

NEW PERSPECTIVES

The Next Trip: Talking to Patients about the End of Life

Laura Dingfield, MD, in conversation with Charmaine Wright, MD

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One of my favorite patients told me that the secret to life was growing older but not old. Just three years ago, I marveled at her ability to attend daily mass in the morning and destroy her fellow card players at bridge in the afternoon. Now that her health is declining, she has moved in with her daughter and is currently unable to leave the house. My practice is fortunate to have a nurse practitioner who visits homebound patients. In follow up to a recent home visit, I called my patient to ask a bit about her end-stage heart failure—but more about her grace. She said a large part of living well in her 80s was knowing everything she could about where she was headed. Before her trip to France eight years ago, she learned a new language, researched places to stay, booked her passage, and told her family and friends about what she wanted to do during her trip. She faces her time now with that same attitude and wants to talk to her family and friends about the end of life, what she calls “her next and most important trip.”

It is estimated that there are 3.6 million homebound adults in the United States over age 65. These individuals suffer from a wide range of medical and psychiatric co-morbidities and are repeatedly hospitalized. In order to honor patient preferences in both inpatient and outpatient health care settings, it is crucial for providers to engage all patients—especially these high-risk individuals—in discussions of advance directives, including living wills and appointment of health care proxies. Preemptive conversations regarding end-of-life decision making are particularly important, as physicians and family members are not

able to consistently predict patient preferences.

Thinking about my patient’s advice and the increasing size of the homebound population, I sat down with a medicine-pediatric resident to hear her thoughts on helping families plan and talk about growing older with their homebound loved ones and how she is learning to incorporate advanced directives discussions into her practice.

CW: Do you expect that families with a homebound loved one have talked about the end of life? How have you learned more about these discussions?

LD: Despite their importance, few patients complete advance directives, and the use of advance directives in the homebound population has not been previously examined. I sought to better understand the use of advance directives in a cohort of elderly homebound patients in West Philadelphia by administering a short 11-question survey on the subject to patients or their family members. I also hoped to identify avenues for future interventions to increase completion of advance directives. Patients participating in the survey were recruited from a home-based primary care program at our academic urban practice.

CW: What were the results from the survey?

LD: I administered the telephone survey to a total of 16 individuals; four surveys were completed by family members because patients carried diagnoses of dementia or intellectual disability. Almost all survey participants were familiar with living wills and the roles of power of attorney (87.5% and 94%, respectively).

However, only 25% of those surveyed had completed a living will, and only 44% had officially appointed a power of attorney. Slightly less than half of those surveyed were interested in receiving more information about advance directives, and most participants wished to receive information directly from their physician. Amazingly, 67% of participants cited not being asked by their physician as the primary reason that they had not completed an advance directive.

CW: What surprised you most?

DL: The results of the survey were very informative, but I was even more struck by how willing patients and their family members were to discuss end of life planning with me, a stranger on the other end of the telephone line. I had anticipated resistance, but I met none. Patients were eager to tell me about the plans that they already had in place. Those who had not completed advance directives recognized the importance of end-of-life planning and had thought about it, even if they had not put anything into writing. It was an issue that resonated strongly with the patients and family members who I interviewed. Patients wanted to have their stories and desires heard and often had started these discussions without encouragement by a physician.

CW: How has this changed your practice moving forward?

DL: After leaving these conversations, I am motivated and encouraged to discuss end of life not just with patients who are or may soon become homebound but every aging patient. These discussions can

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be difficult because of a patient's desire to remain independent, but just as your patient learned a new language and told everyone what she wanted to do on her trip to France, so should we handle these discussions with our patients. Sitting down, learning, and talking about the options with an aging patient can take the burden off the families, and they become more aware of their loved one's choices. These candid discussions open the door to smoother transitions when

the loved one becomes more dependent or homebound. I've found a lot of resources through our practice's social worker and online as well. Longtermcare.gov is a great place to learn about the different kinds of assisted care for patients, as well as payment and planning options. Silver Connections or the Department of Aging are national resources that will provide senior case management; veterans have an Aid and Attendance program that will provide monetary assistance for

caregiver support. I have also found the *Five Wishes* (<http://www.aging-withdignity.org/five-wishes.php>) resource to be extremely useful in helping my patients express what they want their loved ones to know about future health care decisions.

CW: Thank you, Dr. Dingfield. I hope we are all inspired to have these important discussions with families, promoting the dignity of our patients as they age.

SGIM