

## ***Palliative Care Rounds***

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# Does This Dementia Patient Meet the Prognosis Eligibility Requirements for Hospice Enrollment?

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### ***Key Words***

*Dementia, hospice care, life expectancy, nursing homes, predictive value of tests, prognosis, severity of illness index*

## ***Introduction***

Patients with dementia can benefit from hospice services for their end-of-life care. For most of these patients, the last year of life is one of protracted disability, and they usually succumb to infectious complications and eating difficulties.<sup>1</sup> For these patients, burdensome transitions to hospital care with little evidence of clinical benefit are common.<sup>2</sup> Hospice care results in more consistent pain management,<sup>3</sup> lower rates of hospitalization near the end of life,<sup>3,4</sup> and higher family perceptions of the quality of care.<sup>4-7</sup>

The six-month prognosis eligibility requirement may create a barrier for some patients with advanced dementia. This requirement states that to be hospice eligible, the attending physician and hospice medical director (HMD) must certify that, to the best of their judgment, the patient will more likely than

not die within six months.<sup>8</sup> Patients who demonstrate a slowly declining trajectory, with periodic exacerbations, pose a challenge to clinicians trying to determine hospice eligibility. Given that more than five million Americans now suffer with Alzheimer's disease,<sup>9</sup> optimizing end-of-life care is a significant problem for a substantial number of decedents each year.

## ***Case Description***

Mrs. C. is an 85-year-old widowed homemaker with Alzheimer's disease who was recently admitted to a nursing home following a hip fracture three months ago. That event was complicated by delirium and a congestive heart failure (CHF) exacerbation. Her ejection fraction showed moderate systolic dysfunction (35%). She also has hypertension, osteoporosis, and asymptomatic coronary artery disease. Although no longer able to walk, she has fairly preserved language skills and can assist with transfers and most activities of daily living. She does not have the capacity to discuss most of the medical treatment decisions, and defers to her daughter as her surrogate. She has lost 20 lbs. over the last two years (10 lb. in the last year) and weighs 174 lbs. Her daughter

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thinks her mother is nearing the end of life and asks whether her mother is eligible for the Medicare benefit based on her prognosis. Her physician does not expect her to die within six months but decides to look for prognostic data in the literature to better understand her prognosis.

### **Medicare Hospice Benefit Eligibility Criteria**

The Medicare hospice regulations limit the benefit to patients who will die within six months from their disease process. The benefit was designed mainly with cancer patients in mind.<sup>10</sup> The ability of physicians to reliably make this prognostic determination—particularly for noncancer illnesses—was immediately questioned after the regulations were written.<sup>11</sup> In 1996, the National Hospice and Palliative Care Organization (NHPCO) developed noncancer eligibility guidelines through a consensus process<sup>12</sup> and these were adapted by the Center for Medicare and Medicaid Services and further refined by the regional fiscal intermediaries that administer the hospice benefit. Although the NHPCO guidelines criteria are not evidence based and have been shown to be poor predictors of survival for patients with dementia,<sup>13</sup> they remain the principal resource for the clinicians tasked with determining hospice eligibility. The criteria are listed in Table 1.

Usage of these criteria poses practical problems for clinicians. First, patients with

advanced dementia often do not progress in the linear fashion as described in the Functional Assessment Staging Test (FAST),<sup>14</sup> which is a critical element of these guidelines. Data used in the development of the FAST staging system are surprisingly sparse, based on a cross-sectional evaluation of 56 patients (50 of whom were found to have followed the FAST progression), and do not link their FAST stage to prognosis.<sup>15</sup> Second, some of the qualifying complications, such as aspiration pneumonia and an “upper” urinary tract infection, are hard to determine definitively, particularly when symptoms such as cough and dysuria may be treated empirically with minimal diagnostic testing. Finally and most importantly, these guidelines discriminate poorly between patients with dementia who will die within six months and those who will not. Although studies of small cohorts of patients correlated declines in their FAST scores with a limited six-month prognosis,<sup>16,17</sup> these studies were unable to adjust for important comorbidities that have a bearing on patient survival. Furthermore, a study examining the performance of the NHPCO criteria as predictors of survival in patients with dementia already enrolled in hospice found no significant relationship between the guidelines and survival at six months.<sup>18</sup> It is a common experience that patients who do not meet these criteria may die within six months.<sup>1</sup>

Using evidence-based criteria to determine the prognosis for hospice eligibility also poses problems for clinicians. Rigorous efforts over

Table 1  
**Medicare Hospice Benefit Eligibility Criteria for Dementia<sup>25</sup>**

Patients will be considered to be in the terminal stage of dementia (life expectancy of 6 months or less) if they meet the following criteria. The medical record of the patients with dementia should show all of the following characteristics:

1. Stage seven or beyond according to FAST;<sup>a</sup>
2. Unable to ambulate without assistance;
3. Unable to dress without assistance;
4. Unable to bathe without assistance;
5. Urinary and fecal incontinence, intermittent or constant; and
6. No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words.

Patients should have had one of the following within the past 12 months:

1. Aspiration pneumonia;
2. Pyelonephritis or other upper urinary tract infection;
3. Septicemia;
4. Decubitus ulcers, multiple, stages 3 and 4;
5. Fever, recurrent after antibiotics; and/or
6. Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl.

<sup>a</sup>Functional Assessment Staging Test. Stage 7a is unable to ambulate without assistance.<sup>14</sup>

the last two decades to develop predictive instruments for survival in dementia have been met with limited success.<sup>18–23</sup> Nevertheless, clinicians can find these predictive instruments useful for providing evidence for hospice eligibility.

### ***A Suggested Approach for Clinicians to Establish Hospice Eligibility***

Despite these difficulties with prediction, attending physicians treating patients with dementia must establish a six-month prognosis defended in a short narrative written by the HMD (with the input of the attending physician) to begin hospice enrollment. This is an important responsibility because enrollment decisions, if not done carefully, can trigger financial penalties for hospices and allegations of fraud.<sup>24</sup> Fig. 1 shows a suggested four-step approach for this collaborative determination.

In Step 1, clinicians can see if the patient meets the criteria for Medicare hospice enrollment, which are based on the NHPCO criteria in Table 1. In Step 2, the clinicians can look for whether their patient has comorbidities that allow them to qualify for hospice under another noncancer illness, such as heart, lung, or kidney disease. In Step 3, clinicians can consider whether the patient might meet the NHPCO guidelines for debility, which allow for a physician's detailed description of other clinical factors, such as weight loss, abnormal physiology, or lab results, that bear on a patient's

six-month mortality, which are not captured in the enrollment criteria for other specific illnesses.<sup>25</sup> Finally, in Step 4, a clinician may find it helpful to consult with an HMD to review features of the patient's course that can help a patient qualify under the first three steps.

Applying this four-step approach to Mrs. C., she does not meet the NHPCO criteria in Table 1 (Step 1). Although she could conceivably be considered FAST 7, with her inability to ambulate independently, she neither meets the other functional requirements nor has any of the secondary conditions of aspiration pneumonia, upper urinary tract infection, or sufficient weight loss in the past year. In addition, she has no life-limiting comorbid illness (Step 2). Perhaps other prognostic research can establish a six-month mortality prediction for debility based on her two primary diagnoses: a recent hip fracture and dementia (Step 3). Patients with advanced dementia have nearly 50% mortality with hip fractures,<sup>26</sup> but Mrs. C. had made it through the postoperative period and is less impaired with her dementia than the patients in that study.

Mitchell's Advanced Dementia Prognostic Tool (ADEPT) offers an alternative to using the FAST criteria in trying to estimate whether a patient with dementia has a sufficient likelihood of dying in the next six months to allow hospice admission.<sup>20</sup> ADEPT improves on similar prior attempts to develop prognostic instruments<sup>19</sup> by studying a large national sample of nursing home patients, using reliable and easily determined clinical data obtained from

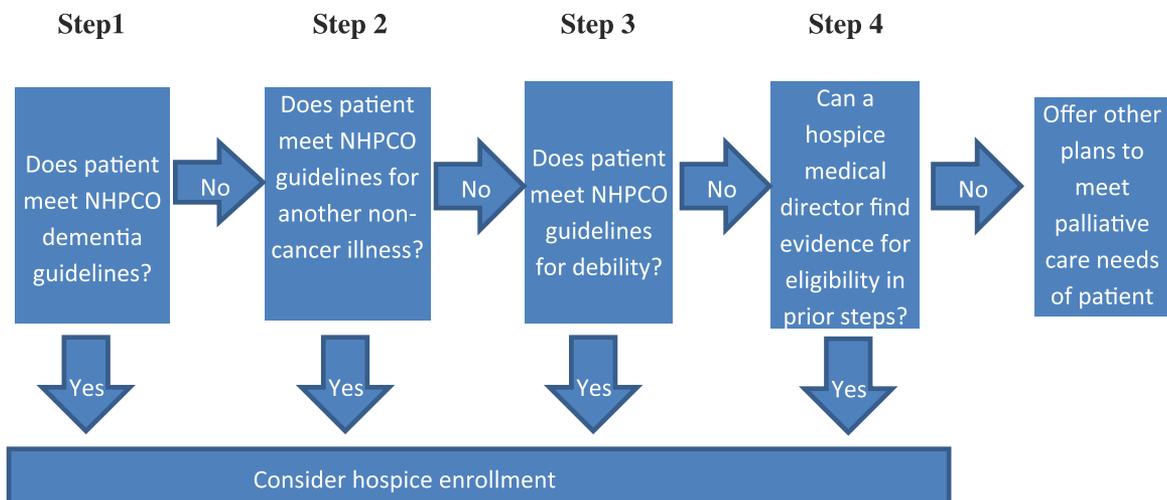


Fig. 1. Suggested approach for determining Medicare Hospice Benefit eligibility for patients with dementia.

the Minimum Data Set, and doing both retrospective and prospective validation. Table 2 shows the point scoring of this tool and the six-month probabilities of death associated with each risk score.

### ***Applying the ADEPT Model to Help Determine Hospice Eligibility***

The McMaster group suggests focusing on several questions when evaluating articles for determining prognosis.<sup>27</sup>

#### *Are the Results Valid?*

ADEPT has the characteristics of a valid prognostic model. It is derived from a representative and well-defined sample of patients at a similar point in the course of their disease, namely all patients with advanced dementia ( $n = 222,405$ ) captured by the Minimum Data Set. Follow-up was for one year and 91% complete. In addition, standards exist for grading the level of evidence for clinical prediction rules. ADEPT meets the second of four levels, having been validated in a large prospective study.<sup>28</sup> Level I requires prospective validation plus an impact analysis that demonstrates a beneficial change in clinician behavior.<sup>29</sup>

#### *What Are the Results and How Precise Are They?*

How likely is it that Mrs. C. will die in six months, and how precise is that estimate? With an ADEPT score of 9.8 (age 85 [5.0 points], recent nursing home admission [3.3 points], and CHF [1.5 points]), her predicted six-month mortality is 17%, similar to the six-month mortality of nondemented older patients with hip fractures.<sup>30</sup> To look at the precision of this estimate, we need to consider the model's receiver operating characteristic (ROC) curve, which plots the sensitivity of a test (the likelihood that the test will identify a subject with the characteristic) against (1-specificity). A test that performed perfectly would have an area under the ROC curve of 1, and a test that performed no better than chance would have an area of 0.5.<sup>31</sup> The ADEPT model had an area under the ROC curve of 0.68 in the retrospective and 0.67 in the prospective validation, which is fair. For comparison, the authors calculated the area under the ROC curve for the NHPCO hospice eligibility criteria to be only

0.53, which essentially adds no more information beyond chance.

#### *Were the Study Patients Similar to the Patient?*

An important difference between Mrs. C. and the ADEPT patients is that Mrs. C. has clear goals of care for palliative rather than disease-oriented care, which might mean that she belongs to a subset of patients who are sicker and have a higher likelihood of dying. The ADEPT model does not incorporate this information or her recent hip fracture.

#### *Will the Results Help a Physician Counsel the Patient's Daughter?*

The ADEPT model should not rule out hospice referral for this patient, but it does strongly suggest that the patient is not eligible for hospice, using dementia as the life-limiting diagnosis. In addition, ADEPT also provides a useful reminder for use in counseling the daughter of how difficult it is to predict which patients are in the last six months of life. Table 2 shows that only 3.6% of dementia patients had a score of 16 or more, with a 50% mortality risk. Given these realities, the clinician, nurses, and the daughter could have a plan to monitor the patient for the kind of developments that should trigger a re-evaluation of hospice eligibility. Also, this may be a good juncture to pursue other options to improve end-of-life care, such as working with the nursing staff, perhaps with the advice of a palliative care consultant, to modify her care plan for responding to predictable crises and to review the orders for life-sustaining treatment.

### ***Reviewing Mrs. C.'s Hospice Eligibility Two Years Later***

Mrs. C. has shown a slow and steady decline in her cognitive function with increased functional dependence. She is now bedfast and is occasionally incontinent of urine and stool. Her verbal abilities have declined to one or two words at a time, such as "OK," or to calling her daughter's name. Her weight has slowly declined to 150 lbs., with a 10 lb. weight loss in the last year. Her medical conditions have remained stable. Again, in applying the four-step approach to Mrs. C., first examine the NHPCO criteria in Table 1 (Step 1). The patient's functional abilities are now at the FAST 7c level, but there are no

Table 2  
**Advanced Dementia Prognostic Tool (ADEPT).  
 Patient Characteristics, Point Scores, and  
 Associated Six-Month Survival Probabilities<sup>a</sup>**

Characteristics	Points in Risk Score
Recent NH admission (past 90 days)	3.3
Age (in years; per five-year increment)	
65–69	1.0
70–74	2.0
75–79	3.0
80–84	4.0
85–89	5.0
90–94	6.0
95–99	7.0
>100	8.0
Male	3.3
Shortness of breath	2.7
At least one pressure ulcer $\geq$ Stage 2	2.2
ADL score = 28 <sup>b</sup>	2.1
Bedfast most of day	2.1
Insufficient oral intake <sup>c</sup>	2.0
Bowel incontinence <sup>d</sup>	1.9
BMI < 18.5 kg/m	1.8
Weight loss <sup>e</sup>	1.6
Congestive heart failure	1.5
	Observed Probability of Death Within Six Months
<b>Total Risk Score</b>	
1 (minimum score)	0.01
>1–2	0.04
>2–3	0.05
>3–4	0.06
>4–5	0.06
>5–6	0.08
>6–7	0.10
>7–8	0.12
>8–9	0.15
>9–10	0.17
>10–11	0.21
>11–12	0.25
>12–13	0.29
>13–14	0.34
>14–15	0.40
>15–16	0.46
>16–17	0.52
>17–18	0.57
>18–19	0.64
>19–20	0.67
>20–21	0.73
>21–22	0.77
>22–23	0.83
>23–24	0.83
>24–25	0.88
>25–26	0.88
>26–27	0.83
>27–28	0.95
>28–32	1.00

NH = Nursing Home; ADL = Activities of Daily Living; BMI = Body Mass Index.

<sup>a</sup>Adapted from Mitchell et al.<sup>20</sup>

<sup>b</sup>Sum of scores in seven domains of function including bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. Each is scored on a five-point scale (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A score of 28 represents complete functional dependence.

qualifying conditions evident. The patient's weight loss does not meet the 10% in six months criterion, and there have been no recent pneumonias or urinary tract infections. There are apparently no other significant comorbid illnesses (Step 2). Looking for other support for her six-month mortality with the ADEPT score (Step 3), she still has a six-month mortality of only 34% (age 87 [five points], bowel incontinence [1.9 points], CHF [1.6 points], bedfast [2.1 points], and activities of daily living > 28 [2.1 points] for a total score of 13.7).

Mrs. C.'s physician has found ADEPT helpful in showing that the patient is within striking distance of hospice eligibility, with a 34% six-month mortality prediction, and decides to obtain a consultation with the HMD (Step 4). The HMD recommends measuring the clearance of Mrs. C's albumin (3.2) and creatinine (which has risen to 2.4); she points out that this creatinine clearance of only 17.7, combined with the patient's CHF, nearly meets the Medicare criteria for hospice entry under the diagnosis of end-stage renal disease. This fact, combined with her other comorbidities of worsening dementia and declining nutritional status, also could make the case for hospice entry under the category of debility. The HMD includes mention of the ADEPT score in her narrative statement in support of enrollment.

Mrs. C. enrolls in hospice and has an uneventful four months, during which time hospice was helpful in providing additional support for counseling the patient's daughter about future scenarios for managing the complications of advanced dementia and managing her anticipated grief. Mrs. C. suddenly awakens with severe dyspnea and an altered mental status one morning. Her symptoms are rapidly brought under control with oral morphine ordered in anticipation of such a crisis, even before the hospice nurse arrives 45 minutes later. She never regains consciousness, and dies peacefully at her nursing facility within a day. The daughter is grateful for the timely referral to hospice and is satisfied with the care her mother received.

<sup>c</sup>Not consuming almost all liquids in previous three days or <25% of food uneaten at most meals.

<sup>d</sup>Bowel incontinence occasionally, frequently, or always (vs. rarely or never).

<sup>e</sup>Recent weight loss is defined as >5% body weight in prior 30 days or >10% in prior 180 days.

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## References

1. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538.
2. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212–1221.
3. Miller SC, Mor V, Wu N, et al. Does receipt of hospice care in nursing homes improve the management of pain at the end-of-life? *J Am Geriatr Soc* 2002;50:507–515.
4. Teno JM, Gozalo PL, Lee IC, et al. Does hospice improve quality of care for persons dying from dementia? *J Am Geriatr Soc* 2011;59:1531–1536.
5. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Patients dying with dementia: experience at the end of life and impact of hospice care. *J Pain Symptom Manage* 2008;35:499–507.
6. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2010;58:2284–2291.
7. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *J Am Med Assoc* 2004;291:88–93.
8. Gazelle G. Understanding hospice—an underutilized option for life's final chapter. *N Engl J Med* 2007;357:321–324.
9. Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer's disease in the US population: prevalence estimates using the 2000 census. *Arch Neurol* 2003;60:1119–1122.
10. Hospice Association of America. Hospice: An HAA/NAHC historical perspective. Available from <http://www.nahc.org/haa/history.html>. Accessed August 4, 2012.
11. Brody H, Lynn J. The physician's responsibility under the new Medicare reimbursement for hospice care. *N Engl J Med* 1984;310:920–922.
12. National Hospice Organization. Medical guidelines for determining prognosis in selected non-cancer diseases. *Hosp J* 1996;11:47–63.
13. Fox E, Landrum-McNiff K, Zhong Z, et al. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. *J Am Med Assoc* 1999;282:1638–1645.
14. Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull* 1988;24:653–659.
15. Sclan SG, Reisberg B. Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. *Int Psychogeriatr* 1994;4(Suppl 1):55–69.
16. Luchins DJ, Hanrahan P, Murphy K. Criteria for enrolling dementia patients in hospice. *J Am Geriatr Soc* 1997;45:1054–1059.
17. Hanrahan P, Raymond M, McGowan E, et al. Criteria for enrolling dementia patients in hospice—a replication. *Am J Hosp Palliat Care* 1999;16:395–400.
18. Schonwetter RS, Han B, Small BJ, et al. Predictors of six-month survival among patients with dementia: an evaluation of hospice Medicare guidelines. *Am J Hosp Palliat Care* 2003;20:105–113.
19. Mitchell SL, Kiely DK, Hamel MB, et al. Estimating prognosis for nursing home residents with advanced dementia. *J Am Med Assoc* 2004;291:2734–2740.
20. Mitchell SL, Miller SC, Teno JM, Davis RB, Shaffer ML. The Advanced Dementia Prognostic Tool (ADEPT): a risk score to estimate survival in nursing home residents with advanced dementia. *J Pain Symptom Manage* 2010;40:639–651.
21. Volicer BJ, Hurley A, Fabiszewski KJ, Montgomery P, Volicer L. Predicting short-term survival for patients with advanced Alzheimer's disease. *J Am Geriatr Soc* 1993;41:535–540.
22. Marsh GW, Prochoda KP, Pritchett E, Vojir CP. Predicting hospice appropriateness for patients with dementia of the Alzheimer's type. *Appl Nurs Res* 2000;13:187–196.
23. van der Steen JT, Mitchell SL, Frijters DH, Kruse RL, Ribbe MW. Prediction of 6-month mortality in nursing home residents with advanced dementia: validity of a risk score. *J Am Med Dir Assoc* 2007;8:464–468.
24. Coté TR, Kinzbrunner BM, eds. The hospice medical director manual, 2nd ed. Glenview, IL: American Academy of Hospice and Palliative Medicine, 2012.
25. U.S. Government: Medicare. Local coverage determination (LCD) for hospice determining terminal status (L13653). Available from [www.medicare.gov](http://www.medicare.gov). Accessed April 14, 2012.
26. Morrison RS, Siu AL. Survival in end-stage dementia following acute illness. *J Am Med Assoc* 2000;284:47–52.
27. Laupacis A, Wells G, Richardson WS, et al. Users' guides to the medical literature: V. How to use an article about prognosis. *J Am Med Assoc* 1994;272(3):234–237.
28. Mitchell SL, Miller SC, Teno JM, et al. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs. hospice eligibility guidelines. *J Am Med Assoc* 2010;304:1929–1935.
29. McGinn T, Wyer P, Wisnivesky J, et al. [Chapter 17.4] Clinical prediction rules. In: Guyatt G, Rennie D, Meade MO, Cook DJ, eds. *Users' guides to*

the medical literature: A manual for evidence-based clinical practice, 2nd ed. New York: McGraw-Hill, 2008. Available from <http://www.jamaevidence.com/content/3347345>. Accessed April 1, 2012.

30. Haentjens P, Magaziner J, Colon-Emeric CS, et al. Meta-analysis: excess mortality after hip

fracture among older women and men. *Ann Intern Med* 2010;152:380–390.

31. Lasko TA, Bhagwat JG, Zou KH, Ohno-Machado L. The use of receiver operating characteristic curves in biomedical informatics. *J Biomed Inform* 2005;38:404–415.