Editorial

Expectation Conversations About the Very Predictable Events in Advanced Dementia

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If you’re caring for an older adult with advanced dementia, odds are you’ll be asked to participate in a critical decision in the next 6 months and the decision will likely center on administration of antibiotics, hydration, or nutrition. The article entitled, “Critical decisions for older people with advanced dementia: A prospective study in long-term institutions and district home care” in the June issue of the Journal by Franco Toscani et al 1 offers interesting insights into the dialogue clinicians who care for persons with advanced dementia face.

Few studies have described the types of decisions that are made for this population. The aim was to describe treatments, discomfort, and critical decisions made for patients with advanced dementia. Critical decisions were defined as decisions that involved starting, withdrawing, or withholding treatment that the medical team deemed critical to a patient’s survival and/or quality of life. The study was conducted in 2 regions of Italy with different approaches to persons with advanced dementia with one region relying on nursing homes and the other on home care teams for supportive care. The study only included patients with advanced dementia as assessed by a Functional Assessment Staging Tool (FAST) ≥7. Discomfort was assessed every 2 weeks until death or through 6 months of follow-up. Only 3 nursing home patients had an advance directive, but more than 80% received weekly and 14% monthly visits from a relative. Most patients (73%) in both cohorts were able to be followed for 6 months and 20% were not followed for the full time period due to death, which was identical in the nursing home and home care cohort. Critical decisions were made for 60% of nursing home and 43% of home care residents over the 6-month study period, and most of the decisions focused on nutrition, treatment of an infection, or worsening disease.1

Several key issues emerge from this study, including the role of autonomy in persons with advanced dementia, understanding what treatments are in the best interest of this vulnerable patient population, understanding what treatments may harm these individuals, and broader issues pertaining to social justice and population health.1 Using a medical ethical perspective, the most common framework in the United States, we can frame these questions around 4 guiding principles:

- Respect for autonomy by ensuring the patient is both informed and able to participate in medical decision-making.
- Beneficence mandating that clinicians act in the best interests of their patients.
- Non-maleficence guiding clinicians not to harm patients.
- Justice requiring fair and equitable treatment for all.

Ideally in a society valuing these principles, those with dementia would have been informed well in advance of disease progression about the typical clinical course associated with dementia and given an opportunity to document preferences for care based on their personal values. In the absence of such directives, input would be sought from those who know the values of the patient and all efforts would be focused on providing beneficent, nonmaleficent care. Regardless of who is making decisions, an understanding of illness trajectory in advanced dementia is necessary before making declarations about care preferences.

The patients in this study followed a predictable course of illness observed in similar cohorts of persons with advanced dementia.1 In the CASCADE study of nursing home residents with advanced dementia, more than half died during the 18-month study period, infections and nutrition were common complications, and occurrence of these events was associated with high rates of 6-month mortality.2 Importantly, CASCADE residents whose proxies understood the clinical course and poor prognosis of the disease were less likely to recommend aggressive interventions, such as hospital transfer, tube feeding, or intravenous therapy in the last 3 months of life (adjusted odds ratio 0.12, 95% confidence interval 0.04–0.37).2

Although some advanced care planning documents speak to the common critical decisions that arose in the Toscani et al study1 (mainly decisions pertaining to nutrition, hydration, antibiotics, hospitalization, and decline associated with chronic illness), both the CASCADE and Toscani et al1 studies emphasize the specificity with which these conversations could occur at the time of diagnosis. In the absence of available advance care planning documents completed by the patient, an “expectation conversation” would seem to be a very reasonable alternative at the time of admission to a nursing home or home care. The physician or other appropriately trained staff could speak with family members about the likelihood that one of these critical decisions may need to be made in the coming weeks and

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months. A care plan could then be developed to guide staff when one of these predictable critical decision points arise, much the way a do-not-resuscitate order guides staff and family in the event of a cardiac arrest.

An interesting aspect of the Toscani et al study is that almost none of these residents had an advance directive and the vast majority of the decisions were made without input of family in the nursing home cohort (despite regular presence of family in the nursing home). The lack of specific directives limiting aggressive care in the United States has been associated with higher utilization of feeding tubes, more terminal hospitalizations, more aggressive care for pneumonia, higher health care expenditures, worse family satisfaction with end-of-life care, poorer family mental health outcomes, and lower use of hospice.

The authors report that recent initiatives may be changing this pattern of paternalism, but it is important to note that approximately one-third of the critical decisions in the nursing home cohort had the single purpose of prolonging survival. This is important for 2 reasons. First, it suggests that these clinicians believe that many of the available interventions were life prolonging when in fact this may not be the case, as is discussed later in this editorial. Second, it brings up the role of paternalism in times of “life-and-death” decisions. In the United States, paternalism has given way to autonomy, but some have questioned whether this trend places undue burden on some family members who look to clinicians for guidance about “life-and-death” decisions. It would be helpful to further characterize how much “palliative paternalism” took place in these nursing homes in which the physician struck a balance between family autonomy and paternalism based on their knowledge of disease course and how that approach ultimately effected family bereavement.

In the home care cohort, with 90% of patients classified as having very advanced dementia (FAST 7C-F) and a mean age of 87 years, family members were regularly involved in decision-making and twice as many critical decisions in this setting had the single purpose of prolonging survival. The authors attribute this focus on prolonging survival in a group of elders with very advanced disease to a cultural bias toward interventions intended to prolong survival among Italian physicians. The conundrum of preserving life and the ethical principles of beneficence and nonmaleficence begin to appear as we look at the number of critical decisions made regarding reducing symptoms and suffering. Clearly, the physicians were faced with patients they feared were suffering. In the nursing home cohort, 81% of the critical decisions were focused on reduction of symptoms and suffering, whereas 57% of those in the home care cohort centered on these concerns.

Regardless of a preference for treatments focused on life prolongation, patients with symptoms resulting from a systemic infection in the context of advanced dementia have a poor prognosis. Although these infections may be reversible in the short term, they are often a harbinger of impending death regardless of antibiotic treatment that often results in only temporary improvement. In a study of 54 Veterans Affairs Nursing Home residents with advanced dementia who were treated with antibiotics for respiratory infections, mortality at 10 days was 48%, and in a study of patients diagnosed with pneumonia, the 10-day and 6-month mortality was 48% and 74%, respectively. Frequent use of antibiotics in residents of nursing homes with advanced dementia is leading to development and transmission of multidrug-resistant organisms. In a 1-year study of 362 residents with advanced dementia living in a Boston area nursing home, 72% were treated with antimicrobials but only 44% met minimal clinical criteria supporting use of antimicrobials. After 1 year, 48% of previously noncolonized residents had acquired a multidrug-resistant organism.

Can clinicians ease suffering without the use of antibiotics? Investigators in 2 Dutch nursing homes followed 24 residents who were expected to die within a week and measured physical discomfort, pain, and overall suffering twice daily. Low symptom burden was observed even in those who did not receive antibiotics with the use of treatments aimed at providing comfort. Practice guidelines have recently been developed to guide clinicians focused on relief of the distressing symptoms associated with pneumonia and the other common signs and symptoms encountered with progressive dementia.

In the home care cohort, 26% of the critical decisions involved a decision to be hospitalized compared with only 3% in the nursing home cohort. The authors explain that many of the procedures that prompted a discussion about hospitalization among home care patients could be performed in nursing homes that were in many ways similar to subacute nursing home facilities in the United States and this explains the differences in decisions regarding hospitalization. Hospitalization is common in advanced dementia, and some estimate that as many as 75% are avoidable, either because hospital-level care is unnecessary or inconsistent with preferences. Pneumonia, which was a common precipitant for hospitalization in this study, and the most common reason for hospitalization among advanced dementia patients in general, can often be treated with equal efficacy in the nursing home or community, with fewer burdens to the patient and less cost to the health care system. Hospitalizations are generally not an ideal means of relieving suffering because they can involve painful procedures, placement of feeding tubes, further decline in cognition, and frequently do not improve end-of-life outcomes for persons with advanced dementia.

Can clinicians ease suffering without artificial hydration and nutrition? Nutritional problems in the Toscani et al study led to 20% of the critical decisions in the nursing home cohort and 24% in the home care cohort. In the United States, it is estimated that as many as one-third of nursing home residents with advanced dementia have feeding tubes; the prevalence in the Toscani et al study was approximately 10% in both the nursing home and home care cohorts for tube feeding and 15% for artificial hydration (intravenous or subcutaneous). Artificial hydration was also a common impetus for critical decisions in the nursing home cohort. The primary reason for initiating artificial hydration and nutrition was to ease suffering and prolong life, but evidence indicates that in advanced dementia these interventions do not prolong survival or improve quality of life.

Placement of a feeding tube can lead to pain; increased risk of aspiration; pressure ulcers; feeding-related gastrointestinal symptoms, such as diarrhea; restraint use to prevent removal of the tube; fluid imbalance; and actually increase in the perception of hunger. Similar to the data observed for administration of antibiotics, most residents who experienced placement of feeding tubes were no longer living 1 year after placement (mortality 64%) and median survival was 56 days after placement. Based on this evidence, the American Board of Internal Medicine Foundation Choosing Wisely campaign, which seeks to promote conversations supported by evidence, recommends the following, “Don’t insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feeding.” This recommendation is endorsed by the American Academy of Hospice and Palliative Medicine, AMDA—The Society for Post-Acute and Long-Term Care Medicine, and the American Geriatrics Society.

Although advance directives were not commonly available in this study to guide treatment decisions, the authors describe a new initiative in one of the regions where the study was conducted that will require physicians to make treatment decisions with the family or legally appointed guardian. Decision aid videos followed by a structured interdisciplinary care plan meeting may improve surrogate
knowledge about illness trajectory in advanced dementia and enhance the quality of communication between care providers and family members. The feasibility of this approach has been demonstrated, and a large randomized controlled trial is under way to further test the effectiveness of this approach.27

Another interesting feature of this study was the use of 2 different models of long-term supports and services to care for persons with advanced dementia. In one region of Italy, care for persons with advanced dementia was provided in nursing homes, whereas another region provided home services to meet the needs of those with advanced dementia. As “rebalancing” efforts seek to increase home and community-based supports in the United States, there is likely much to learn from communities that have taken a home care approach in lieu of relying on nursing home care routinely for persons with advanced dementia. In a study of the effect of place of residence on quality of life for persons with Alzheimer disease, a slightly better quality of life was observed for persons residing in a nursing home,3,34 but most data on the relationship between quality of care and supports and services pertains to hospice support in nursing homes for those with advanced dementia.9,9,30

Most patients in this study would have been eligible for hospice in the United States by virtue of having dementia at a FAST stage 7C-F and at least one medical complication in the past year.29 Benefits of hospice provided to patients with advanced dementia include the following: a lower probability of hospitalization during the last 30 days of life (19% versus 39% for hospice versus nonhospice patients),30 a higher probability of regular treatment for daily pain (44% versus 27%),12,31 and greater family satisfaction with care.12,32 Although suffering was measured by the Discomfort Scale—Dementia Alzheimer Type every 2 weeks in the Toscani et al study,1 the authors do not specifically comment on trends over the course of the study in this article. Mean values were significantly higher in the nursing home cohort compared with the home care cohort, but were consistent with scores achieved after resolution of distressing symptoms associated with illness in previous studies.33 Hopefully we will see these authors report on discomfort trends over time in the 2 cohorts and the association with different approaches to treatment in future publications.

All of the patients in this study1 had advanced dementia and were therefore not able to actively engage in autonomous decision-making. Ideally, we would be able to look to an advance directive for guidance, but in this study almost none of the patients had such a document available. Even in the United States, where significant effort has been made to encourage advance directive completion, advance care planning among persons with dementia is low.30 Consensus guidelines recommend initiating advance care planning discussions after the patient has come to terms with the diagnosis of dementia and is ready to participate in advance care planning. Experts recommend that clinicians describe the process in terms of “certain possibilities” and emphasize personal choice and autonomy while remaining mindful of financial considerations and spousal involvement.14

“Expectation conversations” with patients soon after diagnosis, and with family members when patients no longer have the capacity to participate in such decisions, can be supplemented by decision aids. Decision aids have been developed describing the lack of evidence to support use of artificial hydration and nutrition, as well as the risks and potential benefits of antibiotics and hospitalizations. In a randomized controlled trial designed to improve feeding tube decisions using a decision aid presented to family caregivers, those who received a decision aid felt less conflicted and were more likely to discuss feeding options with a health care provider.35 In another study, surrogate decision makers experienced less decisional conflict and demonstrated increased knowledge about their decisions when a tube-feeding decision aid was available.36 As clinicians work to develop tools to support compassionate care of persons with advanced dementia, clarity may prevail. First, emphasis on advance care planning soon after diagnosis may allow greater autonomy in advanced disease. Second, efforts to disseminate palliative care models of care focused on symptom management would allow clinicians to act in the best interests of their patients. Third, interventions traditionally believed to be life prolonging are increasingly viewed as harmful. The emerging body of evidence on illness trajectory suggests that the risks of interventions, such as tube feeding, antibiotics, and hospitalization, often outweigh the potential benefits, and if we adhere to the principle of nonmaleficence, it is incumbent on clinicians to discuss these risks with patients and families. Just as many of the decisions in the Toscani et al study1 were made independently from family members, many family caregivers in the United States report either no or minimal communication with clinicians related to the decision for their loved one to receive a feeding tube.37

Finally, this study1 brings to light larger issues of equity in care and justice. Are we trading an easier act of writing a prescription for the harder conversation about why we’d prefer not to write a prescription and placing communities at risk by contributing to drug resistance? Can we seek equitable treatment in the form of social supports that permit care in the most appropriate environment rather than the ones that exist by default? It is striking that one community provided advanced dementia care in nursing homes while another community provided all advanced dementia care with home care services. Certainly there were situations in both communities in which the optimal care environment was not available, and clearly care practices were very different in the 2 communities, raising questions about equality of social supports and services. This imbalance of supports and services is certainly not unique to these study communities, but illustrates how adaptable communities can be depending on what resources are made available.

Until decision aids are widely available and evidence-based, a few things are clear. There are very predictable critical decisions that will likely need to be made for persons with advanced dementia. We need to know what to do when a pneumonia develops, how we will handle problems with nutrition and hydration, and whether or not hospitalization is desired for worsening conditions. The evidence for these interventions is available, and guidelines are being developed to aid in symptomatic management. These guidelines can be used to train staff and loved ones to respond to the very predictable events that will occur for persons with advanced dementia. Robust care plans and expectation conversations hopefully will be routine and allow clinicians to replace the phrase, “There's nothing more we can do” with, “There's much more we can do for your loved one.”

References


