Lown Right Care

Reducing Overuse and Underuse

Diagnosing Dementia and Clarifying Goals of Care

Nick Bott, PsyD, and Ann Lindsay, MD, Stanford University School of Medicine, Stanford, California

Case Scenario

Sally is a 78-year-old retired teacher. She has hypertension and uses insulin to treat her diabetes mellitus. She lives independently with the help of a hired caregiver who visits three days per week to shop for groceries and cook. Her daughter lives nearby and visits two times per day to check Sally's blood glucose level and administer her insulin. Sally's daughter notices that Sally's memory has been worsening recently and joins her at her next primary care appointment. Unfortunately, the doctor brushes aside the memory concerns, attributing them to old age, and instead spends most of the visit managing Sally's diabetes.

In the following days, the caregiver notices Sally is acting strange. At the emergency department, a workup for altered mental status reveals a urinary tract infection with sepsis. Sally is admitted overnight for intravenous antibiotics and becomes increasingly confused and agitated. The overnight resident physician sedates her with intramuscular antipsychotics and applies soft restraints to keep her from getting out of bed. An expected one- to two-night hospitalization turns into a weeklong stay attributed to delirium. At the end of the hospitalization, Sally is deconditioned from being bedbound. She is discharged to a skilled nursing facility for rehabilitation; however, after 30 days, Sally is still having difficulty with activities of daily living and her memory function has worsened significantly.

See related *FPM* article at https://www.aafp.org/fpm/2019/0100/p11.html.

Lown Institute Right Care Alliance is a grassroots coalition of clinicians, patients, and community members organizing to make health care institutions accountable to communities and to put patients, not profits, at the heart of health care.

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The average skilled nursing facility costs more than $100,000 per year, and Sally quickly depletes her life savings before qualifying for Medicaid. Similar scenarios are all too common across the United States. Why is it difficult to provide the right care to adults with dementia?

Clinical Commentary

The current fragmentation and failure of dementia care are a problem of framing. Even if dementia is diagnosed correctly,[1] it is viewed indiscriminately, as an additional problem on the list, such as hypertension or diabetes. Prescribing acetylcholinesterase inhibitors is often the first and last clinical action physicians perform because of brief clinical encounters and the lack of a disease-modifying treatment.[2] In reality, dementia is a life-limiting terminal illness for the patient and a life-altering diagnosis for the patient's family or caregivers. The median survival rate after a diagnosis of dementia is 3.7 years.[3] Numerous studies show the value of outpatient care models involving education, counseling, care coordination, and personalized care planning and management.[4,5] Even without existing dedicated outpatient care programs, primary care physicians have much to offer patients.[6,7] A diagnosis of dementia should be considered the primary problem under which care for all other problems is organized. For example, certain chronic disease monitoring and treatment for long-term clinical benefits might be reconsidered.

Approximately two out of three older adults with dementia will be hospitalized at least once per year.[8] Many of these hospitalizations are preventable.[9] Prevention is critical because, once hospitalized, individuals with dementia have longer stays, require more care, and more often have complications leading to cognitive and functional decline, most notably delirium.[10,11] Individuals with dementia also have higher rates of rehospitalization, institutionalization, and mortality after discharge.[12] The high risk of iatrogenic harm

when individuals with dementia are hospitalized can be considered a "hospital allergy."

Outpatient clinicians play a critical role in the management of patients with cognitive impairment and dementia. Brief paper-pencil assessments include the Mini-Cog, Addenbrooke's Cognitive Examination, and the Montreal Cognitive Assessment.[13] Case finding for suspected cognitive impairment provides an opportunity to step back and ensure that the direction of health care being pursued is in line with the goals and values of the patient and family. These goals should inform advance care planning such as health optimization for elective surgeries, caregiver support, and end-of-life care.[14] A thoughtful pause opens the door for intelligent intervention that is goal congruent and invaluable for reducing complications and preventable morbidity.

Prehabilitation is the practice of optimizing physiologic parameters prior to unavoidable surgery for improving postoperative outcomes. Prehabilitation has significant promise in assisting people with dementia. Research has shown that physical exercise and diet are associated with improvements in functional and mortality outcomes. Current evidence suggests that simply measuring frailty may decrease mortality.[15,16]

Hospital at Home[17] is a well-validated model for delivering medical care for nearly one-third of the conditions that lead to hospitalization in individuals with dementia.[9,18] Eligibility criteria for Hospital at Home include the presence of a target condition (e.g., community-acquired pneumonia, congestive heart failure, chronic obstructive pulmonary disease), age 65 or older, and a residence within the geographical catchment area. Specific exclusion criteria exist for each target condition. Although there is not currently a payment mechanism for Hospital at Home in the fee-for-service Medicare program, a 30-day bundled payment model is being evaluated. Some accountable care and managed care organizations already use Hospital at Home, including Medicare advantage programs and the U.S. Department of Veterans Affairs.

To encourage comprehensive case finding, management, and continuity of care for individuals with cognitive impairment, the Centers for Medicare and Medicaid Services has implemented a new Medicare *Current Procedural Terminology* (CPT) billing code, 99483, which can be reported twice per year.[19,20] To bill for CPT code 99483, the clinician must perform assessments of safety, physical functioning, cognition, and neuropsychiatric and behavioral symptoms. The visit also requires a complete medication review, an advance care planning discussion, the creation and documentation of an ongoing care plan, and consideration of caregiver needs. Assessment of caregiver needs is critical for comprehensive care of individuals with dementia, because caregiver distress is associated with increased health care utilization and costs, particularly among women.[21] Care for caregivers can reduce costs for individuals with dementia through delayed long-term care placement and decreased unpaid caregiving hours.[22-24]

TAKE-HOME MESSAGES FOR RIGHT CARE

- Corroboration and fact-finding when memory problems are brought up should include informant report of changes in cognition and/or function whenever possible.
- Brief assessments of cognition and function are an important way to determine the presence of cognitive impairment. Brief paper-pencil assessments include the Mini-Cog, Functional Activities Questionnaire, Addenbrooke's Cognitive Examination, and the Montreal Cognitive Assessment.
- If cognitive impairment or dementia is present, adequate rapport and a patient-centered discussion will reduce distress associated with a new diagnosis.
- When dementia is present, reprioritization of the patient's health care needs is important. This includes reduced chronic disease management and increased sensitivity to the potential of iatrogenic harm of inpatient hospitalization.
- The presence of dementia provides an important "pause point" to align health care delivery with the patient's goals of care, such as prompting the completion or reconsideration of these goals.
- Alternatives to inpatient hospitalization, such as the Hospital at Home model, provide an environment for ambulatory-sensitive conditions that can mitigate risks of delirium and other inpatient complications.

Resolution of Case

The alternate ending to Sally's story starts in the family physician's office. Her physician inquires further about Sally's observed memory loss. He learns about the help Sally receives from a hired caregiver and the role her daughter fills with medication management. The doctor focuses on their concerns about underlying cognitive impairment or dementia and decides to address her other health conditions at a later visit. The

physician administers the Mini-Cog and Functional Activities Questionnaire, which suggest cognitive impairment, prompting further evaluation for dementia.[25,26] Although the news is difficult for Sally and her daughter, Sally's physician is able to answer their questions about prognosis and trajectory, and a follow-up visit is scheduled to create a care plan. Although Sally's daughter already visits her mother regularly, and she receives some outside help, additional support may be beneficial. Additionally, nonpharmacologic treatments such as aerobic exercise and diet may further improve Sally's health and quality of life. As Sally's daughter leaves, she tells the physician that it is helpful to know what has been going on with her mother and to be able to plan for the future for her mother and herself.

Address correspondence to Nick Bott, PsyD, at nbott@stanford.edu. Reprints are not available from the authors.

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