Being Mindful: Difficult Decisions in Advanced Dementia and End Stage Renal Disease

Aziz A. Ansari, DO, SFHM, FACP, Daniel Pomerantz, MD MPH FACP, and Kevin Smith, MD

Dr. Ansari (AANSAR1@lumc.edu) is an associate professor in the Department of Medicine at Loyola University Medical Center and associate director of the Division of Hospital Medicine and the Medical Director of the Home Hospice Program. Dr. Pomerantz (dpomeran@montefiore.org) is an assistant professor in the Departments of Medicine and Family Medicine at the Albert Einstein College of Medicine and the director of palliative care at Montefiore New Rochelle Hospital. Dr. Smith (kevsmith@lumc.edu) is an assistant professor in the Department of Medicine and the Department of Pediatrics and associate chief medical officer for quality and safety at Loyola University Medical Center.

The number of patients suffering from chronic illness continues to increase; however, advances in technology often promote longevity, but not necessarily optimal quality of life. Two life-limiting illnesses that often raise the question of how to balance quantity and quality of life are advanced dementia (AD) and end stage renal disease (ESRD). Prognostic uncertainty and unpredictability are common to each of these conditions. Both AD and ESRD are especially challenging for clinicians trying to guide families through difficult decisions about the use of artificial nutrition and hydration (ANH) or initiating hemodialysis (HD). Many clinicians lack an understanding of the evidence for and against initiating these aggressive interventions in such patients. Given that this level of uncertainty can cloud the picture of the true benefits of these treatments, patients and families are often inadequately prepared and empowered to make fully informed decisions. In addition, many providers lack the communication skills training required to discuss patient and family values that should guide these decisions or are not trained to convey the idea that less aggressive interventions can improve quality of life, without hastening death.

Dementia is an extremely common condition affecting 24.3 million people worldwide,1 and is anticipated to affect 13.2 million in the US by 2050.2 In the United States, it is also the fifth leading cause of death for people over the age of 65 years with Alzheimer’s disease being the most prevalent type, followed by vascular, Lewy Body, and other rarer forms of dementia.3 Feeding difficulty in AD is common, with 85.8% of nursing home residents with AD experiencing eating problems in a retrospective study.4

What is often underappreciated is that AD is a terminal condition with a six month mortality of 25% and a median survival of 1.3 years. This life expectancy is similar to better recognized terminal conditions such as metastatic breast cancer5 and advanced congestive heart failure.6 Despite this limited life expectancy, a growing number of patients with AD are receiving feeding tube placement for their eating problems. There are many factors that influence the use of feeding tubes, including absence of advance directives, legal and regulatory fears of nursing home administrations regarding weight loss, and the Medicare and Medicaid reimbursement models for feeding tubes. More concerning are the misperceptions of the value of feeding tubes by the clinicians who are helping families to manage this challenging decision.

A survey of primary care physicians from the AMA Masterfile in 2003 showed that a majority of physicians who responded felt that a percutaneous endoscopic gastrostomy (PEG) tube reduced aspiration pneumonia, improved pressure ulcer healing, improved survival, and was the standard of care.7 A survey of family members reported that in cases where patients had a feeding tube inserted, 13% reported that a physician had no discussion with the family about insertion, and when he/she did, 41% of the conversations lasted less than 15 minutes. Further, 52% of families felt the clinicians strongly favored feeding tube insertion.8

These experiences are in sharp contrast to what the literature actually says. A Cochrane review of six observational studies showed no evidence that enteral feeding prolonged survival, improved quality of life, enhanced nutrition, or decreased the risk of pressure ulcers.9 Other studies concluded that patients who had a feeding tube inserted were more likely to develop pressure ulcers,10 did not have a reduced risk of aspirations;11 had increased use of restraints, and required more hospital days. In addition, 20% of patients required replacement or repositioning of the tube.12 The periprocedural mortality of patients with dementia who undergo PEG tube placement is 6-28%,13 and 64% die within a year after placement, with a median survival of only 56 days. Patients with feeding tubes may be isolated and lose the social stimulation that accompanies hand feeding. AD continues to follow its natural course regardless of interventions we may be able to perform. Our professional challenge is to support patients and their families while providing accurate information about the role of artificial nutrition in AD.

As with dementia, physicians seem to have misunderstandings...
about the burdens and benefits of hemodialysis in frail elderly people. Patients over the age of 75 years are the fastest growing group undergoing HD initiation in the United States. However, mortality exceeds 50% within the first year after starting HD in patients older than 80 years of age.\textsuperscript{14,15}

Few studies exist comparing the survival benefit of conservative therapy with HD. In the studies that have been performed, the survival benefit appears to dissipate in elderly patients with significant co-morbidities such as ischemic heart disease.\textsuperscript{16} Other studies have found no survival benefit in patients over 80 years or over 70 years with co-morbidities.\textsuperscript{17,18} Furthermore, initiating HD in patients with poor performance status, who are referred to as “frail”,\textsuperscript{19} elderly patients with falls, and those with cognitive impairment,\textsuperscript{20} may actually be harmful. Patients on HD often have chronic pain significantly more often than the general population, which also affects quality of life.

Conservative therapy may offer a more patient-centered approach, as elderly patients on HD are more likely to be hospitalized and die in the hospital.\textsuperscript{21,22} Patients managed conservatively have a median survival time of 13 to 18 months\textsuperscript{13,18,22} with fewer hospitalizations and a greater likelihood of dying at home. HD also is unlikely to maintain functional status. In a retrospective study of 3702 nursing home patients who were started on HD, only 13% maintained their functional status at one year.\textsuperscript{15} Co-morbidities and baseline disability appear to be the most significant factors that will determine decline. In fact, conservative therapy actually may be more useful in maintaining or preventing a sharp decline in functional status.\textsuperscript{23} Since HD is a therapy that can significantly affect mortality, functional status, and quality of life, it should be considered similarly to chemotherapy when assessing a patient’s fitness for such a burdensome intervention.

As with dementia, many physicians do not have a good understanding of the lack of benefit of HD in many elderly patients, and they may lack the communication skills to guide a patient and family through this difficult decision. This lack of shared decision making may explain why up to 30% of patients older than 75 years withdraw from HD, which suggests that the ability to counsel patients about foregoing HD should be a core competency for any physician who deals with this condition.\textsuperscript{24} Patients surveyed often regretted their decision to start HD and reported that they had not had a discussion about end of life care with their physician.\textsuperscript{25} National guidelines recommend patients complete advance directives when initiating HD, but few patients accomplish this task, and when they do, it rarely includes stopping HD.\textsuperscript{26} Palliative care involvement is likely to be beneficial as a joint palliative care and nephrology program in Australia showed improvement in symptoms and quality of life scores.\textsuperscript{18}

Palliative care providers can help patients with AD or elderly patients considering initiating HD. Given the large number of these patients, primary care providers must be comfortable having these challenging discussions incorporating the scientific evidence and patient centered value based themes. Some tips for this type of conversation include the following:

1. Obtain the caregiver’s and patient’s perception of illness;
2. Give relevant data;
3. Elicit concerns and goals based on evidence;
4. Present goals based on patient and caregiver values;
5. Be mindful of prognostic uncertainty;
6. Make a recommendation with permission; and
7. Balance realism and hope.

By utilizing these conversations mindfully and applying the best available evidence, generalists can be more patient centered in their care of these vulnerable patients. Patients and families will be able to make fully informed decisions based on their goals. Along with advance directives, we can ensure that our patients are given the opportunity to determine an appropriate plan for care that respects their wishes and values.

References


