Editorials

To Prepare Patients Better: Reimagining Advance Care Planning

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Dana could not talk about it. She did not even want to think about it. Three years ago, she was diagnosed with metastatic colon cancer. At that time, she was surprised when her family physician, Dr. Lee, started a conversation with her about what she hoped for and worried about related to her illness. Over time, with ongoing discussions, Dr. Lee encouraged her to select a health care proxy and talk with her family about her goals. Some office visits were brief, with a 15-minute check-in around a specific symptom, and others were lengthier and involved her sons for support in decision-making. As symptoms progressed and chemotherapy options became slim, Dr. Lee began to ask what mattered most to her. Then, one morning, Dana awoke with new abdominal pain and was diagnosed with a malignant bowel obstruction.

Forty-five million Americans live with one or more serious illnesses, many of which are life-limiting and marked by functional decline.[1] Family physicians play a pivotal role in the care of these patients through their deep, longitudinal relationships. One-third of board-certified family physicians report using palliative care skills in their practices.[2] Although some clinicians view advance care planning as a discrete task—a form to be filled out, a decision to be made—we suggest thinking about it as an iterative and integrative process.[3] In these two ways, process-oriented advance care planning better prepares patients for medical decision-making.

First, process-oriented advance care planning is *iterative*, focusing on early and recurring discussions of the patient's goals and values related to the illness. Clarifying goals and values also helps ensure that they can be incorporated into later medical decision-making. For example, a clinician can reflect with a patient on how a treatment might help achieve an identified goal or offer a recommendation about treatment that aligns with the goal. In Dana's case, Dr. Lee periodically asked her the following questions: What are your hopes for your health? What are your worries? If your illness were to progress, what would be most important? Although some clinicians worry that these discussions may make the patient anxious or depressed, the data suggest the opposite.[4,5] These questions helped Dana become accustomed to thinking about the possibility of getting sicker. Because of these conversations, Dr. Lee knew that being at home was important to Dana long before there was any decision to be made.

Second, process-oriented advance care planning is *integrative*, allowing patients and families to better understand the anticipated course of the illness. This understanding arises from iterative goals and values conversations, which enhance patients' capacity to think about the future and comfortably discuss it with clinicians. Patients can then incorporate their understanding of the illness into goals, values, and decisions. Family members or other trusted loved ones may be invited into these discussions as the patient wishes. When patients have a more accurate view of their prognoses, they may have clearer opinions about how they want their care to proceed, such as earlier enrollment in hospice and placing limits on resuscitative efforts.[6,7]

Some clinicians note barriers to holding these conversations. Many clinicians have not been trained to assess or discuss patient goals and values. Trained to find solutions to problems, clinicians may initially struggle with the discussion's abstract nature. When asked about barriers to holding these conversations, clinicians often cite lack of time, with full schedules and short visits.[8] The iterative approach helps here because one lengthy conversation can be divided into multiple "touches" during a clinical course, some of which may be provided by other staff members (e.g., trained social workers or nurses). Although many seriously ill patients see subspecialists, the connection with a family physician is often enduring—with the family physician acting as a resource even when a patient enters hospice care.[9]

Some physicians find it beneficial to use a guide to break down the conversation into a series of scaffolding questions.[10] A guide, such as the Serious Illness Conversation Guide,[11] helps seasoned clinicians learn a patient-tested, research-based approach that is time-efficient, teaches a clear framework to learners, and enables structured communication between colleagues.[12] Teaching methods such as role play are also critical for building these skills.[13]

The Center to Advance Palliative Care provides educational videos at https://www.capc.org/providers/palliative-care-videos-podcasts/. Sample conversations using the Serious Illness Conversation Guide are available at https://www.youtube.com/watch?v=N-rfsAmaMvQ&feature=youtube. As clinicians become more comfortable conducting these conversations, patients will in turn become more accustomed to sharing their goals and values with their family physicians.

Dr. Lee's support helped Dana prepare. She had time to adjust to her prognosis, could reflect on her values, and was used to speaking with her physicians about difficult topics. When she developed the bowel obstruction, her sons gathered to her bedside with Dr. Lee and her oncologist. Together, they reflected on those conversations. Dr. Lee understood that Dana valued being at home at the end of life and recommended hospice. Dana agreed. She was ready.

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References

1. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington D.C.: National Academies Press; 2015:36-38.
2. Ankuda C, Jetty A, Bazemore A, Petterson S. Provision of palliative care services by family physicians is common. *J Am Board Fam Med*. 2017;30(2):255-257.
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(2):245-255.
4. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
5. Paladino J, Bernacki R, Hutchings M, et al. Effect of conversations about values and goals on anxiety in patients. *J Clin Oncol*. 2015;33(29 suppl):9.
6. Jackson VA, Jacobsen J, Greer JA, Pirl WF, Temel JS, Back AL. The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: a communication guide. *J Palliat Med*. 2013;16(8):894-900.
7. Shen MJ, Trevino KM, Prigerson HG. The interactive effect of advanced cancer patient and caregiver prognostic understanding on patients' completion of do-not-resuscitate orders. *Psychooncology*. 2018;27(7):1765-1771.
8. Weckmann MT. The role of the family physician in the referral and management of hospice patients. *Am Fam Physician*. 2008;77(6):807-812.
9. Rosenberg LB, Greenwald J, Caponi B, et al. Confidence with and barriers to serious illness communication: a national survey of hospitalists. *J Palliat Med*. 2017;20(9):1013-1019.
10. Sanders JJ, Curtis JR, Tulsky JA. Achieving goal-concordant care: a conceptual model and approach to measuring serious illness communication and its impact. *J Palliat Med*. 2018;21(S2):S17-S27.
11. Bernacki R, Hutchings M, Vick J, et al. Development of the serious illness care program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open*. 2015;5(10):e009032.
12. Lakin JR, Koritsanszky LA, Cunningham R, et al. A systematic intervention to improve serious illness communication in primary care. *Health Aff (Millwood)*. 2017;36(7):1258-1264.
13. Markin A, Cabrera-Fernandez DF, Bajoka RM, et al. Impact of a simulation-based communication workshop on resident preparedness for end-of-life communication in the intensive care unit. *Crit Care Res Pract*. 2015;534879. ■