

Advance Care Planning: Creating a Climate for Critical Self-Reflection

By Cara Wallace, Ph.D., LMSW

Advance care planning (ACP) for end-of-life care has a renewed public interest with the recent popularity of Atul Gawande's best-selling book on end-of-life care,¹ national debates surrounding current death with dignity legislation, and publicity surrounding The Conversation

of ACP and preparing for the end of life,⁶ the process is fraught with both professional and personal barriers. On the professional side, physicians report barriers such as language or medical interpretation issues, patients' limited health literacy, patients' mistrust of the health care

each of us has a history that tells a story about how and why we chose to pursue the degree and career path we did. Our early experiences on this path contribute to this story and the shaping of an individual to a clinician. Maybe, there are clues within this history that have the power to impact how we interact with patients and families in ACP.

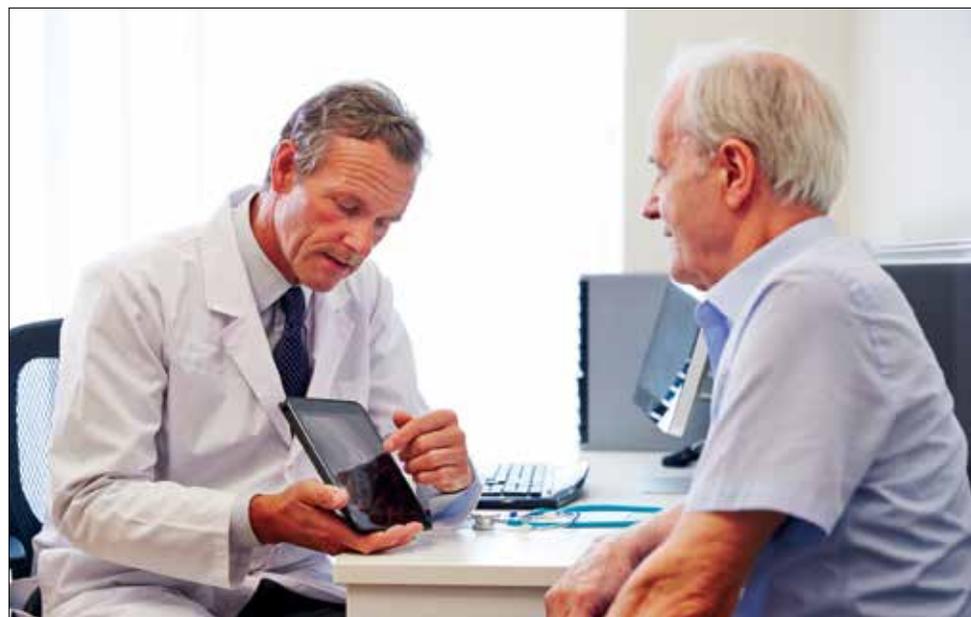
In an autobiography written as he was faced with his own terminality,¹² Dr. Paul Kalanithi recounts many of the professional experiences that taught him about working with patients on the brink between life and death:

"Amid the tragedies and failures, I feared I was losing sight of the singular importance of human relationships, not between patients and their families but between doctor and patient. Technical excellence was not enough. As a resident, my highest ideal was not saving lives—everyone dies eventually—but guiding a patient or family to an understanding of death and illness."

Dr. Kalanithi's reflections allowed him to connect his professional experiences with his personal life, enabling him to be clearer about not only what he wanted in his own healthcare, but also as a skilled clinician, how to communicate with patients and family members about wishes of their own. This reflective process is one that few of us engage in, but that likely has direct relevancy to how we practice direct patient care.

In a current, ongoing study with SLU colleagues, Drs. Dulce Cruz and

(continued on page 21)



Project,² a movement which encourages everyone to have conversations about their end-of-life wishes. Beginning in January 2016, Medicare now reimburses physicians and other qualified health care providers for voluntary ACP sessions with patients and their families.³ While these are encouraging signs that, as a culture, we are becoming more comfortable with conversations surrounding end-of-life care, in practice, many providers do not always talk to their patients about ACP, even when opportunities emerge in a clinical visit.⁴ When communication does occur, the quality and content of these conversations varies.⁵

Though practitioners overwhelmingly agree on the importance

system, and a lack of understanding about patients' cultural or religious beliefs surrounding death, dying and decision-making.⁷ Other reported barriers include lack of knowledge about available services, lack of training, and lack of standardized criteria for referrals.^{8,9} On the personal side, even physicians do not have formal conversations about their own ACP with their own providers and families,¹⁰ citing lack of time as a primary reason for why communication and completion have not occurred.¹¹

As a provider, you can perhaps see yourself within these barriers and you already recognize ACP as a potential area for improvement in working with patients. For others, maybe this is less on your radar. Yet,



Advanced Care Planning

(continued from page 15)

Jennifer Ohs, we are examining potential connections between:

- 1) practitioners' personal and professional history with loss;
- 2) their own completion of (and communication about) advance directives; and
- 3) attitudes and current practices surrounding ACP and referrals to hospice and palliative care.

Initial analysis of nearly 180 health care practitioners (physicians, nurse practitioners, RNs, social workers and others) demonstrates strong correlations between a person's history of loss (both professionally and personally), completion and communication about one's own directives, and his/her attitudes and practices in professional ACP. Our experiences are inexplicitly connected with how we practice.

Though many of us respectively received training on separating our beliefs, emotions, and experiences from professional practice, we have less understanding and practice with acknowledging the connections between them, or how to handle the inevitable impact of the personal on the professional. In a text examining emotional and countertransference responses in palliative and end-of-life care,¹³ clinician Renee Katz posits the following:

"We propose that our professional work...is extremely personal in nature, that we are profoundly influenced by our patients and their families as much as they are impacted and influenced by us, and that our emotional responses do impact the clinical moment—whether we want them to or not, whether we are aware or not, whether we can admit it or not."

More than likely, each of us is concerned about assisting our patients with planning for their end-of-life care though many barriers remain.



Perhaps the place to start is not just in having the conversations within our own lives, but also in exploring how our own experiences and emotions shape our practices and preferences, both personally and professionally. Maybe it is within this critical self-reflection where we can find meaningful connection to the stories of our patients, and perhaps then we can engage in more effective advance care planning for all of us.

References

1. Gawande, A. *Being mortal: medicine and what matters in the end*. New York: Macmillan Books; 2014.
2. The Conversation Project. In collaboration with the Institute for Healthcare Improvement. Retrieved from <http://theconversationproject.org/>; 2017.
3. Kaiser Family Foundation. 10 FAQs: Medicare's role in end-of-life care. Retrieved from <http://files.kff.org/attachment/factsheet-10-faqs-medicares-role-in-end-of-life-care>; 2015.
4. Ahluwalia SC, Levin JR, Lorenz KA, Gordon HA. Missed opportunities for advanced care planning communication during outpatient clinic visits. *J Gen Int Med* 2012;27:445-451.
5. Trice ED, Prigerson HG. Communication in end-stage cancer: A review of the literature and future research. *J Hlth Comm* 2009;14: 95-108.
6. Steinhauser KE, Christakis, NA, Clipp EC., McNeilly M, Grambow S, Parker J, Tulsky J. A. *Preparing for the end of life: preferences of patients, families, physicians, and other care providers*. *J Pain Symptom Mgt* 2001;22:727-737.
7. Periyakoil VS, Neri E, Kraemer H. No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PloS one*, 2015;10, e0122321. doi:10.1371/journal.pone.0122321.
8. Schenker Y, Crowley-Matoka M, Dohan D, Rabow MW, Smith CB, White DB, ... & Arnold, R. M. (2014). Oncologist factors that influence referrals to subspecialty palliative care clinics. *J Oncology Practice*, 2014;10:e37-e44.
9. Ahmed N, Bestall JE, Ahmedzai SH, Payne SA, Clark, D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*, 2004; 18: 525-542.
10. Gallo JJ, Stratton JB, Klag MJ, Meoni LA, Sulmasy DP, Wang N, Ford DP. Life-sustaining treatments: What do physicians want and do they express their wishes to others? *J Am Ger Soc* 2003;51:961-969.
11. Go RS, Hammes BA, Lee JA, Mathiason MA. Advance directives among health care professionals at a community-based cancer center. In *Mayo Clinic Proceedings* 2007; 82, 12:1487-1490. Elsevier.
12. Kalanithi P. *When breath becomes air*. New York: Random House; 2016.
13. Katz RS, Johnson TA. *When professionals weep: Emotional and countertransference responses in palliative and end-of-life care*. New York: Routledge; 2016.

