Estimating Prognosis for Nursing Home Residents With Advanced Dementia

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Context Survival varies for patients with advanced dementia, and accurate prognostic tools have not been developed. A small proportion of patients admitted to hospice have dementia, in part because of the difficulty in predicting survival.

Objectives To identify factors associated with 6-month mortality in newly admitted nursing home residents with advanced dementia and to create a practical risk score to predict 6-month mortality in this population.

Design, Setting, and Participants This was a retrospective cohort study of data from the Minimum Data Set (MDS). All Medicare or Medicaid licensed nursing homes in New York and Michigan were included. Participants had advanced dementia and were admitted to New York nursing homes between June 1, 1994, and December 30, 1998 (derivation cohort, n=6799), and to Michigan nursing homes from October 1, 1998, through July 30, 2000 (validation cohort, n=4631).

Main Outcome Measures MDS factors associated with 6-month mortality were determined in the derivation group, and the resulting mortality risk score was evaluated in the validation cohort. Risk score performance was compared with the cut point of 7c on the Functional Assessment Staging (FAST) scale.

Results Among residents with advanced dementia, 28.3% (n=1922) died within 6 months of nursing home admission in the derivation cohort; 35.1% (n=1626) died in the validation cohort. The 6-month mortality rate increased across risk scores (possible range, 0-19): 0 points, 8.9% mortality; 1 to 2, 10.8%; 3 to 5, 23.2%; 6 to 8, 40.4%; 9 to 11, 57.0%; and at least 12, 70.0% in the validation cohort. The area under the receiver operating characteristic (AUROC) curve for predicting 6-month mortality was 0.74 and 0.70 in the derivation and validation cohorts, respectively. Our risk score demonstrated better discrimination to predict 6-month mortality (AUROC, 0.64 for a cutoff of ≥6 points vs 0.51 for FAST stage 7c).

Conclusion A risk score based on 12 variables from the MDS estimates 6-month mortality for nursing home residents with advanced dementia with greater accuracy than existing prognostic guidelines.

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MANY FAMILIES AND HEALTH care professionals in the United States believe that palliation is the most appropriate goal for patients with end-stage dementia.[1] However, many nursing home residents dying with advanced dementia in the United States do not receive optimal palliative care.[2]

Accurately estimating the life expectancy of persons with advanced dementia is difficult and hinders palliative care in this population.[3-6] Prognostic information is important in guiding end-of-life decision making[7] and, in the United States, for determining hospice eligibility. Medicare beneficiaries must have an estimated life expectancy of less than 6 months to be eligible for hospice. In a nationwide survey, 80% of hospices cited difficulties in predicting survival as a major problem in the delivery of care to enrollees with a primary diagnosis of dementia.[1,8] Less than 1% of US hospice enrollees have a primary diagnosis of dementia.

Few studies have attempted to develop statistical models to predict the 6-month survival of persons with a primary diagnosis of advanced dementia.[3,5] The National Hospice Organization eligibility guidelines for patients with dementia are based primarily on the Functional Assessment Staging (FAST) criteria.[9,10] These criteria have been criticized because they were not derived from empirical data, do not accurately predict 6-month survival, and cannot be applied to the majority of patients with dementia whose disease does not progress linearly.[3-6]

Therefore, the objectives of this study were to identify factors associated with 6-month mortality in newly admitted nursing home residents with advanced dementia and to create a practical risk score to predict survival in this population.

METHODS

Data Sources

The institutional review board at Hebrew Rehabilitation Center for Aged approved the conduct of this study.

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The Omnibus Budget Reconciliation Act of 1987 requires that all Medicare- and Medicaid-certified nursing facilities in the United States periodically conduct federally mandated standardized, comprehensive assessments of all residents by using the Resident Assessment Instrument (RAI). The Minimum Data Set (MDS) is the assessment component of the RAI.[11-14]

The MDS contains information on each resident's functional, medical, cognitive, psychologic, and social status. Assessments are required on admission, at quarterly intervals thereafter, and whenever there is significant change in resident status. Data are collected by trained professionals (ie, nurses, social workers, and therapists), and each MDS item has its own explicit definition and coding conventions. The interrater reliabilities for the MDS items used in study were determined from data collected for clinical purposes in comparable nursing homes across the country.[12-14] The reliabilities range from 0.50 to 0.99, with 6 variables having reliabilities below 0.70.

The model was derived by using MDS data from newly admitted residents to all licensed Medicare or Medicaid nursing homes (n=634 facilities) in New York between June 1, 1994, and December 30, 1998 (MDS version 1.0). The model was validated[15] with MDS data from newly admitted residents to all licensed Medicare or Medicaid nursing homes (n=440 facilities) in Michigan from October 1, 1998, through July 30, 2000 (MDS version 2.0). The variables used in this study were defined identically in MDS versions 1.0 and 2.0.

Population

The derivation and validation data sets comprised persons aged at least 65 years and with advanced dementia whose reason for their MDS assessment was nursing home admission. Advanced dementia was defined as having a diagnosis of dementia (Alzheimer disease or other causes) and a Cognitive Performance Score of 5 or 6.[16,17] The Cognitive Performance Score uses 5 MDS variables to group residents into 7 hierarchical cognitive performance categories. A Cognitive Performance Score of 5 or 6 (severe or very severe impairment with eating problems) generally corresponds to a Mini-Mental State Examination score of no more than 5.[16,17]

Mortality Data

Mortality data and MDS information were matched in the validation and derivation data sets before the initiation of this study. Slightly different methods were used to identify residents who died. In the derivation cohort, residents who had MDS information beyond 6 months of their admission date were considered to be alive. For the remaining residents, death information was obtained from the National Death Index.[18] Matches were attempted on 11 variables to provide a complete match, partial match, or no match with an individual's information. Residents in the derivation cohort for whom a complete match was found and whose death date was within 6 months of admission to the nursing home were designated as having died within 6 months. Residents not in the National Death Index or whose death date was beyond 6 months of their admission date were considered alive at 6 months. Residents with partial or ambiguous matches were excluded from the study. Of the 7014 residents meeting our inclusion criteria, 215 residents (3.1%) had partial matches in the National Death Index and were excluded from the sample, leaving 6799 residents for inclusion in the analysis.

In the validation cohort, the Michigan Death Registry was used to obtain death data. All residents in the Michigan MDS data set were linked to the Michigan Death Registry by using the 8 variables. Satisfactory matches obtained for residents in the validation cohort with a death date within 6 months of admission to the nursing home were designated as having died. If a satisfactory match was not obtained, then the resident was designated as alive.

Resident Characteristics

According to the National Hospice Organization guidelines,[9] related publications,[3-6,10,19-24] and clinical experience, resident characteristics that were believed to be associated with 6-month mortality were selected from the MDS assessment completed within 21 days of nursing home admission. These variables included demographic data, functional status, diagnoses, and other health conditions. Advance directives and specific treatments (eg, tube feeding) were not considered as independent variables because our intent was to develop a prognostic model based on factors intrinsic to the residents' health status rather than to examine how different management strategies influence survival.

Demographic data included age, sex, and race or ethnicity (white vs nonwhite). Race and ethnicity are defined in the MDS form. Other studies of survival and dementia have included race[21] as a prediction variable. Functional ability was assessed with the Activities of Daily Living (ADL) scale (range=0, independent in all, to 28, dependent in all).[25] A variable that describes a resident as bedfast most of the time was also included.

Diagnoses included in the analyses were diabetes mellitus, congestive heart failure, asthma or emphysema/chronic obstructive pulmonary disease, cancer, pneumonia or other respiratory tract infection, cardiac dysrhythmias, any fracture in the previous 180 days, urinary tract infection in the previous 30 days, and septicemia. Other health conditions included were edema, hallucinations or delusions, recurrent lung aspirations, bowel incontinence, weight loss (>5% in the previous 30 days or >10% in the previous 180 days), dehydration, insufficient fluids (did not consume almost all liquids in previous 3 days), fever, pressure ulcers (with at least some loss of skin integrity), shortness of breath, chewing or swallowing problems, no more than 25% of food eaten at most meals, not awake most of the day (morning and afternoon), the need for oxygen therapy in the previous 14 days, and body mass index (BMI). We also examined whether residents were identified as having an unstable condition, which is defined in the MDS as a condition that causes the resident's usual cognitive,

Table 1. Description of Functional Assessment Stages and Comparable Minimum Data Set Variables

Functional Assessment Stage	Minimum Data Set Variable
6a = Improperly putting on clothes without assistance/cueing occasionally or more frequently over the past weeks	Limited or more extensive assistance required to dress on at least several occasions during the last 7 days
6b = Unable to bathe properly (eg, difficulty adjusting water temperature) occasionally or more frequently over the past weeks	Supervision or more assistance required to bathe during the last 7 days
6c = Inability to handle the mechanics of using the toilet occasionally or more frequently over the past weeks	Limited or more extensive assistance required to use the toilet on at least several occasions during the last 7 days
6d = Urinary incontinence occasionally or more frequently over the past weeks	Urinary incontinence at least twice a week
6e = Bowel incontinence occasionally or more frequently over the past weeks	Bowel incontinence at least twice a week
7a = Ability to speak limited to ≤1 intelligible word in an average day	Rarely/never makes self understood
7b = All intelligible vocabulary is lost	Rarely/never makes self understood
7c = Nonambulatory	Extensive assistance (or total dependence) required for locomotion (ie, move between locations) during the last 7 days

Figure 1. Mortality Risk Index Score for Stratification of Residents Into Levels of Risk for 6-Month Mortality

Score Sheet to Estimate 6-Month Prognosis in Nursing Home Residents With Advanced Dementia

Risk Factor From Minimum Data Set	Points	Score
Activities of Daily Living Scale = 28*	1.9	____
Male Sex	1.9	____
Cancer	1.7	____
Congestive Heart Failure	1.6	____
Oxygen Therapy Needed in Prior 14 Days	1.6	____
Shortness of Breath	1.5	____
<25% of Food Eaten at Most Meals	1.5	____
Unstable Medical Condition	1.5	____
Bowel Incontinence	1.5	____
Bedfast	1.5	____
Age >83 y	1.4	____
Not Awake Most of the Day	1.4	____
Total Risk Score, Rounded to Nearest Integer Possible Range, 0-19		☐

**The Activities of Daily Living Scale is obtained by summing the resident's self-performance ratings on the Minimum Data Set for the following 7 functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. In the Minimum Data Set, functional ability is rated on 5-point scale for each activity (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A total score of 28 represents complete functional dependence.*

If Total Risk Score is...	Risk Estimate of Death Within 6 Months, %
0	8.9
1 or 2	10.8
3, 4, or 5	23.2
6, 7, or 8	40.4
9, 10, or 11	57.0
≥12	70.0

functional, or behavior pattern to fluctuate, be precarious, or deteriorate.

Comparison With FAST

The FAST scale[10] is used to assess functional change among patients with dementia and consists of 7 major stages with a total of 16 successive stages and substages (possible range, stages 1-7f). Stage 7 represents the most advanced dementia and consists of 6 substages, 7a to 7f. These stages are defined as follows: 7a, speech is limited to 1 to 5 words; 7b, all intelligible vocabulary is lost; 7c, nonambulatory; 7d, unable to sit independently; 7e, unable to smile; and 7f, unable to hold head up. Stage 7c of the FAST scale has been suggested by the National Hospice Organization as an appropriate cutoff to enroll persons with a primary diagnosis of dementia into hospice.[9] To be considered as stage 7c, patients must have progressed through all the previous stages of the FAST scale sequentially.

To compare the ability of our risk score to predict 6-month survival with that of FAST, variables were chosen from the MDS that most closely match the description of FAST stages 6 through 7c (TABLE 1). Residents with all of the following characteristics were considered to be at FAST stage 7c: limited or more extensive assistance needed for dressing and toileting, supervision or more assistance needed for bathing, urinary and fecal incontinence at least twice a week, rarely or never able to make themselves understood, and inability to ambulate without extensive assistance.

Statistical Analyses

Derivation of Model and Risk Score. Survival time was the dependent variable for all analyses. For residents who died within 6 months of nursing home admission, survival was defined as the duration between the admission and death dates. Residents who did not die within 6 months of nursing home admission were censored (considered alive). Independent variables included all the aforementioned resident characteristics.

Age, ADL score, and BMI were dichotomized to ease interpretation of the

hazard ratio and to simplify the mortality risk score. Age was dichotomized at the median (>83 years); BMI was dichotomized at no more than 21 because this cutoff is below the range considered normal by standard clinical nutritional assessment[26] and because it also represented the median value. ADL score was dichotomized at 28 because this value represented complete functional dependence and was the 75th percentile in the distribution of ADL scores for the derivation cohort. Analysis of these characteristics as dichotomous vs continuous variables did not change the prognostic power of the final survival model's comparable *c* statistic.

Unadjusted associations were analyzed with Cox proportional hazards models (SAS Institute Inc, Cary, NC; version 6.11). Characteristics that were significantly ($P \leq .05$) associated with survival in these unadjusted analyses were entered into Cox proportional hazards regression model in a stepwise fashion. To derive the most parsimonious model and because of the large sample size, only variables associated with survival at a significance level $P < .001$ after the stepwise procedure were retained in the model. Including variables not meeting this level of significance did not improve the predictive ability of the final model. Hazard ratios, 95% confidence intervals, and *P* values were derived from these analyses. Proportional hazards assumptions were met (time interaction terms for the covariates had a $P > .05$).

A mortality risk index score was created to stratify residents into different levels of risk for 6-month mortality (FIGURE 1). A point value was assigned to each characteristic according to the hazard ratios in the final multivariate model from the derivation cohort. Point values were summed for all mortality-related characteristics present for each resident and rounded to the nearest integer (values of 0.5 were rounded up to the next highest integer).[15] Risk scores ranged from 0 to 19, and 6 risk categories were created by combining risk scores with similar mortality rates in the derivation cohort (0, 1-2, 3-5, 6-8, 9-11, and ≥12).

Validation of the Model. We applied the mortality risk score developed by using the derivation cohort to the validation cohort and determined the proportion of residents in the validation cohort who died in each risk category, as defined by the hazard ratios obtained in the derivation cohort.

Operating Characteristics of the Model and Risk Score. To examine the discrimination of our risk score, we determined the *c* statistic, representing the area under the receiver operating characteristic (AUROC) curve.[27] We calculated the *c* statistic for the derivation and validation cohorts by using logistic regression, with 6-month mortality as the outcome and the risk score as the sole independent variable. Testing in the validation cohort was based on the risk score created from the derivation cohort.

We also used logistic regression to determine the *c* statistic for FAST stage 7c simulated with MDS variables to estimate the ability of FAST criteria to predict 6-month mortality in the validation co-

Table 2. Characteristics of Residents With Advanced Dementia and Their Associations With 6-Month Mortality in the Derivation Cohort (n = 6799)

Characteristic	No. (%) of Residents	Unadjusted HR (95% CI)
Demographic		
Age >83 years, median	3075 (45.2)	1.5 (1.4-1.7)
Male sex	2257 (33.2)	1.8 (1.6-1.9)
Nonwhite race/ethnicity	1366 (20.1)	1.2 (1.1-1.4)
Functional status		
Activities of daily living score = 28*	1747 (25.7)	2.5 (2.3-2.8)
Bedfast	523 (7.7)	2.6 (2.3-3.0)
Diagnosis		
Diabetes mellitus	1113 (16.4)	1.4 (1.2-1.5)
Congestive heart failure	958 (14.1)	2.1 (1.9-2.3)
Asthma or emphysema/COPD	520 (7.6)	1.6 (1.4-1.8)
Cancer	575 (8.5)	2.1 (1.8-2.4)
Pneumonia or respiratory tract infection	641 (9.4)	1.8 (1.6-2.0)
Cardiac dysrhythmia	768 (11.3)	1.4 (1.2-1.6)
Any fracture in the previous 180 days	594 (8.7)	1.0 (0.9-1.2)
Urinary tract infection	1343 (19.8)	1.3 (1.1-1.4)
Septicemia	53 (0.8)	1.8 (1.2-2.7)
Other health conditions		
Edema	1155 (17.0)	1.5 (1.3-1.7)
Hallucinations or delusions	181 (2.7)	1.0 (0.7-1.3)
Aspiration	107 (1.6)	2.1 (1.6-2.8)
Bowel incontinence	5334 (78.4)	2.3 (2.0-2.7)
Recent weight loss	1074 (15.8)	1.9 (1.7-2.1)
Dehydration	370 (5.4)	1.7 (1.4-2.0)
Insufficient fluid intake	742 (10.9)	1.6 (1.4-1.8)
Fever	533 (7.8)	2.1 (1.8-2.4)
Pressure ulcers	1159 (17.0)	1.7 (1.5-1.9)
Shortness of breath	240 (3.5)	3.6 (3.0-4.3)
Unstable medical conditions	1626 (23.9)	1.9 (1.8-2.1)
Chewing or swallowing problem	2331 (34.3)	1.8 (1.6-1.9)
<25% of food eaten at most meals	2458 (36.2)	1.5 (1.4-1.6)
Not awake most of day	474 (7.0)	2.1 (1.8-2.4)
Body mass index <21, median†	3404 (50.1)	1.4 (1.3-1.5)
Oxygen therapy in prior 14 days	565 (8.3)	3.1 (2.7-3.5)

Abbreviations: CI, confidence interval; COPD, chronic obstructive pulmonary disease; HR, hazard ratio.
*Total activities of daily living score (0-28) is the sum of scores in each of 7 domains of function, including bed mobility, dressing, using the toilet, transfer, eating, grooming, and locomotion. Each is scored on a 5-point scale (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A score of 28 represents complete functional dependence.
†Body mass index was calculated as weight in kilograms divided by the square of height in meters.

hort. A *c* statistic for a single cut point on our score was calculated in the validation set to compare with FAST stage 7c.

To examine the practical application of using the risk score to predict 6-month mortality, we calculated the sensitivity, specificity, and positive and negative predictive values for various cut points in the risk score to predict 6-month mortality for the derivation and validation cohorts. We generated ROC curves for the derivation and validation cohorts according to these analyses.

RESULTS

Risk Score Derivation

The derivation cohort consisted of 6799 residents with advanced dementia who were admitted to New York nursing homes during the study period, of whom 28.3% (n=1922) died within 6 months.

TABLE 2 describes the characteristics of the residents in the derivation cohort and the unadjusted associations between each independent variable and survival. Only fracture and hallucinations or delusions were not significantly associated with survival. All other variables were entered into the stepwise multivariate Cox proportional hazards model. The final model included the following variables: ADL score of 28, male sex, cancer, the need for oxygen therapy, congestive heart failure, shortness of breath, no more than 25% of food eaten at most meals, an unstable condition, bowel incontinence, bedfast, older than 83 years, and not awake most of the day (TABLE 3).

Using the hazard ratios in the final multivariate model, we calculated a risk score for each resident. For example, an 85-year-old male resident with advanced dementia who was bedfast and totally functionally dependent (ADL score, 28), had congestive heart failure, and used oxygen had a risk score of 1.4+1.9+1.5+1.9+1.6+1.6=9.9, or 10 after rounding to the nearest integer. Risk scores with similar mortality rates were combined to produce 6 risk categories. TABLE 4 shows by category the proportion and number of residents in the derivation cohort who died and also presents the percentage of residents in the total sample within each risk category. Those with risk scores of 3, 4, and 5 represented 46.2% of the derivation data set.

Table 3. Multivariate Proportional Hazards Model of Characteristics Associated With 6-Month Mortality Among Residents With Advanced Dementia in the Derivation Cohort (n = 6799)

Characteristic	HR (95% CI)
Activities of daily living score = 28*	1.9 (1.7-2.1)
Male sex	1.9 (1.7-2.1)
Cancer	1.7 (1.5-1.9)
Oxygen therapy	1.6 (1.4-1.8)
Congestive heart failure	1.6 (1.4-1.7)
Shortness of breath	1.5 (1.3-1.9)
<25% Food eaten	1.5 (1.4-1.7)
Unstable medical conditions	1.5 (1.3-1.6)
Bowel incontinence	1.5 (1.3-1.7)
Bedfast	1.5 (1.3-1.7)
Age >83 years, median	1.4 (1.3-1.6)
Not awake most of day	1.4 (1.2-1.6)

Abbreviations: CI, confidence interval; HR, hazard ratio.
*Total activities of daily living score (0-28) is the sum of scores in each of 7 domains of function including bed mobility, dressing, using the toilet, transfer, eating, grooming, and locomotion. Each is scored on a 5-point scale (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A score of 28 represents complete functional dependence.

Risk Score Validation

In the validation cohort, 4631 older persons with advanced dementia were admitted to Michigan nursing homes, of whom 35.1% (n=1626) died within 6 months. Table 4 presents the number and proportion of residents in each risk category in the validation cohort and the proportion of those who died. Risk categories were calculated by using the hazard ratios from the derivation set. The mortality rates in each category were similar to those in the derivation cohort, except for a higher proportion of residents dying with a score of 0 and a lower proportion dying with risk scores of at least 12 (Table 4). Those with risk scores of 3, 4, and 5 represented 37.9% of the validation cohort.

Operating Characteristics

The *c* statistic representing the AUROC curve was 0.74 in the derivation cohort and 0.70 in the validation cohort (FIGURE 2).

TABLE 5 presents the operating characteristics of the risk score at various cut points to predict 6-month mortality in the validation and derivation cohorts. A potential application of this approach would be to consider severely demented residents with risk scores above specific cut points as eligible for hospice services while excluding residents with lower scores. For example, if hospice eligibility included only residents with risk scores of 9 or higher, then according to the validation data, 59.7% of enrollees would die within 6 months of admission (positive predictive value), but only 28.7% of residents with advanced dementia who died within that period would be eligible for the program (sensitivity). With broader inclusion criteria, for example, a risk score cutoff of 6 or higher, only 46.6% of enrollees would die within 6 months, and 72.8% of residents with advanced dementia who died within that time would be eligible for hospice care.

Table 4. Proportion of Residents With Advanced Dementia in Each Risk Category and Those Who Died Within 6 Months of Nursing Home Admission in Derivation (n = 6799) and Validation Cohorts (n = 4631)

	Total No. (%) Residents		No. (%) Residents Who Died	
Risk Score*	Derivation Cohort	Validation Cohort	Derivation Cohort	Validation Cohort
0†	272 (4.0)	56 (1.2)	4 (1.5)	5 (8.9)
1-2	938 (13.8)	278 (6.0)	79 (8.4)	30 (10.8)
3-5	3141 (46.2)	1755 (37.9)	666 (21.2)	407 (23.2)
6-8	1795 (26.4)	1727 (37.3)	732 (40.8)	698 (40.4)
9-11	517 (7.6)	648 (14.0)	332 (64.2)	369 (57.0)
≥12	136 (2.0)	167 (3.6)	109 (80.1)	117 (70.0)

*Risk score is based on point assignments from hazard ratios obtained from the derivation cohort.
†Residents with a risk score of zero did not have any of the characteristics included in the final prognostic model.

Application of FAST

In the validation cohort, 20.2% (n=937) of residents with advanced dementia met the simulated MDS criteria for FAST stage 7c, of whom 38.5% died within 6 months of nursing home admission (positive predictive value). Only 22.2% of residents who died within 6 months met the criteria for FAST stage 7c (sensitivity). When we used logistic regression to predict death at 6 months, the *c* statistic for the simulated FAST stage of 7c was 0.51 in the validation cohort, indicating poor discrimination. In comparison, the *c* statistic using the single cut point of at least 6 in our risk score was 0.64.

COMMENT

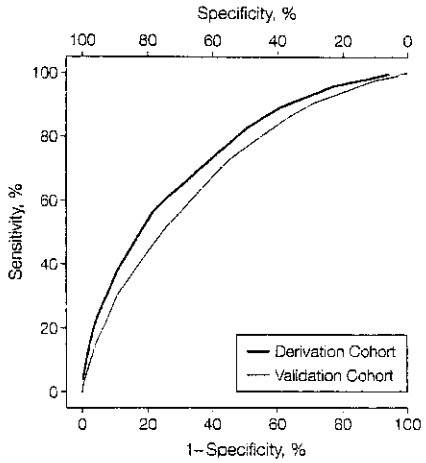
In this study, we have derived and validated a model to predict 6-month mortality for nursing home residents with advanced dementia. Our risk score offers an improvement over existing prognostic guidelines used in this population because it is based on empiric data, has greater predictive power, and uses standardized, readily available MDS assessments.

The few investigations that have specifically identified factors associated with survival in advanced dementia differ from our study in important ways, so comparisons are limited.[3,5,19-21,23] Nonetheless, our study confirms that the following characteristics are associated with poorer survival in advanced dementia: older age,[3,21,23] greater functional impairment,[3,5,19,21,23] male sex,[21,23] cardiovascular disease,[21] diabetes mellitus,[21] and poor nutritional status.[5,21] These factors are also associated with increased mortality in dementia, regardless of the stage.[21,23,29] We also found that the risk factors for death among nursing home residents with advanced dementia were similar to those of the general nursing home population,[22] of which a substantial proportion have dementia. The need for oxygen therapy and not being awake most of the day were the only additional factors that we identified to be specifically associated with survival in advanced dementia.

Earlier work demonstrates the challenge of estimating short-term prognosis among patients with advanced dementia.[3,5,20] Our risk score demonstrates moderately good power to predict 6-month survival among newly admitted nursing home residents with advanced dementia. It performed better than stage 7c of FAST when simulated with MDS variables, which had a predictive ability that was equal to chance. Moreover, in a study involving 47 hospice enrollees with dementia, 41% of enrollees could not be staged by using FAST criteria because their disease had not progressed in the ordinal sequence of the scale.[5]

Advanced dementia is an incurable, progressive condition for which palliation is often the primary goal of care, regardless of life expectancy. Although our model predicted 6-month survival in advanced dementia with greater accuracy than available prognostic systems, these analyses highlight the practical limitations of using prognostic estimates as criteria to determine access to palliative care services. For example, with respect to the Medicare hospice program, narrow eligibility criteria ensure that the majority of enrollees will die within 6 months but exclude a substantial proportion of persons with advanced dementia who also die during that period. With broader inclusion criteria, a greater proportion of patients who die within 6 months would be eligible for hospice services, but a larger percentage of enrollees would survive beyond 6 months. Similar problems were demonstrated when prognostic criteria from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment study were used to determine hospice eligibility for seriously ill hospitalized patients with other noncancer diagnoses.[28] More restrictive inclusion criteria would be an acceptable approach provided that high-quality palliative care was available to all residents with advanced dementia within the existing framework of comprehensive nursing home management. Alternatively, broader eligibility criteria would be a reasonable strategy if hospice were willing to enroll persons

Figure 2. Receiver Operating Characteristic (ROC) Curves for Risk Score's Prediction of 6-Month Mortality in the Derivation (n=6799) and Validation Cohorts (n=4631)



The area under the ROC curve is 0.74 in the derivation cohort and 0.70 in the validation cohort.

Table 5. Operating Characteristics of Selected Risk Score Cutoffs to Predict 6-Month Mortality Following Nursing Home Admission for Residents With Advanced Dementia

Risk Score Cutoff	Derivation Cohort (n = 6799)	Validation Cohort (n = 4631)
	Sensitivity*	
≥1	99.8	99.7
≥3	95.7	97.8
≥6	61.0	72.8
≥9	22.9	28.7
≥12	5.8	7.2
	Specificity†	
≥1	5.5	1.7
≥3	23.1	9.9
≥6	73.8	54.8
≥9	95.6	88.8
≥12	99.4	98.3
	Positive Predictive Value‡	
≥1	29.4	35.4
≥3	32.9	37.0
≥6	47.9	46.6
≥9	67.4	59.7
≥12	79.7	70.2
	Negative Predictive Value§	
≥1	98.5	91.2
≥3	93.1	89.5
≥6	82.8	78.8
≥9	75.9	69.9
≥12	72.8	66.2

*Sensitivity: proportion of residents who died within 6 months of admission with a risk score above cut point.
†Specificity: proportion of residents who survived beyond 6 months of admission with a risk score below cut point.
‡Positive predictive value: proportion of residents with a risk score above the cut point who died within 6 months of admission.
§Negative predictive value: proportion of residents with a risk score below the cut point who survived beyond 6 months of admission.

needing palliative care for longer than 6 months.

This study has some limitations that deserve comment. First, the prognostic model was derived in a population of older persons with advanced dementia who were recently admitted to a nursing home. Therefore, our risk score may not be generalizable to residents who have lived in nursing homes for longer periods or for those living in the community. Second, by using admission data to predict death within 6 months, we could not account for changes in health status during the interim period that may influence survival. Although we considered all acute illnesses available in the MDS data set as independent variables, it is possible that other factors associated with high short-term mortality in advanced dementia were unavailable for analysis. Moreover, there may not have been adequate power to demonstrate statistically significant associations between uncommon conditions (eg, septicemia) and 6-month mortality. Third, the risk score was derived and validated with data collected retrospectively. Prospective validation would be helpful to further assess the usefulness of the risk score in clinical practice.[29] Finally, despite our best efforts to define FAST stage 7c by using MDS variables, our simulation closely approximates but does not replicate the original scale.

Recent work indicates that the median survival after the onset of symptoms of dementia is shorter than previously estimated (3-6 years),[30,31] underscoring the need to plan for the end stage of this illness. High-quality palliative care should be available to the large proportion of persons with advanced dementia who will be cared for in nursing homes. Determining the best way to provide that care deserves the attention of health care providers and policy makers. If hospice eligibility continues to require a high likelihood of death within 6 months, then the majority of patients with advanced dementia in nursing homes will not receive hospice services. Therefore, alternative strategies to deliver comprehensive palliative care to this population should be sought.[32,33] While these issues are debated, the risk score derived in this study offers a practical approach for estimating with reasonable accuracy the 6-month prognosis of older nursing home residents with advanced dementia.

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Study concept and design: Mitchell, Hamel.
Acquisition of data: Morris, Fries.
Analysis and interpretation of data: Mitchell, Kiely, Hamel, Park, Morris, Fries.
Drafting of the manuscript: Mitchell, Kiely, Hamel, Morris, Fries.
Critical revision of the manuscript for important intellectual content: Mitchell, Kiely, Hamel, Park, Morris, Fries.
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