treatment or to assess or reassess one’s values and desires in the context of serious or life-threatening illness as it unfolds. “*Adaptive* care planning” would be planning as we go, taking into consideration the dynamic changes that occur in practice.

It may be hard to achieve goals stated much earlier, when life-threatening or end-stage manifestations of the illness seem abstract or far in the future, a vague idea of illness rather than a rib cage that lights up on computed tomography, or a pallor visible to a friend in the street. Perhaps it is more important to be responsive or adaptive to the issues ACP intends to address in the moment, letting the decision-making process be similar to adjusting one’s diabetes mellitus medication(s) or those for hypertension,

cardiovascular disease, or depression. Responding to new information, little by little, and keeping an eye on the overarching future goal, even when that changes over time, seem to make more sense.

CONCLUSION

As it is, many of us have a hard time planning ahead for things far less complicated than ACP. Yet, we have become obsessed with this concept of “advance care planning” where we ask patients to make decisions in advance about the care or treatment they would or would not want IF they receive a diagnosis of a serious or life-limiting illness, rather than creating a culture of care planning that allows for agility, responsiveness, flexibility, and room for changing needs, views, or goals.²

It is time to refocus our approach of asking patients for an ACP document, which can only be hypothetical. We should replace the concept of ACP with an approach that emphasizes *adaptive care planning* in which treatment decisions in response to serious illness, changing diagnosis, prognosis, or personal circumstances are made when most relevant. As said by Hammond in her *BBC Future* article, “When you imagine how you’ll feel at a future date, you’re unaware of subtle but powerful biases that frame the way you think.”¹ Care planning that is flexible, longitudinal,⁷ and adaptive, that allows us to walk alongside our patients, supporting them step by step instead of expecting them to follow a document completed years earlier embodies care planning reenvisioned.

ACKNOWLEDGEMENTS

I thank M. Carrington Reid, MD, PhD, of New York-Presbyterian Hospital/Weill Cornell Medical College,

Cornell University, and Christina L. Bell, MD, MS, of Hawaii Permanente Medical Group, Honolulu, HI, for their suggestions and review of multiple iterations of this manuscript.

Additional Information: This article is dedicated to the memory of my two friends, whose friendships I will always treasure.

Conflict of Interest: The author has no conflicts.

Author Contributions: S.Y.M. takes full responsibility for the contents of the manuscript and satisfies the requirements for authorship.

Sponsor's Role: There is no sponsor to report.

Sandra Y. Moody, MD, BSN

Department of Post-Graduate Education, Kameda Medical Center, Kamogawa City, Japan

Department of Medicine/Division of Geriatrics, University of California, San Francisco/ San Francisco VA Health Care System, San Francisco, California

REFERENCES

1. Hammond C. Medical myths/psychology: why predicting our future feelings is so difficult. *BBC Future* (online). <https://www.bbc.com/future/article/20200825-why-predicting-our-future-feelings-is-so-difficult>. Published August 27, 2020. Accessed August 27, 2020.
2. Morrison RS. Advance directives/care planning: clear, simple, and wrong. *J Palliat Med*. 2020;23(7):878-879. <https://doi.org/10.1089/jpm.2020.0272>.
3. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. 2010;153(4):256-261. <https://doi.org/10.1059/0003-4819-153-4-201008170-00008>.
4. Scheurer D. Important considerations in how we use advanced care planning documentation. *MEDPAGE TODAY'S KevinMD.com* (online). <https://www.kevinmd.com/blog/2017/07/important-considerations-use-advanced-care-planning-documentation.html>. Published July 17, 2017. Accessed March 19, 2020.
5. White DB, Angus DC, Shields AM, et al. A randomized trial of a family-support intervention in intensive care units. *N Engl J Med*. 2018;378(25):2365-2375. <https://doi.org/10.1056/NEJMoa1802637>.
6. Langbaum T, Smith TJ. Time to study metastatic-cancer survivorship. *N Engl J Med*. 2019;380(14):1300-1302. <https://doi.org/10.1056/NEJMp1901103>.
7. Periyakoil VS, Blinderman CD, Schechter WS. Longitudinal coaching and decision support provided by a patient-family liaison promotes goal-concordant care. *J Am Geriatr Soc*. 2020;68(9):1933-1935. <https://doi.org/10.1111/jgs.16684>.