
FIELD NOTES | SPRING 2015

Dying Well: Choose Your Beverage

By Esther Park & Gladys Rodriguez

“Hey, do you have a few minutes to talk?” We both knew that was code for: “I have something I need to get off my chest, and it may take a couple hours.” We’ve been debriefing together since our first year of medical school—over meals, workouts, and late-night chats. The conversations have been an avenue to laugh, de-stress, and reflect. In the process, we’ve shared difficult experiences that have forced us to question and explore different approaches to caregiving. We’d like to share the stories of two patient encounters; their last days of life couldn’t have been any more different.

“One coold beer, please!” It felt like a typical night at the local bar. One almost expected to see a bartender rush to slide an ice-cold bottle to the customer. But this was not the bar, and there was no bartender. This was the seventh floor of the hospital, with an exhausted intern struggling to enter an order for pharmacy to send the in-house beer to Mr. R. “It’s on its way!” he exclaimed. Apparently, they do this for special situations. “Anything he wants, you give him,” were the attending’s instructions. Mr. R winked and gave a laugh. You would never think Mr. R had just a few months, perhaps weeks, to live. Mr. R had advanced leukemia and was admitted for in-hospital hospice with comfort measures only. “I want to spend my last days doing what I like the most—drinking with my friends.” And that’s what he did, having a few beers each day surrounded by friends and family, laughing and telling stories.

The intern decided to leave the expiration date blank on that pharmacy order. Two weeks later, Mr. R passed away peacefully.

We debriefed about this patient—the beer and the peace that surrounded his death. His final days struck us; they made us reflect on what it means to have a good death, and perhaps more importantly, what it *takes* to have a good death.

“Please, can I have some water?” The answer was always an unremitting and indisputable “no.” Mr. P was an elderly gentleman admitted to the floor for weakness and disorientation. Unfortunately, his melanoma had metastasized to the brain. The neurosurgery, oncology, and medicine teams all weighed in, making different treatment suggestions to the already overwhelmed family members who were understandably reluctant to make any definite decisions.

Mr. P could still mumble a few words during pre-rounds. When asked, “Mr. P, how are you doing this morning?” he would shake his head restlessly and stare. “Please, water.” His lips were dry and scaly. His IV line had been lost again, and after several failed attempts on his arms, the nurses were able to find a “usable” vein in his leg. They came in and struggled to draw blood. “They should just let him go,” they whispered.

Mr. P was clearly thirsty, but the resident said he couldn’t have any water. If the brain compression worsened, he would need an emergency decompressive craniectomy. There was also an aspiration concern. The team members assured each other they were not dehydrating him—he was receiving adequate IV fluids. Yet, questions still remained. Why did Mr. P not have the right to drink water whenever he pleased so he could die a bit more comfortably? Why should doctors dictate how patients die or what they can drink—or not drink? The

psychiatry consultant helped answer some of the questions. Mr. P lacked the capacity to make medical decisions. He could no longer decide if or when he would drink. His condition declined; the irregular respirations with gasping were ominous. Mr. P was eventually transferred to another hospital closer to his family, where he died several days later.

We debriefed about Mr. P too. Because he was deemed incapable of making medical decisions, it was up to his oldest son to decide—to decide if the father would receive comfort measures or the full spectrum of medical interventions. And this was a huge burden for the son. Undoubtedly, it was an unfair situation for the son, who was deeply troubled at not knowing his father's end-of-life wishes. It was also unfair for Mr. P, who did not deserve to be dying thirsty and restless. If only they had made these end-of-life decisions earlier on, we thought, matters would have been easier for both of them. We've learned that the process by which they're made is complex but an essential part of good care.

Advance care planning (ACP) has long been championed as a crucial component of quality health care (Detering et al.; De Vleminck et al.; Hickman et al.; Steinberg). It goes beyond DNR/DNI (do not resuscitate/do not intubate) and entails a wider range of end-of-life care plans meant to protect the patient's autonomy, including preferences regarding artificial nutrition and hydration, comfort care, healthcare proxies, and more. Still, these decisions are often predictions, based on the patient's desires at the time of the planning. They are desires that can change as the patient's circumstances change, and the advance directive should be updated accordingly in keeping with the patient's evolving goals and desires for end-of-life care.

The benefits of ACP have been well documented—benefits Mr. P and his family surely would have appreciated. Elderly patients who discuss ACP with their healthcare providers report greater satisfaction with their inpatient or outpatient visits (Tierney et al.; Detering et al.). This satisfaction extends to family members of the deceased, who experience less post-traumatic stress, anxiety, and depression than family members of patients without ACP (Detering et al.). In addition, a recent systematic review and meta-analysis found that ACP interventions increased several measures of quality end-of-life care (Houben et al.). These measures included completion of advance directives and concordance between the patient’s preferences for end-of-life care and the care given. However, these findings were based on an analysis of randomized controlled trials (Houben et al.; Detering et al.); ACP may not be as effective in actual practice. For instance, 76 percent of physicians whose patients had advance directives believed their patients did not have advance directives or did not know if their patients had one (Virmani, Schneiderman and Kaplan). Still, recent studies have been encouraging. Where trained professionals routinely facilitate ACP, there is reason to believe substitute decisions in end-of-life care can more accurately reflect the desires of the patient.

Yet, despite the perceived benefits of advanced care planning, it is not widely practiced.

According to a Pew Research Center survey, only 29 percent of adults have a living will (De Vleminck et al.). Physicians are involved in the development of just 12 percent of advance directives (J. Teno et al.), and most of the discussions are about the patients’ emotions and life perspectives rather than about specific end-of-life treatment preferences (Virmani, Schneiderman and Kaplan).

In the midst of busy practices, hospital admissions, and pagers ringing without regard, it is easy for ACP to become lost. There is also the fear of instilling hopelessness—that asking a patient

with advanced cancer if she would like to be resuscitated in the future will cause her to think she's nearing the end (De Vleminck et al.). Other barriers to physician participation in ACP include a lack of self-confidence in guiding ACP discussions; the belief patients should be the one to initiate ACP, and the question of timing. Should one broach the topic of ACP when the patient is still healthy, when he or she has been diagnosed with a serious illness, or when the patient has reached the last week of life? ACP is nuanced and dynamic; it is no wonder its implementation has been difficult. Perhaps Mr. P was one of the victims of these obstacles. Still, the care of a terminally or seriously ill patient goes beyond resuscitation, artificial nutrition, or antibiotic treatment, and all that may be covered in a living will or discussed with a healthcare proxy. There does seem to be such a thing as *dying well*. Mr. R had gone through the process of dying well. Patients consistently view preparation of family members for one's death, maintaining dignity, having funeral arrangements in order, and physical touch as being important at the end of life (Steinhauser et al.). It is important for them to be at peace with God, to be able to help others, to get to say their goodbyes—to feel their life is complete. Without a doubt, ACP is important. But there are many other ways to engage in the aim of upholding patients' values, even in the absence of a living will. Calling the chaplain, talking with family members about the patient's projected clinical course, and holding the patient's hand are just a few.

We've learned ACP isn't perfect. Advance directives are often too vague to be helpful in making end-of-life decisions (J. M. Teno et al.). Surrogates tend to make substitute decisions that overestimate the patient's desire for aggressive treatments (Ditto et al.). Physicians are sometimes unaware an advance directive even exists (Virmani, Schneiderman and Kaplan). However, ACP is not without its benefits (Tierney et al.; Detering et al.; Houben et al.), and

there have been promising developments such as POLST (Physician Orders for Life-Sustaining Treatment) forms that better specify treatment preferences (Hickman et al.). ACP is worth pursuing and worth improving. Our experiences with seriously and terminally ill patients have only confirmed the importance of having early discussions regarding end-of-life care and of remaining vigilant to the desires of a patient who wants to die well. We may embarrass ourselves while fumbling through the details of different end-of-life treatment options or take a few extra paces outside the patient's door before gaining enough courage to go in and broach the topic of ACP. But we will remember Mr. R as the example of one who died well and step in with courage before another Mr. P cannot make his own decisions. Hopefully, in the middle of it all, a patient will be able to get his water while the other is getting his beer.

References

- De Vleminck, A., et al. "Barriers and Facilitators for General Practitioners to Engage in Advance Care Planning: A Systematic Review." *Scand J Prim Health Care* 31.4 (2013): 215-26. Print.
- Detering, K. M., et al. "The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial." *BMJ* 340 (2010): c1345. Print.
- Ditto, P. H., et al. "Advance Directives as Acts of Communication: A Randomized Controlled Trial." *Arch Intern Med* 161.3 (2001): 421-30. Print.
- Hickman, S. E., et al. "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program." *J Am Geriatr Soc* 58.7 (2010): 1241-8. Print.
- Houben, C. H., et al. "Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis." *J Am Med Dir Assoc* 15.7 (2014): 477-89. Print.
- Steinberg, K. E. "Advance Care Planning: Just Do It!" *J Am Med Dir Assoc* 15.7 (2014): 454-6. Print.
- Steinhauser, K. E., et al. "Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers." *JAMA* 284.19 (2000): 2476-82. Print.
- Teno, J., et al. "Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the Support Intervention. Support

Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment." *J Am Geriatr Soc* 45.4 (1997): 500-7. Print.

Teno, J. M., et al. "Do Advance Directives Provide Instructions That Direct Care? Support Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment." *J Am Geriatr Soc* 45.4 (1997): 508-12. Print.

Tierney, W. M., et al. "The Effect of Discussions About Advance Directives on Patients' Satisfaction with Primary Care." *J Gen Intern Med* 16.1 (2001): 32-40. Print.

Virmani, J., L. J. Schneiderman, and R. M. Kaplan. "Relationship of Advance Directives to Physician-Patient Communication." *Arch Intern Med* 154.8 (1994): 909-13. Print.