Prediction of Mortality in Community-Living Frail Elderly People with Long-Term Care Needs

Elise C. Carey, MD,* Kenneth E. Covinsky, MD, MPH, $^{\dagger \ddagger}$ Li-Yung Lui, MA, MS, S Catherine Eng, MD, $^{\dagger \parallel}$ Laura P. Sands, PhD, ‡ and Louise C. Walter, MD $^{\dagger \ddagger}$

OBJECTIVES: To develop and validate a prognostic index for mortality in community-living, frail elderly people.

DESIGN: Cohort study of Program of All-Inclusive Care for the Elderly (PACE) participants enrolled between 1988 and 1996.

SETTING: Eleven PACE sites, a community-based long-term care program that cares for frail, chronically ill elderly people who meet criteria for nursing home placement.

PARTICIPANTS: Three thousand eight hundred ninetynine PACE enrollees. The index was developed in 2,232 participants and validated in 1,667.

MEASUREMENTS: Time to death was predicted using risk factors obtained from a geriatric assessment performed by the PACE interdisciplinary team at the time of enrollment. Risk factors included demographic characteristics, comorbid conditions, and functional status.

RESULTS: The development cohort had a mean age of 79 (68% female, 40% white). The validation cohort had a mean age of 79 (76% female, 65% white). In the development cohort, eight independent risk factors of mortality were identified and weighted, using Cox regression, to create a risk score: male sex, 2 points; age (75–79, 2 points; 80–84, 2 points; \geq 85, 3 points); dependence in toileting, 1 point; dependence in dressing (partial dependence, 1 point; full dependence, 3 points); malignant neoplasm, 2 points; congestive heart failure, 3 points; chronic obstructive pulmonary disease, 1 point; and renal insufficiency, 3 points. In the development cohort, respective 1- and 3-year mortality rates were 6% and 21% in the lowest-risk group (0–3)

From the *Division of General Internal Medicine, College of Medicine, Mayo Clinic, Rochester, Minnesota; †Division of Geriatrics, University of California at San Francisco, San Francisco, California; †San Francisco Veterans Affairs Medical Center, San Francisco, California; *Research Institute of California Pacific Medical Center, San Francisco, California; †On Lok Senior Health Services, San Francisco, California; and *Purdue University School of Nursing, Center for Healthcare Engineering, Center for Aging and the Life Course, West Lafayette, Indiana.

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Address correspondence to Louise C. Walter, MD, VA Medical Center 181G, 4150 Clement Street, San Francisco, CA 94121. E-mail: Louise.Walter @ucsf.edu

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points), 12% and 36% in the middle-risk group (4–5 points), and 21% and 54% in the highest-risk group (>5 points). In the validation cohort, respective 1- and 3-year mortality rates were 7% and 18% in the lowest-risk group, 11% and 36% in the middle-risk group, and 22% and 55% in the highest-risk group. The area under the receiver operating characteristic curve for the point score was 0.66 and 0.69 in the development and validation cohorts, respectively.

CONCLUSION: A multidimensional prognostic index was developed and validated using age, sex, functional status, and comorbidities that effectively stratifies frail, community-living elderly people into groups at varying risk of mortality. J Am Geriatr Soc 56:68–75, 2008.

Key words: mortality; aging; frailty; functional impairment; long-term care; palliative care

Frailty has been defined as "a state of high vulnerability for adverse health outcomes included in the limit of the limit for adverse health outcomes, including disability, dependency, falls, need for long term care, and mortality."¹ Previous work has described a growing subset of patients who do not die of one defined terminal illness but instead experience a slow decline over many years that is characterized by multiple comorbidities, progressively impaired function or cognition, and a terminal phase of variable duration—a trajectory that has been termed progressive frailty.²⁻⁵ This group of patients often suffers gradual loss of functional reserve, characterized by an increased susceptibility to illness combined with a decreased ability to rebound from such insults.^{4,6} Most of these patients require some form of long-term care, either in the community, with paid and unpaid caregivers, or in a long-term care facility, such as a nursing home. It is estimated that 17% of Medicare beneficiaries aged 65 and older and 70% of those aged 85 and older require some form of long-term care, based on their requirements for assistance with instrumental activities of daily living (IADLs) and activities of daily living (ADLs).⁷ Of elderly people requiring long-term care, onethird live in a nursing home, and the remaining two-thirds

live in the community with ADL and IADL assistance.⁷ Caring for this growing population of frail elderly people generates many challenges for our healthcare system, in that they can live for months to years in a continuous state of poor health before death. The path between the onset of frailty and death can take such a variable course that it can be challenging for clinicians to discern when to transition from intensive medical management to end-of-life care in this vulnerable group of patients.

Although community-living, frail elderly people with multiple comorbidities and functional impairments are at higher risk for death than are their healthy counterparts,⁶ no mortality prediction indices have been developed for this vulnerable group of patients. The absence of methods of mortality prediction in frail elderly people is a major impediment to appropriate care.³ For example, it is often difficult to distinguish elderly people who will survive for years and therefore benefit from screening, specific medical interventions, and advance care planning from those who are rapidly approaching the end of their lives and who may, consequently, benefit from appropriate end-of-life services. Furthermore, most patients want clinicians to discuss prognosis with them, 8,9 but clinicians often avoid discussions of prognosis, because they lack confidence in their prognostic estimates. 10 A prognostic model that could stratify community-living long-term care patients into groups at varying risk for mortality would be beneficial in increasing clinicians' confidence in their prognostic estimates, which might increase their willingness to discuss prognosis with their patients.

Patients enrolled in the Program of All-Inclusive Care for the Elderly (PACE) were subjects of this study. PACE is an ideal cohort for studying frail elderly people in that it is a national, capitated, community-based long-term care program that cares for frail, chronically ill elderly people, all of whom are certified as eligible for nursing home placement. ^{11–13} PACE is designed to keep nursing home–eligible seniors in the community and in their homes longer, thereby delaying or preventing nursing home placement. The question addressed by this study is whether the national PACE database could be used to develop an accurate, easy-to-use prognostic index that could stratify frail, elderly, community-living, long-term care patients into groups according to their risk of mortality.

METHODS

Participants

The 4,241 individuals who enrolled at 11 demonstration sites of PACE between May 1, 1988, and December 31, 1996, were eligible for the study. To develop and validate the predictive index, the sample was divided into two groups according to region. The index was developed in PACE participants from the western region of the United States, including PACE sites in northern California, Colorado, Oregon, and Texas, and the index was validated in the eastern and midwestern regions of the country, including PACE sites in Massachusetts, South Carolina, Wisconsin, New York, and Michigan. The predictive index was validated in a different region of the country from where it was developed in order to test the generalizability of the index, as well as its diagnostic accuracy. ¹⁴ Three hundred

forty-two participants (8.1%) who were missing major predictor variables were excluded, including 50 (2.2%) from the development cohort and 292 (14.9%) from the validation cohort. This left a final analytical cohort of 3,899, including 2,232 participants in the development cohort and 1,667 participants in the validation cohort.

Each patient's initial enrollment examination was used as the zero point for the analyses, and each patient was followed until death or until the final censor date of December 31, 1997. An interdisciplinary healthcare team evaluated all patients in person according to a standard protocol. Patients in this cohort were followed for a mean \pm standard deviation of 2.5 \pm 1.6 years, with follow-up periods ranging from 0 to 9.6 years.

Data Source

DataPACE, which contains a uniform set of demographic, functional, and clinical data on patients enrolled at the 11 PACE demonstration sites, was the data source for these analyses. Sources of data included patients, caregivers, nurses, social workers, and physicians, and data were prospectively collected as patients were enrolled and followed in the program. DataPACE includes a consistent set of variables collected at all sites, detailed guidelines for recording data consistently at all sites, and centralized training and quality assurance procedures. Specific definitions and protocols were outlined for each data element in detailed procedure manuals, data collection staff were trained to a standard of reliability, and a central coordinating center monitored data collection to assure reliability.¹⁵

Measures

Risk Factors for Mortality

Multiple dimensions of illness and functioning, including demographics, comorbid medical conditions, and functional status, were examined. All of these predictors were assessed at the time of the patient's enrollment in PACE.

Demographic characteristics included age, sex, and marital status. The physician assessed comorbid conditions during the intake history and physical examination, which included a review of records and available laboratory data. Diseases and conditions were considered comorbidities if they were active medical problems, if they were problems that were currently controlled using diet or medications, if they contributed to the participant's disability, or if they affected the management of the participant's care. Comorbid conditions included anemia, recurrent pneumonia, renal insufficiency or failure, pressure ulcer, malignant neoplasm, diabetes mellitus, dementia, depression, cerebrovascular disease, coronary artery disease, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and bowel or bladder incontinence. Whether the participant had moderate or severe cognitive impairment, defined as having six or more errors on the 10-point Short Portable Mental Status Questionnaire (SPMSQ), 16 and whether the patient had been admitted to the hospital within the 6 months before enrollment were also considered.

In measuring functional status, a comprehensive assessment of activities of daily living (ADL), instrumental activities of daily living (IADL), and other functional

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measures was included. The ADLs assessed were bathing, toileting, transferring, eating, dressing, and walking across a room. Each ADL was assessed to determine whether the patient was independent, partially dependent, or fully dependent in the task. Patients were considered independent if they performed the entire activity without supervision all of the time. They were considered partially dependent if they required assistance from another person only some of the time or with only part of the task. They were considered fully dependent if they required assistance for the entire activity all of the time. The IADLs assessed included meal preparation, shopping, housework, laundry, heavy chores, managing money, taking medications, and using transportation. For IADLs, whether the patient was independent or dependent in the task was determined, with dependence defined as requiring another person to complete every component of the task for the patient. Also, whether formal or informal caregiver assistance was provided in the home at the time of enrollment and whether the patient had vision impairment, hearing impairment, or an expressive or receptive form of communication impairment were determined.

Definition of Outcome

The primary outcome of interest was time to death, from the time of enrollment in PACE through the final censor date, December 31, 1997. Mortality was assessed using PACE follow-up procedures and the U.S. National Death Index.¹⁷

Statistical Analyses: Development and Validation of the Predictive Index

As the first step in the development of the predictive index, bivariate analyses using Cox regression were performed in the development cohort in order to determine the relationship between each potential risk factor and mortality. Multivariate analyses were then performed in which all risk factors were placed into a backward stepwise elimination model (P < .05) to determine the final predictors for the prognostic index. Finally, a point scoring system was constructed in which points were assigned to each risk factor using the coefficients (parameter estimates) from the final Cox regression model. The coefficient for each risk factor was divided by the lowest coefficient (partial dependence in the ADL dressing) and rounded to the nearest integer. 18-20 For example, to obtain the point score for CHF, the coefficient for that variable (0.549) was divided by the lowest coefficient (0.197), which rounds to 3. A risk score was then calculated for each patient by adding the points for each risk factor present. The risk groups were created based on the distribution of risk scores within the development cohort, and subjects were divided into risk groups of approximately equal size according to their risk score, to approximate tertiles of risk.

To validate the index, the point scoring system created in the development cohort was applied to the validation cohort, thereby determining risk scores for each participant in the validation cohort. To determine the calibration of the index, the predicted mortality from the development cohort was compared with the observed mortality in the validation cohort at 1 and 3 years. To determine the discrimination of the index, the area under the receiver operating character-

istic curve (AUC) was calculated for the index in the development and validation cohorts.

To assess the contributions of the different components of the final model to the model's overall discrimination, separate AUCs were calculated in the development cohort for age and sex combined, for the comorbid illnesses combined, and for the functional measures alone. All significance levels reported were two-sided, and all analyses were performed using SAS software, version 9.1 (SAS Institute, Inc., Cary, NC).

RESULTS

Characteristics of Participants

The mean age of participants in the development cohort (n = 2,232) was 79 ± 9 . Sixty-eight percent were women, 40% were white, and 94% were eligible for Medicaid. Forty-nine percent had dementia, 50% were dependent in three or more ADLs, and 46% had been hospitalized within the 6 months before PACE enrollment (Table 1). One-year mortality was 13%, and 3-year mortality was 37%.

The mean age of participants in the validation cohort (n = 1,667) was 79 ± 9 . Seventy-six percent were women, 65% were white, and 95% were eligible for Medicaid. Forty-nine percent had dementia, 52% were partially or fully dependent in three or more ADLs, and 45% had been hospitalized within the 6 months before PACE enrollment (Table 1). One-year mortality was 13%, and 3-year mortality was 36%.

Risk Factors

Table 2 includes the risk factors from Table 1 that were found to be associated with mortality in the bivariate analyses (P < .05). Demographic characteristics associated with mortality included being aged 75 and older, being male, and being married. Functional measures associated with mortality included partial or full dependence in each ADL and dependence in several IADLs. Several comorbid conditions were also associated with mortality, as was hearing impairment, moderate or severe cognitive impairment according to the SPMSQ, and having a hospital admission within the 6 months before enrollment.

Eight of these risk factors were independently predictive of mortality in multivariate analyses (Table 3). These included male sex, being aged 75 and older, dependence in the ADL toileting, partial or full dependence in the ADL dressing, and the presence of several comorbid conditions (malignant neoplasm, CHF, COPD, and renal insufficiency or failure).

Point Scoring System

The points assigned to each of the final risk factors are listed in Table 3. A risk score was assigned to each participant by adding the points for each risk factor present. Risk scores ranged from 0 to 14 points (mean 4.6 ± 2.5) in the development cohort and from 0 to 15 points (mean 4.8 ± 2.7) in the validation cohort.

Patients were divided into three risk groups according to point score, based on the distribution of patients in the development cohort (Table 4). In the development cohort,

Table 1. Patient Characteristics in the Development and Validation Cohorts at the Time of Patient Enrollment in the Program of All-Inclusive Care for the Elderly

	Development Cohort (n = 2,232)	Validation Cohort (n = 1,667)	
Variable	n (%)		
Age			
<75	656 (29.4)	522 (31.3)	
75–79	415 (18.6)	324 (19.4)	
80–84	512 (22.9)	381 (22.9)	
≥85	649 (29.1)	440 (26.4)	
Female	1,511 (67.7)	1,258 (75.5)	
Ethnicity			
White	891 (39.9)	1,075 (64.5)	
Black	314 (14.1)	521 (31.3)	
Hispanic	340 (15.2)	51 (3.1)	
Asian	668 (29.9)	6 (0.4)	
Other	19 (0.9)	14 (0.8)	
Education, years			
<12	1,439 (66.4)	1,168 (70.1)	
≥12	729 (33.6)	498 (29.9)	
Married	391 (17.5)	310 (18.6)	
Medicaid eligible	2,086 (93.5)	1,580 (95.4)	
Received caregiving assistance	1,788 (84.2)	1,505 (91.0)	
at home	.,. 00 (0)	1,000 (01.0)	
Activities of daily living			
Bathing			
Independent	407 (18.3)	226 (13.6)	
Partially dependent	1,385 (62.3)	1,190 (71.5)	
Fully dependent	432 (19.4)	248 (14.9)	
Toileting			
Independent	1,193 (53.7)	900 (54.2)	
Partially dependent	850 (38.2)	603 (36.3)	
Fully dependent	180 (8.1)	159 (9.6)	
Transferring			
Independent	1,209 (54.4)	1,003 (60.3)	
Partially dependent	863 (38.8)	540 (32.5)	
Fully dependent	150 (6.8)	121 (7.3)	
Eating	,	,	
Independent	1,749 (78.6)	1,182 (71.1)	
Partially dependent	424 (19.1)	445 (26.8)	
Fully dependent	52 (2.3)	35 (2.1)	
Dressing	,	,	
Independent	834 (37.5)	503 (30.3)	
Partially dependent	1,175 (52.8)	952 (57.3)	
Fully dependent	217 (9.8)	208 (12.5)	
Walking across a room	(-15)		
Independent	1,033 (46.4)	964 (58.0)	
Partially dependent	952 (42.8)	543 (32.7)	
Fully dependent	240 (10.8)	154 (9.3)	
Dependent in instrumental activ	` '	(010)	
Meal preparation	1,662 (74.8)	1,093 (65.7)	
Shopping	1,850 (83.2)	1,428 (85.9)	
Housework	1,764 (79.3)	1,244 (74.8)	
Laundry	1,844 (83.0)	1,424 (85.6)	
	1,011 (00.0)	(Continued)	

(Continued)

Table 1. (Contd.)

Development Validation Cohor

	Development Cohort (n = 2,232)	Validation Cohort (n = 1,667)	
Variable	n (%)		
Heavy chores	2,104 (94.6)	1,612 (97.0)	
Managing money	1,287 (58.1)	1,117 (68.5)	
Taking medications	829 (37.3)	649 (39.0)	
Transportation	1,770 (79.6)	1,234 (74.2)	
Impaired vision	1,188 (53.4)	741 (44.6)	
Impaired hearing	800 (36.0)	527 (31.7)	
Receptive or expressive communication impairment	635 (28.6)	472 (28.5)	
Bladder incontinence	1,096 (49.3)	934 (56.3)	
Bowel incontinence	475 (21.4)	440 (26.5)	
Short Portable Mental Status Qu	estionnaire score		
0–5	1,356 (61.2)	1,043 (62.8)	
6–10	861 (38.8)	618 (37.2)	
Anemia	214 (9.6)	342 (20.5)	
Recurrent pneumonia	36 (1.6)	33 (2.0)	
Renal failure or insufficiency	131 (5.9)	188 (11.3)	
Pressure ulcer	48 (2.1)	62 (3.7)	
Malignant neoplasm	213 (9.5)	191 (11.5)	
Diabetes mellitus	505 (22.6)	448 (26.9)	
Dementia	1,090 (48.8)	812 (48.7)	
Depression	582 (26.1)	439 (26.3)	
Cerebrovascular disease	662 (29.7)	536 (32.1)	
Coronary artery disease	523 (23.4)	445 (26.7)	
Congestive heart failure Chronic obstructive pulmonary disease	392 (17.6) 274 (12.3)	294 (17.6) 213 (12.8)	
Hospital admission 6 months before enrollment	951 (45.8)	750 (45.3)	

1-year mortality ranged from 6% in the lowest-risk group (0-3 points) to 21% in the highest-risk group (> 5 points). The results were similar in the validation cohort, with the lowest-risk group (0-3 points) having a 7% 1-year mortality and the highest-risk group (>5 points) having a 22% 1-year mortality. Three-year mortality in the development cohort ranged from 21% in the lowest-risk group (0-3 points) to 54% in the highest-risk group (>5 points). The validation cohort had a similar 3-year mortality rate; 3-year mortality in the lowest-risk group (0-3 points) was 18%, and 3-year mortality in the highest-risk group (>5 points) was 55%. The point scoring system had a slightly better discrimination in the validation cohort than in the development cohort, with an AUC for mortality of 0.66 in the development cohort and 0.69 in the validation cohort.

Kaplan–Meier survival curves of the three risk groups demonstrate that the groups had distinct survival trajectories and that these differences persisted over the entire 6-year time course shown in Figure 1.

To assess the extent to which the different components of the model contributed to the overall discrimination of the model, separate AUCs were calculated examining 72 CAREY ET AL. JANUARY 2008-VOL. 56, NO. 1 JAGS

Table 2. Bivariate Associations Between Risk Factors and Mortality in the Development Cohort

Variable	Mortality, %	Hazard Ratio (95% Confidence Interval)
Age		
<75	31.4	1.00
75–79	36.4	1.26 (1.02–1.56)
80–84	43.4	1.42 (1.17–1.75)
>85	46.7	1.72 (1.44–2.05)
Sex		= (=100)
Male	44.5	1.35 (1.17–1.54)
Female	37.1	1.0
Married		
Yes	42.7	1.23 (1.04–1.45)
No	38.8	1.0
Activities of daily living		
Bathing		
Independent	28.8	1.0
Partially dependent	38.8	1.39 (1.14–1.70)
Fully dependent	51.6	1.79 (1.43–2.24)
Toileting		,
Independent	33.1	1.0
Partially dependent	46.2	1.44 (1.25–1.65)
Fully dependent	50.6	1.70 (1.35–2.14)
Transferring		()
Independent	32.8	1.0
Partially dependent	47.7	1.43 (1.25–1.64)
Fully dependent	46.7	1.46 (1.13–1.88)
Eating		(
Independent	37.7	1.0
Partially dependent	45.8	1.25 (1.06–1.46)
Fully dependent	50.0	1.42 (0.96–2.10)
Dressing		(
Independent	32.9	1.0
Partially dependent	41.5	1.36 (1.17–1.58)
Fully dependent	53.9	1.92 (1.55–2.39)
Walking across a room		(
Independent	33.2	1.0
Partially dependent	45.1	1.33 (1.15–1.53)
Fully dependent	44.6	1.44 (1.16–1.79)
Instrumental activities of da		()
Meal preparation	, ,	
Independent	31.0	1.0
Fully dependent	42.4	1.35 (1.14–1.59)
Shopping		
Independent	29.1	1.0
Fully dependent	41.6	1.41 (1.15–1.72)
Housework		(1112)
Independent	30.7	1.0
Fully dependent	41.8	1.41 (1.18–1.69)
Laundry		(
Independent	31.8	1.0
Fully dependent	41.1	1.34 (1.10–1.62)
Managing money		1.01 (1.10 1.02)
Independent	35.4	1.0

Table 2. (Contd.)

Variable	Mortality, %	Hazard Ratio (95% Confidence Interval
Fully dependent	42.4	1.22 (1.07–1.40)
Taking medications		
Independent	36.8	1.0
Fully dependent	43.9	1.22 (1.06–1.39)
Hearing impairment		
No	35.3	1.0
Yes	47.1	1.32 (1.16–1.51)
Bladder incontinence		
No	35.9	1.0
Yes	43.2	1.41 (1.23–1.61)
Bowel incontinence		
No	37.1	1.0
Yes	47.8	1.59 (1.37-1.86)
Short Portable Mental Sta	atus Questionnaire s	score
0–5	36.8	1.0
6–10	43.8	1.19 (1.05–1.37)
Anemia		
No	38.9	1.0
Yes	45.3	1.24 (1.01-1.54)
Recurrent pneumonia		
No	39.2	1.0
Yes	61.1	1.83 (1.20-2.79)
Renal failure or insufficie	ncy	
No	38.5	1.0
Yes	55.7	2.25 (1.77-2.87)
Pressure ulcer		
No	39.4	1.0
Yes	43.8	1.55 (1.01-2.39)
Malignant neoplasm		
No	38.6	1.0
Yes	47.9	1.59 (1.29-1.95)
Diabetes mellitus		
No	38.9	1.0
Yes	41.8	1.22 (1.04-1.42)
Coronary artery disease		
No	37.5	1.0
Yes	46.3	1.40 (1.20-1.62)
Congestive heart failure		
No	36.0	1.0
Yes	56.1	2.00 (1.72-2.33)
Chronic obstructive pulm	onary disease	
No .	38.9	1.0
Yes	44.2	1.44 (1.19–1.74)
Hospital admission 6 mo	nths before enrollm	· · · · · · · · · · · · · · · · · · ·
No	35.2	1.0
Yes	42.0	1.22 (1.06–1.40)

different groups of variables separately. In the development cohort, using age and sex alone as predictors of death resulted in an AUC of 0.61, whereas using only comorbidities as predictors of death resulted in an AUC of 0.64. Adding functional measures increased the AUC of the model from 0.63 (without function) to 0.66.

(Continued)

Table 3. Risk Factors Associated with Mortality in Multivariable Analysis and Associated Point Scores

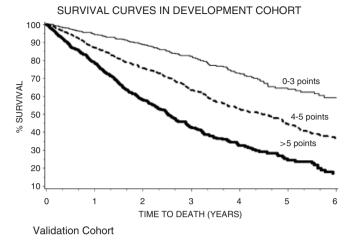
Risk Factor	Hazard Ratio (95% Confidence Interval)	Estimated Points
Male	1.4 (1.2–1.6)	2
Age		
75–79	1.3 (1.1–1.7)	2
80–84	1.6 (1.3–1.9)	2
≥85	1.8 (1.5–2.1)	3
Dependence in toileting	1.3 (1.1–1.5)	1
Dressing		
Partially dependent	1.2 (1.0-1.4)	1
Fully dependent	1.6 (1.3–2.1)	3
Malignant neoplasm	1.6 (1.3–1.9)	2
Congestive heart failure	1.7 (1.5–2.0)	3
Chronic obstructive pulmonary disease	1.3 (1.1–1.6)	1
Renal failure or insufficiency	1.6 (1.3–2.1)	3

DISCUSSION

A multidimensional prognostic index that effectively stratifies frail, community-living long-term care patients into groups at varying risk of mortality was developed and validated using age, sex, functional status, and comorbidities. It applies a simple point scoring system, and all the necessary variables can be obtained from a routine clinical evaluation. The index was well calibrated, based on the similarity between the mortality rates in the development and validation cohorts for the three risk groups according to point score. The index also showed good discrimination, with AUCs for mortality of 0.66 and 0.69 in the development and validation cohorts, respectively.

In developing the index, variables from multiple domains of risk, including demographics, functional status, communication impairments, and medical comorbidities, were considered. In the final multivariate model, the eight variables that remained independently predictive of death included being male, being aged 75 and older, two functional status measures (dependence in the ADLs toileting and dressing), and four comorbid illnesses, with being aged 85 and older, CHF, and renal failure conferring the most increased risk. The patients that were found to be at the highest risk of dying had multiple risk factors simulta-

Development Cohort



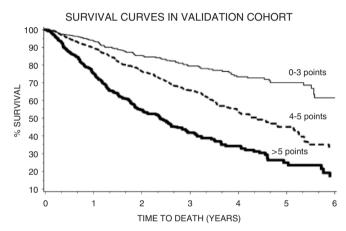


Figure 1. Survival curves according to risk group. (A) Development cohort. (B) Validation cohort.

neously. This is consistent with prior work that has found that death and other adverse outcomes in elderly people frequently result from multiple causes and that it is rare for a single aspect of health status to be the sole or dominant predictor. ^{19, 21} Another important finding in the study was that impaired functional status remained a strong independent predictor of mortality, substantially increasing the accuracy of the prognostic model, which is consistent with prior work in other populations that has found that functional status reflects the severity and end result of many different illnesses and psychosocial factors. ^{19–22}

Table 4. Mortality Rates According to Risk Score in the Development and Validation Cohorts **Subjects** 1-Year Mortality 2-Year Mortality 3-Year Mortality Development Validation Development Validation Development Validation Development Validation Cohort Cohort Cohort Cohort Cohort Cohort Cohort Cohort Risk Score n % 0-3 769 6.4 6.8 13.8 14.5 20.9 18.1 572 4-5 703 518 12.1 10.8 24.3 24.8 36.2 35.7 > 5 751 572 20.6 22.2 39.7 40.5 54.1 55.1

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To the authors' knowledge, this is the first validated prognostic index to predict death in community-living longterm care patients, all of whom are at high risk of death and in whom accurate prognostication is known to be difficult. Our index was superior to using age and sex alone, functional measures alone, or comorbidities alone. As a whole, PACE participants have a high burden of illness, and more than one-third of the patients in the study died within 3 years after enrollment. This is a much higher mortality rate than would be expected from age alone. For example, the mean age of the sample was 79, and the 3-year mortality rate of the 79-year-old PACE patients was 38%. This is much higher than the expected 3-year mortality rate of a 79-year-old in the United States as calculated from the U.S. Life Tables, which is 16%.²³ Despite the overall degree of morbidity and the higher mortality in this sample, the index was able to identify three risk groups with a threefold difference in mortality, with the highest-risk group having a 55% mortality rate over 3 years. Even the lowest-risk group in PACE had a higher 3-year mortality rate, 18%, than that reported for 79-year-olds in the U.S. Life Tables.²³ The ability of this index to discriminate between patients at low and high risk for death compares favorably with prediction indices developed for other outcomes in frail elderly people, such as models to predict delirium,²⁴ but the AUC of this index is lower than that of some indices designed to predict short-term outcomes in hospitalized older adults^{19,22,25,26} or in population-based samples that include a broader range of sick and well elderly people. 20,21,27 This is not surprising, because this index predicts mortality over a longer time interval and in PACE patients, who carry high burdens of functional dependencies and illness—a group in whom prognostic stratification is notoriously challenging. Thus, in effect, this was an attempt to distinguish between the sick and the very sick—between groups of patients all of whom were entering their final years of life.

The PACE program cares for frail, nursing homeeligible elderly people who are able to stay in the community with the assistance of PACE. Although these are sick patients with a high burden of illness, they are not unlike other frail elderly people living in the community with long-term care needs. The majority of frail elderly people who qualify for long-term care services live in the community rather than nursing homes, and they are a rapidly growing segment of the population.⁷ Improving the ability to assess mortality in this ever-growing group of patients is therefore relevant to improving the care of many older adults.

This prognostic model provides an objective estimate of mortality that can be used in a number of settings to assess risk of dying in frail elderly people with long-term care needs. Because it was possible to distinguish groups of very ill patients with a threefold difference in mortality, this index could be useful in risk adjustment, which is essential to evaluating medical effectiveness, quality of care, and healthcare outcomes for the purpose of health policy decision-making and in the setting of clinical research.²⁸ In addition, using the index as a tool to account for baseline illness severity in settings in which frail elderly people receive medical care may have implications for risk-based reimbursement systems. For example, a prognostic index such as this one might be an improvement over existing

methods of calculating individual risk scores used to establish rates of reimbursement, in that this index accounts for functional status. However, the focus of the prognostic model is on the prediction of mortality rather than costs, so additional studies will be required before determining whether to include function in designing capitated payment rates for PACE.²⁹ Additionally, in clinical settings, the index could be useful in supporting clinician judgment about prognosis, because there is evidence that clinician judgment used in conjunction with a prognostic model is more accurate than either alone. 26,30,31 Multiple studies have shown that patients would like clinicians to discuss prognosis with them. 8,9 Indices such as this one, which lend confidence to clinician judgment about prognosis, may help clinicians interact more productively with patients and their families about this difficult topic.

Although this index will not be helpful in determining hospice eligibility as the Medicare Hospice Benefit is currently defined, it identifies a group of patients who are more likely than not to die over the following 3 years. In this group of patients, education about disease process, prognosis, and potential future care needs, as well as ongoing discussions about goals of care, advance directives, and code status, are especially urgent. The onset of frail health often indicates that there is likely to be a change in the medical care that the patient will need and want. This index should not be used to deny care from which patients may benefit or that may be life-prolonging, but it should instead be considered to be a tool that can assist clinicians better meet patients' needs by allowing for the provision of care based on each individual patient's goals of care as determined in the light of realistic expectations about prognosis.

Although a strength of this study is that a large sample of vulnerable, community-living long-term care patients from across the United States was studied, there are several methodological considerations that should be taken into account in evaluating the results. First, information was not available about patient preferences for care or do-notresuscitate or do-not-intubate status. Second, the presence of comorbid illnesses was based on clinician judgment rather than a strict definition (e.g., there was no specific creatinine clearance defining renal failure), and information was not available about severity of illness. Comorbidity being defined according to clinician judgment is not dissimilar to what one might find with administrative data. Third, as with all indices, the index requires testing in settings outside of PACE, including nursing homes. Finally, although the patients cared for by PACE are likely generalizable to frail, community-living long-term care patients in the United States, it is possible that frail elderly people being cared for through PACE survive longer because of access to a broad range of services and to consistent care across settings.

In conclusion, a prognostic index using eight accessible variables, including age, sex, functional status, and several comorbid conditions, was developed and validated. The index is easy to use and includes variables that can be obtained in the course of a routine clinical examination. The index effectively stratifies older adults into groups at varying risk of mortality, and it reinforces the importance of considering multiple domains in assessing prognosis in older patients. It also highlights the challenges of prognostication in frail elderly people and the

need for developing a more-compassionate care system that meets the care needs for the last years of life in the evergrowing population of frail elderly people with long-term needs.

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Dr. Eng is the Medical Director of On Lok Senior Health Services, which is a PACE site. We do not, however, view her employment as a conflict of interest, because there was no benefit to PACE, On Lok, or Dr. Eng for her participation in this study. She gave of her own time for this study and did not benefit financially. Moreover, the data were collected years before the study was conceived, and Dr. Eng had no role in managing, analyzing, or interpreting the data.

Author Contributions: Each of the authors contributed to this work in multiple ways. Drs. Carey, Covinsky, and Walter actively participated in all phases of the project, including study concept and design, data analysis oversight, data interpretation, and preparation of the manuscript. Ms. Lui performed all of the data analyses, participated in interpretation of the data, and assisted in the preparation of the manuscript. Dr. Eng participated in study concept and design and in preparing the manuscript. Dr. Sands assisted with interpretation of the data and with preparation of the manuscript.

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