

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

Meaghann S. Weaver, MD, MPH, FAAP,¹ Lori Wiener, PhD,² Shana Jacobs, MD,³ Cynthia J. Bell, PhD, RN,⁴
Vanessa Madrigal, MD,⁵ Kim Mooney-Doyle, PhD, RN, CPNP-AC,⁶ and Maureen E. Lyon, PhD, ABPP⁷

Dear Editor:

"I feel alive."—Adolescent when asked how he felt about completing advance care planning.

A recent editorial from Dr. Sean Morrison presented his observations that funding for research to support advance care planning (ACP) could now be ended because the funding did not result in care improvements (preferences voiced by patients not followed at end of life, etc.).¹ We strongly believe that ACP is effective in adolescent care models due to the unique developmental elements of caring for these age cohorts. Although adolescents under the age of majority may lack legal decisional rights due to age, their life season represents a time of increasing autonomy and a maturing capacity to participate in informed decision making. For this age group, ACP represents safe, worthwhile, clarifying, and caring communication. We appreciate Dr Morrison's recognition that "there are some populations in which advance directives play important roles" and share this reply to emphasize the essential role of ACP for adolescent populations and their families.

As Dr. Morrison points out, conducting ACP discussions is not simple, and knowing how to initiate and sustain these important conversations within clinical settings is challenging. However, in our clinical and research experiences, ACP discussions with children and teens provide a safe place to process hopes, fears, and preferences for end-of-life care. Although these discussions are often met with concern about increasing the anxiety inherent to that young person's diagnosis, anxiety about ACP decreased in adolescents after completing several pages of an ACP guide²; and anxiety also decreased after an ACP intervention compared with controls.³ One year after an ACP intervention with 105 adolescent-family dyads, adolescents who communicated their treatment preferences had fewer disease-specific

symptoms.³ The adolescents' family caregivers were also significantly less anxious. In another ACP trial, families had more positive appraisals of their caregiving,⁴ than families who did not have these conversations. Data from these studies support the idea that ACP allows adolescent patients and their families to have less anxiety, not more, demonstrating that the conversations themselves are not harmful.

Adolescents and families who participate in family-centered ACP find the conversations to be worthwhile, notably with a greater understanding of end-of-life wishes and a higher likelihood of receiving early palliative care. In a robust multisite assessor-blinded parallel-group randomized control trial (*FACE pACP*), ACP surrogates were eight times more likely than controls to have an excellent understanding of adolescent patients' treatment preferences.³

A majority of chronically ill adolescents prefer to play an active role in their medical decision making. ACP for adolescent cohorts represents empowerment for the patient and clarity for the family caregivers, as family understanding of patient wishes is notably poor for dying a natural death and being off machines that extend life.⁵ In a study that evaluated what adolescents and young adults living with a life-threatening disease would want to be included in an ACP document, they reported being able to choose and record (1) the kind of medical treatment they want and do not want, (2) how they would like to be cared for, (3) information for their family and friends to know, and (4) how they would like to be remembered after their death.⁶

Adolescent ACP can compassionately "break the ice" for families and provides structure to allow adolescents and their family caregivers to confidently make care decisions as disease progresses. This is especially important due to the risk of regret that parents can experience after the death of their child. In a landmark national Swedish study of

¹Division of Pediatric Palliative Care, Children's Hospital and Medical Center, Omaha, Nebraska, USA.

²Pediatric Oncology Branch, National Cancer Institute, Center for Cancer Research, National Institutes of Health, Bethesda, Maryland, USA.

³Division of Oncology, Children's National Medical Center, Washington, DC, USA.

⁴College of Nursing, Wayne State University, Detroit, Michigan, USA.

⁵Pediatric Critical Care and Pediatric Ethics Program, Division of Pediatric Critical Care Medicine, Department of Pediatrics, Children's National Health System, Washington, DC, USA.

⁶Department of Family and Community Health, University of Maryland School of Nursing, Baltimore, Maryland, USA.

⁷Children's National Hospital/Center for Translational Science and George Washington School of Medicine and Health Sciences, Washington, DC, USA.

bereaved parents written by Ulrika Kreicbergs and colleagues published in the *New England Journal of Medicine* in 2004, no parent regretted talking to their child about death, whereas 27% ($n=69$) of bereaved parents who did not talk with their child about death lived with regret. In a more recent study of bereaved parents published in *Palliative Medicine* by Wendy Lichtenthal and colleagues' team in 2020, 73% of bereaved parents endorsed regret and 33% endorsed unfinished business (both were associated with distress while caregiving and prolonged grief symptoms). The most common regrets reported were about treatment decisions and the most common unfinished business, not engaging in conversations with the child about end of life. Parents who participated in ACP discussions endorsed greater preparation for their child's death, decreased suffering, and decreased decisional regret.⁷

Preliminary results from a study assessing the use of the ACP guide, *Voicing My CHOICES*, found that adolescents talk less about their preferences for care with their providers than their friends and family members, preferring that providers raise these issues with them, rather than the other way around.² Importantly, these studies used structured conversation guides to facilitate discussions with adolescents. Data-driven conversation guides, such as *Voicing My CHOICES* (available from Aging With Dignity), are available to assist care providers who wish to enter into these difficult but necessary discussions with patients facing life-limiting illnesses. Indeed, ACP benefits not only patients and family caregivers, but also providers. Physicians benefit from an extra layer of support to avoid the first conversation about goals of care occurring in the intensive care unit.

Preferences do change over time and patient/family dyads who participate in ongoing ACP discussions are more likely to stay on the same page even as preferences change. In addition, adolescents are more likely to give their family leeway to do what they think is best at the time, knowing their end-of-life treatment preferences.^{7,8} So, strict concordance between advance directives and end-of-life treatment in the last month of life is not necessarily the "holy grail." Rather, ACP is an essential component of ongoing discussions that empower families to honor the adolescent's voice and unique individuality amidst unexpected challenges.

Pediatric ACP developed in part in response to adolescents' spontaneous sharing with their nurses, case managers, social workers, and psychologists a desire to limit treatments in their last days. We share a few examples that illustrate the importance and worthwhile nature of helping adolescent patients have their voice heard through ACP:

- A 14-year-old perinatally HIV-infected adolescent told his case manager he did not want to undergo another surgery.
- A 20-year-old adolescent dying of AIDS came out of a semicomatose state and said to her nurse in the middle of the night, "Who ever gave my uncle permission to make decisions for me?"
- A 15-year-old adolescent with recurrent leukemia shared in her written ACP guide that she preferred to die at home and wanted her doctors to perform an autopsy to learn more about her disease to help others with her type of leukemia.

- In a survey study an adolescent revealed he had wanted everything done, but he had changed his mind (he was in a wheel chair with peripheral neuropathy) but had not yet told his mother or his nurse practitioner.
- A 17-year-old adolescent shared through an ACP intervention that she had prepared legacy letters for her siblings even though her family was not yet openly discussing her end-of-life timeline with one another. This resulted in Child Life fostering open dialogue within the family structure.

In each of these cases, the sharing of preferences led to a change in treatment decisions allowing the young person's wishes to be known. Adolescents and their family caregivers want to have ACP conversations and they want to have them early in the course of their serious illness.^{5,7} All adolescents living with a serious illness and their families should have access to and provision of ACP. To do this, funding is needed to support implementation research to ensure that high-quality programs are safe, clarifying, caring, and worthwhile to patients, families, and clinicians. The core of adolescent ACP is structured authentic communication, which acknowledges life is finite and is a gift of love from the adolescent with a serious illness to their family. Adolescent ACP provides clear and empowering directives to health care providers amidst the uncertainty of living with advanced and serious illnesses. They also provide powerful and lasting legacies for bereaved parents.

Acknowledgment

The study team thanks the Children's National Pediatric Palliative Care Special Interest Group for formative content review.

Disclaimer

This content is solely the responsibility of the authors and does not necessarily represent the official views of the NINR, the NIH, or the American Cancer Society.

Funding Information

Multiple studies cited here were supported by the National Institutes of Health (NIH), National Institute of Nursing Research (NINR), Award Number R01NR014052-05; and NIH/NINR Award Number 1R01 1NR012711-05; and by the NIH/National Institute of Mental Health (NIMH) Award Number R34 MH 072541-03; and by the American Cancer Society Award Number PEP-10-171-01-PCSM. This research was supported (in part) by the Intramural Research Program of the NIH.

References

1. Morrison RS: Advance directives/care planning: Clear, simple, and wrong. *J Palliat Med* 2020;23:878–879.
2. Wiener L, Zadeh BS, Battles H, et al. Courageous conversations: Advance care planning and family communication. *Pediatr Blood Cancer* 2018;65:S596.

3. Lyon ME, Garvie PA, D'Angelo LJ, et al.: Advance care planning and HIV symptoms in adolescence. *Pediatrics* 2018;142:e20173869.
4. Thompkins J BJ, Friebert S, Needle J, et al.: Effect of Family Centered (FACE) advance care planning (ACP) on families' appraisals of caregiving for their teen with cancer. *J Clin Oncol* 2020;38 (15_Suppl):e22533.
5. Friebert S, Grosseohme DH, Baker JN, et al.: Congruence gaps between adolescents with cancer and their families regarding values, goals, and beliefs about end-of-life care. *JAMA Network Open* 2020;3:e205424.
6. Wiener L, Zadeh S, Battles H, et al.: Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics* 2012;130:897–905.
7. DeCoursey DD, Silverman M, Oladunjoye A, Wolfe J: Advance care planning and parent-reported end-of-life outcomes in children, adolescents, and young adults with complex chronic conditions. *Crit Care Med* 2019;47:101–108.
8. Lyon, ME, Jacobs, S, Briggs, L, et al.: Family centered advance care planning for teens with cancer. *JAMA Pediatr* 2013;167:460–467.

Address correspondence to:
Meaghann S. Weaver, MD, MPH, FAAP
Division of Pediatric Palliative Care
Children's Hospital and Medical Center Omaha
8200 Dodge Street
Omaha, NE 68114
USA

E-mail: meweaver@childrensomaha.org