Published in final edited form as:
JAMA Netw Open. ; 2(11): e1914466. doi:10.1001/jamanetworkopen.2019.14466.

Placing value on end-of-life care – time for a new taxonomy?

May Hua, MD, MS[1], **Hannah Wunsch, MD, MSc**[2,3]

[1]Department of Anesthesiology, Columbia University, New York, NY, USA

[2]Department of Critical Care Medicine, Sunnybrook Health Sciences Centre, Toronto, ON, Canada

[3]Department of Anesthesia and Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, ON, Canada

Advocates of advance care planning (ACP) focus on its potential role to help ensure that care delivered is aligned with a patient's values. The importance of ACP at the end of life is increasingly promoted based on the underlying assumption that if patients are properly informed about care options, many will opt for less aggressive care than they otherwise receive. This belief is based on a body of literature that suggests 1) people generally prioritize quality over quantity of life;[1] 2) in the setting of a poor prognosis, patients choose care focused on comfort;[2] and 3) when surveyed, physicians have also preferred non-aggressive care at the end of life.[3] Driving the urgency of these conversations is the concern that much of the care currently provided towards the end of life may be "overly aggressive" and thus, misaligned with true patients' values. Misaligned care is potentially harmful to multiple stakeholders, as it may cause a high degree of symptomatology and be associated with worse quality of death,[4] increase moral distress for providers, and represent low-value care for the health care system.

In this issue of *JAMA Network Open*, a study by Ashana and colleagues provides insights into the relationship between ACP and healthcare use.[5] Using a national insurance database (Medicare Advantage), the authors conducted a retrospective cohort study of patients with serious illness to determine whether the occurrence of an ACP visit was associated with differences in death, healthcare use and costs in the subsequent 6 months. Presence of an ACP visit was determined using the Current Procedural Terminology codes for ACP instituted in 2016; healthcare use was operationalized as emergency room visits, hospitalizations, use of hospice, as well as a range of "intensive therapies". One important finding of the study was that ACP visits were uncommon, occurring only in 4.7% of overall patients, and 14.2% of patients who died during the follow-up period. After use of propensity score methods to adjust for differences in patients' likelihood of receiving ACP (such patients were sicker, with a greater number of comorbidities and higher healthcare use in the year prior), ACP was associated with more hospitalizations with and without ICU and higher overall costs of care, but was also associated with higher rates of hospice use. Although overall rates of intensive therapies were lower for those with an ACP visit, this

---

Corresponding Author: Dr. Hannah Wunsch, Dept of Critical Care Medicine, Sunnybrook Health Sciences Centre, 2075 Bayview Ave, Rm D108, Toronto, ON M5R 3B2, Canada, hannah.wunsch@sunnybrook.ca.

was driven primarily by lower frequency of receiving chemotherapy, which is difficult to interpret as the ACP group had a smaller percentage of individuals with cancer. Other limitations of the study included the potential for misclassification of the ACP visit exposure, and residual confounding by indication despite the use of propensity score methods, as patients with ACP were also more likely to die during the follow-up period. Given these concerns, the authors are appropriately conservative in their conclusions, suggesting that their findings highlight the need for further experimental studies to determine a causal relationship between ACP and patients' outcomes.

However, if patients in this study received "successful" ACP and their outcomes are representative of goal-concordant care, our current conceptualization of healthcare use at the end of life as being generally undesirable may be wrong, or at the very least, inexact. Other recent work is consistent with a potential need to revisit this belief. US studies of physicians as patients that examined actual utilization at the end of life (as opposed to stated preferences upon survey) demonstrated that physicians were no different in their care patterns compared with similar individuals without specific medical knowledge (such as lawyers),[6] and in a Canadian study, physician patients were more likely to be admitted to an ICU and to receive chemotherapy, and were also more likely to receive both hospice and palliative care.[7] Since physicians are arguably the most well-informed consumers of healthcare, these studies, along with the findings from the current study, underscore the possibility that improving goal concordance may sometimes actually result in *increased* healthcare use.

While seemingly paradoxical, hospitalization and ICU use may actually be goal-concordant in patients who would be classified as choosing comfort-focused care. Given that patients and families list adequate symptom control as one of their most important concerns, it may be that for some patients with certain types of terminal illnesses, symptoms are best managed in an acute hospital setting. For example, dyspnea may be particularly scary to experience at home and lead individuals, even with adequate palliative support, to seek hospital care, whereas other symptoms may be more manageable in the outpatient setting. Similarly, intensive care may be preferred to the wards, due to higher nurse-to-patient ratios and the presence of more skilled providers, with more frequent symptom assessment and medication titration. Thus, what appears to be paradoxical may simply indicate an insufficient understanding of the value that certain types of care may hold for patients and families, and how this may ultimately drive care choices. In particular, informed and value-aligned care may look different for patients with different diseases and symptoms.

Ensuring that the care delivered matches the care that is desired by patients and families is the ultimate objective for an ACP intervention, and the current study highlights existing opportunities to better refine our thinking about what constitutes goal-concordant care. Instead of treating utilization as a dichotomous outcome where "more" is always "poor quality care", it may be appropriate to move towards a more nuanced taxonomy of high-quality care, where different types and patterns of healthcare use at the end of life are considered in a manner that best reflects their value to patients and families. Given the difficult choices that patients and families face at the end of life, it is perhaps only fitting that our approach to this issue begins to mirror that complexity.

References

1. Bailoor K, Valley TS, Kukora S, Zahuranec DB. Explaining the Process of Determining Futility Increases Lay Public Acceptance. Annals of the American Thoracic Society. 2019;16(6):738–743. [PubMed: 30789785]
2. Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. N Engl J Med. 2002;346(14):1061–1066. [PubMed: 11932474]
3. Periyakoil VS, Neri E, Fong A, Kraemer H. Do unto others: doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives. PloS one. 2014;9(5):e98246. [PubMed: 24869673]
4. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. J Clin Oncol. 2010;28(29):4457–4464. [PubMed: 20837950]
5. Ashana DC, Chen X, Agiro A, et al. Advance care planning claims and healthcare utilization among seriously ill patients near the end of life. JAMA Network Open. 2019.
6. Weissman JS, Cooper Z, Hyder JA, et al. End-of-Life Care Intensity for Physicians, Lawyers, and the General Population. JAMA. 2016;315(3):303–305. [PubMed: 26784782]
7. Wunsch H, Scales D, Gershengorn HB, et al. End-of-Life Care Received by Physicians Compared With Nonphysicians. JAMA Netw Open. 2019;2(7):e197650. [PubMed: 31339549]