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Dying in the Hospital With Advanced Dementia

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Case Objectives

- Recognize the importance of eliciting patient preferences and goals of care at the end of life.
- Describe the potential benefits of a Physician Orders for Life-Sustaining Treatment (POLST) form.
- Provide one recommendation for improving care at the end of life from the 2015 National Academy of Medicine report, *Dying in America.*
- Describe one simple strategy to ensure primary care providers are aware of in-hospital deaths.

Case & Commentary—Part 1

A 74-year-old woman with history of advanced dementia and end-stage renal disease on hemodialysis was found unconscious at home by her family. Paramedics were immediately called, and they found her without a pulse, in a rhythm of asystole. She was intubated and received cardiopulmonary resuscitation (CPR) with return of spontaneous circulation. Upon arrival in the emergency department, still unresponsive, she was registered under a temporary medical record number. Her examination was notable for hypothermia, hypotension requiring vasopressor infusion, fixed and dilated pupils, and an absence of voluntary extremity movement or brainstem reflexes. Laboratory studies were notable for an anion gap metabolic acidosis, with pH 6.97 and lactic acid 9.2 mg/dL.

Dementia is common in the United States, and Alzheimer disease is the most common form of dementia. It is now the fifth leading cause of death for Americans age 65 and older, and 1 in 3 seniors die with dementia.(1) The median survival from diagnosis ranges from approximately 3 to 7 years.(2,3) Median survival for those with advanced dementia, like this patient, is 1.3 years.(4) Most individuals with dementia will die in a nursing home (67%), but a large minority, such as the woman in this case, will die in the hospital (16%).(5)

Evidence suggests that those with dementia prefer to die at home or in hospice. In one study comparing end-of-life experiences of patients with dementia who were enrolled or not enrolled in hospice, those in hospice were almost 10 times more likely to die in their "location of choice."(6) In that analysis, 76% of those in hospice died at home, and only 7% died in a hospital; in contrast, 45% of patients not enrolled in hospice died in a hospital.(6) Other evidence suggests that caregivers and clinical providers have similar preferences for patients with dementia.(7) Avoiding hospitalization for patients with advanced dementia is not only consistent with the preferences of most, it is also good care. Patients hospitalized with dementia have increased risks of functional decline (8), as well as greater risks of receiving unnecessary care, such as feeding tubes.(9)

For patients with advanced dementia who do end up dying in hospitals, caregivers might not have a clear understanding of a loved one's poor prognosis. Research suggests that if surrogates have a better understanding of their family members' prognosis, there is a lower likelihood of hospital admission. Similarly, those with documented advance directives are less likely to have burdensome treatments at the end of life, including feeding tubes, hospitalizations, and intensive care unit stays in their last months of life.(4,10)

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm is one method to improve the documentation of care wishes at or near the end of life. POLST forms include preferences about code status, as well as general level of medical interventions (comfort care vs. full treatment), antibiotics, and artificial nutrition. A physician signature is commonly required to activate the form, which serves as an order to care providers, regardless of setting.(11) The form is often pink, included in statewide registries for easy access by providers (from physicians to emergency medical technicians [EMTs]), and can be placed in locations in the home, such as on the refrigerator, that are easy to locate. In a study of 572 EMTs in Oregon, 73% had treated patients with a POLST form, and 45% stated the orders changed treatment decisions.(12) Another study in Oregon suggested that 91% of those dying with POLST forms had CPR use consistent with their documented preferences.(13) Studies in other settings such as nursing and hospice facilities suggest that the care patients receive is more likely to be consistent with their preferences when those preferences are clearly documented in a POLST form.(13)

Case & Commentary—Part 2

The patient's permanent medical record was later identified, noting a recently completed POLST form, with DNR/DNI code status recorded. After communication with the family, the patient's care was transitioned to a focus on comfort and the patient died peacefully a few hours later.

Despite the ultimate transition to comfort care, many would agree that this patient's death was less peaceful than she, her family, or her providers would have liked. Her last hours of life included intubation and CPR in the field, transfer to an emergency department (ED), and placement of a central line with vasopressor infusion, none of which were consistent with her goals of care at the end of life. How did this happen?

Most likely, the family member who found her and the EMTs who responded were not aware of this patient's wishes regarding end-of-life care. Despite the encouraging studies about the impact of POLST forms in Oregon, a more recent study of 230 EMTs in New York suggested less than a third had ever seen a POLST form in the field (14), and another study of 178 EMTs noted that POLST forms were often hard to locate when needed.(15) Just as important, many patients near the end of life do not have such forms completed. In another study in Oregon, out of more than 1500 out-of-hospital cardiac arrests, only 5% had a POLST form.(16) Importantly, for those with POLST forms, the vast majority included orders for no resuscitation.(17)

The 2015 National Academy of Medicine (NAM, formerly the IOM) report *Dying in America* provides a path forward.(18) The report offers five recommendations to help prevent scenarios like the one illustrated by this case. First, the NAM recommends the development of standards to foster advance care planning, such that all patients, particularly those at high risk of mortality, are able to share their medical preferences to ensure their medical care is consistent with their goals. Such standards could include the completion and filing of POLST forms for patients at high risk of mortality. In our own institution, we are currently auditing the proportion of patients with malignancies who have care preferences documented in the Advance Care Planning tab of our electronic health record (EHR), and providing that feedback to our oncology providers to foster improvement.

Second, the NAM recommends professional development and education focused on advance care planning. Professional societies may provide such education, which may be required for state licensure or by the ACGME for residency training programs. At our institution, we are utilizing Ariadne Labs' Serious Illness Care Program to train our palliative care physicians to train our oncology providers.(19) Third, the NAM recommends public education to encourage patients and their families to have advance care planning discussions and to engage their physicians in these conversations. Fourth, the NAM recommends that government and commercial payers cover comprehensive care programs for patients with serious illness. Medicare's 2016 decision to reimburse providers for their time when having advance care planning discussions with their patients was a positive step.(20) Covering palliative care and hospice services are other important approaches.

Palliative care services are initiated when patients are diagnosed with serious illness. As illness progresses, the ratio of palliative care to life-prolonging care may gradually increase (Figure). When provided in the context of serious illness, palliative care services include pain management, symptom management, therapies with palliative rather than curative intent (e.g., radiation, milrinone), assistance with complicated medical decision-making, coordination of care with other providers, and emotional and social support. While palliative care may be beneficial for patients at various stages of serious illness, to be eligible for Medicare's hospice care benefit, patients must have an expected survival of 6 months or less.(21) Given the unpredictability of death for patients with advanced dementia, these hospice criteria are often difficult to satisfy, resulting in low rates of hospice enrollment: in 2007, only one third of Americans dying with dementia received hospice care.(3) Regardless of hospice eligibility, palliative care should be offered to patients such as the woman in this case. Evidence suggests that patients with dementia in palliative or hospice care are much more likely to have care consistent with their goals, have greater family satisfaction with their care, and die outside of the hospital setting.(3,22)

Lastly, the NAM recommends the development of health policy strategies to foster advance care planning. This could include support and further development of state registries for cataloguing POLST forms, public reporting of advance care metrics, and pay for performance based on these metrics. Currently, POLST registries are being developed or are available in many states.(18) Improving the documentation of advance care planning information in EHRs (23) and sharing this information through state registries or health information exchanges may also help.(24) If the EMTs in the case above had unfettered access to the patient's POLST form in a state registry prior to arrival at the patient's home, her resuscitation, intubation, and transfer to the hospital in the last hours of her life may have been avoided.

Case & Commentary—Part 3

Two months later, the primary care clinic staff called the patient's home with an appointment reminder, and the family replied that the patient had died. This information was relayed to the primary care provider (PCP) who then called the family, assuming that the patient must have passed away recently. The family informed the PCP that the patient had died 2 months earlier. The family had thought their doctor had been informed of their mother's death and assumed that the PCP was "just too busy" and unable to make it to the hospital to support them. In reality, the PCP had not been contacted, and the electronic health record system had not listed the patient as deceased.

Communication between hospital-based providers and PCPs is challenging, even in the era of the EHR. One study found that only 3 in 4 PCPs were aware that their patient had been hospitalized.(25) A more recent systematic review found similar rates of awareness among PCPs, but the frequency of direct communication between hospital providers and PCPs was much lower (about 1 in 4).(26) While one could argue that communication about a patient's death is among the most important in this context, most discussions of hospital–PCP transitions omit this crucial topic, perhaps owing to an underlying assumption that death is "the end of the story," and thus there is no need for clear communication with the outpatient provider. This case illustrates the fallacy of this thinking.

One might assume that the EHR will notify PCPs of hospitalizations and of significant events, such as death, during a hospital stay. Unfortunately, system limitations often prevent this from happening. To address such challenges, many health systems are designing and implementing standardized discharge summary formats that ensure complete and uniform inclusion of essential information.(27) At our institution, the "summary of care" document required by Meaningful Use is automatically transmitted electronically to identified primary care physicians within our health system 24 hours after hospital discharge.(28) This document includes the hospital course and, as such, allows inpatient clinicians to communicate the circumstances of a patient death to outpatient providers.

In this case, there was yet another important glitch: The patient was registered with a temporary medical record number (MRN) when she arrived at the hospital. Although the care team was subsequently able to access her existing MRN to identify the preexisting POLST form, the temporary MRN associated with her admission was never reconciled with the permanent MRN, thus preventing automated communication with the PCP and others involved in her care. The duplicate records problem is surprisingly daunting.(29) Because clinical emergencies can necessitate the creation of duplicate records (e.g., a patient presenting with possible stroke who needs immediate attention on arrival to the ED), institutions should build systems to ensure the merging of medical records in a timely manner.(27)

Conclusion

This case illustrates opportunities to build and sustain systems to honor individual preferences and goals of care at the end of life, both by aligning policy with practice (in the case of POLST forms) and by aligning systems with practice (in the case of EHRs).(20) As stated by the NAM: "For patients and their loved ones, no care decisions are more profound than those made near the end of life… A person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life should be a national priority."(30) This case vividly illustrates why.

Take-Home Points

- Most with dementia prefer to die somewhere other than a hospital.
- Those with advanced dementia who have advance directives are less likely to have inappropriate care and more likely to have care consistent with their preferences at the end of life.
- The 2015 National Academy of Medicine report, *Dying in America,* offers a roadmap to improving the quality of life for those at the end of life, and their families.
- Communication between hospital-based providers and primary care providers is essential, especially when a hospitalization ends in the death of the patient.

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Figure

Figure. Palliative care model. *Palliative care is initiated when patients are diagnosed with serious illness. As illness progresses, the ratio of palliative care to life-prolonging care may gradually increase. Ultimately, life-prolonging care is discontinued according to patient's wishes or when treatment harms outweigh benefits. At this point, the transition to hospice occurs. After death, palliative care services help family members with bereavement.*

Source: Center to Advance Palliative Care

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