

Predicting Place of Death in the Program of All-Inclusive Care for the Elderly (PACE): Participant versus Program Characteristics

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OBJECTIVES: To assess the relationship between participant-specific and program-specific characteristics and the place of death in the Program of All-Inclusive Care for the Elderly (PACE).

DESIGN: A retrospective, population-based, cross-sectional study.

SETTING: PACE is a community-based managed care model serving a frail, nursing home-eligible population of Medicare beneficiaries.

PARTICIPANTS: Two thousand two hundred sixty-three PACE decedents from 12 sites that were fully capitated for Medicare and Medicaid by mid-1997.

MEASUREMENTS: Participant-specific characteristics include the range of demographic, functional, and cognitive status; skilled care needs; medical conditions; and advance care directives measures. The PACE site-specific indicator was also included to assess the effect of program sites on place of death. Bivariate, logistic, and multinomial logit models were employed.

RESULTS: The probability of death at home is twice as great (45%) for PACE program participants as for the general population of older Americans. Twenty-one percent of PACE participants die in hospitals, compared with 53% of Medicare beneficiaries. Participants who are older and live in the community have a significantly greater ($P < .05$) probability of dying at home than does an average PACE enrollee. Those with a do-not-resuscitate order are 7.4% less likely to die in the hospital than are those without. PACE participants with a live-in informal caregiver are 10.3% ($P < .05$) less likely to die at home than those without a caregiver. When all participant characteristics were accounted for, there remained significant variation in the place of death by PACE plan. We found the least amount of site-specific variation in deaths occurring at

home and the most variation in deaths occurring in hospitals.

CONCLUSION: Nationally, the low rate of home death has prompted some to conclude that “it is unlikely that we will, as a society, decide to take our dying older people back into our homes.” The PACE experience suggests that it is possible to modify this trend. The results indicate that patient and program characteristics are both important in predicting the place of death. The variation across PACE sites suggests that an opportunity for narrowing these gaps, and reducing the proportion of hospital deaths, exists. The PACE end-of-life “practice style” could potentially be applied to other populations and may have important public policy implications. *J Am Geriatr Soc* 50: 125–135, 2002.

Key words: PACE; place of death; end-of-life; decedents

Although most terminally ill Americans would prefer to die at home, few do. Studies have shown that 82% of seriously ill patients prefer to die at home.¹ Forty-three percent of chronically ill community-dwelling older people expressed a preference for home as the site of terminal care.² Between 50% and 70% of patients near death are reported to want to die at home.^{3,4} According to a national survey (Table 1), 65% of older Americans (aged 65 and older) prefer to die at home or in a hospice.⁵ Analysis of actual place of death shows that only 20% die at home or hospice, and 77% die in institutional settings (53% in acute care hospitals).⁶ The images and fears of impersonal death, of expensive and needless end-of-life high-technology treatments, and of painful and unwanted medical interventions have given rise to increasing scrutiny of the care of the dying in both the popular and professional media.^{1,2,7–11}

Prior studies examining the determinants of the place of death focused either on the characteristics of the health-care system or on those of the patients. It has been shown that the characteristics of the local healthcare system exert powerful influence on patients' service utilization, including those near death. Increased rates of nursing home deaths are known to correlate with increased availability

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Table 1. Preferred vs Actual Site of Death: Americans Aged 65 and Older

Site of Death	Preferred Site ⁵	Actual Site ⁶
	%	
Home and hospice	65	20
Hospital	25	44
Nursing home	3	24
Don't know	7	3
Hospital OPD (other)		9
TOTAL	100	100

OPD = outpatient department.

of nursing home beds.¹² Similarly, higher rates of inpatient hospital deaths are associated with greater hospital bed availability.¹³ But these studies have not been able to address concerns that patient rather than healthcare system differences explain these observed geographic variations. Furthermore, most studies have been based on data from the traditional fee-for-service care models; only a few looked at decedents in managed care settings.^{14,15} Studies that examined the importance of patient rather than system characteristics in determining the place of death also have important limitations. The majority of these studies focused on the death experience of cancer patients rather than of a broader group of decedents.^{16–18} The reported associations between the place of death and patient characteristics were rarely based on multivariate statistical models and in many cases were limited to particular settings or sites of care.^{1,19} Because prior studies have generally focused on either patient or healthcare system characteristics, the relative importance of each in determining the place of death is not clear.

The Program of All-inclusive Care for the Elderly (PACE) offers a unique model within which to investigate the influence of both patient and system characteristics. PACE provides a managed care (capitated) continuum of preventive, primary, acute, and long-term care services to nursing home-eligible older persons who reside in the community. All PACE participants have a close and ongoing relationship with their primary care physician and with other program staff members and caregivers. The PACE staffing ratios include one primary care physician, one nurse practitioner, four and a half registered nurses, three social workers, and other professional and paraprofessional staff for each 120 to 150 enrollees.²⁰ The PACE model places high priority on discussing participants healthcare wishes with them and on obtaining advance directives.^{21,22} This promotes an environment that encourages addressing sensitive issues such as end-of-life treatment options and facilitates making difficult choices about the use of critical care technology that can extend life or extend the process of dying. It also creates an environment that encourages good communication between patients and their families and clinicians, and between clinicians themselves, and may therefore hold the promise for improving care at the end of life.

It is within the context of this managed care model that we examine here both patient and healthcare system char-

acteristics as the determinants of the place of death. In undertaking this study we had the following three objectives.

1. To assess the relationship between participant-specific characteristics, including advance directives, and the place of death.
2. To examine PACE site-specific variations in place of death, controlling for important patient characteristics.
3. To compare place of death in PACE and in the fee-for-service Medicare population residing in the same geographic areas.

BACKGROUND

PACE is a community-based alternative care setting for frail, chronically ill older people whose significant functional and cognitive impairments make them eligible for nursing home care. All PACE participants must also be age 55 and older and be receiving Medicare. They may also be eligible for Medicaid. PACE has been modeled after the On Lok program in San Francisco. Since 1990, the PACE model has been replicated in many other sites across the country. Since implementation of the Balanced Budget Act of 1997, PACE has moved from operating under the federal demonstration authority to become a permanent provider status. Currently there are more than 30 PACE sites in 13 states.

PACE is a managed care program that integrates primary, acute, and long-term care services under Medicare and Medicaid capitation arrangement. Care is provided by an interdisciplinary team and includes clinical, social, and support services provided by professional and paraprofessional staff. A key component of the program is a highly developed day program attended by the participants. PACE embodies a philosophical approach to care that emphasizes creativity and flexibility in accommodating services to the needs of individual participants, with a goal of maintaining individuals in their homes.

A typical PACE participant is an 80-year-old Medicaid-eligible widow who is as likely to live at home alone as she is with others. She has multiple medical diagnoses, experiences multiple limitations in activities of daily living (ADLs), and is likely to suffer some degree of cognitive impairment (Table 2). Her life expectancy upon enrollment in the program is approximately 2.5 years (Table 3).

Currently, over 6,000 nursing home-certifiable Medicare beneficiaries receive care from Medicare capitated PACE sites and pre-PACE sites (under Medicaid but not yet Medicare capitation). More than 12,000 Medicare beneficiaries have been cared for by the PACE model since 1990. A number of recent studies offer a more in-depth view of PACE.^{20,23–26}

DATA AND METHODS

Data

The population in this study included all of the participants enrolled in the first 12 PACE sites, all of which were fully capitated (receiving both Medicare and Medicaid capitation payments) by mid-1997. For each PACE site, the data covered the period from the program's inception through mid-1998. The study population included 6,971 individuals, of whom 2,263 had died by mid-1998. Table

Table 2. Descriptive Statistics By Program of All-Inclusive Care for the Elderly (PACE): Through June 1998

PACE Program	Program Waiver Date	Number of Enrollees	Average Age	Percentage	Percentage	Percentage	Average No. ADLs	Average No. of Medical Conditions	Percentage with Dementia
				Female	White %	Medicaid			
All plans		6,971	80.0	71	44	95	3.0	8.1	48
San Francisco, CA	Nov-83	1,066	78.9	65	16	94	2.7	6.4	37
East Boston, MA	Jun-90	632	80.8	77	89	91	2.8	9.4	39
Portland, OR	Jun-90	777	81.0	74	89	93	2.7	8.1	57
Columbia, SC	Oct-90	767	77.8	76	24	99	3.5	7.6	67
Milwaukee, WI	Nov-90	765	78.7	76	48	97	2.8	8.8	47
Denver, CO	Oct-91	522	80.2	68	55	94	2.8	6.9	75
Bronx, NY	Feb-92	816	76.1	69	19	100	2.8	7.6	18
Rochester, NY	May-92	729	80.4	65	79	89	3.5	9.2	55
Sacramento, CA	May-94	302	78.4	71	63	88	3.1	9.1	57
El Paso, TX	Jun-94	330	78.9	64	5	100	3.1	9.1	62
Oakland, CA	Apr-95	146	78.0	63	8	98	3.3	7.3	41
Detroit, MI	May-97	119	78.8	84	6	100	2.1	11.0	50

Note: Statistics shown are for the time period June 1990 through June 1998.
ADL = activities of daily living.

2 presents some descriptive characteristics of each program. (The identities of the PACE sites are coded A through L in the other Tables and Figure 1; the order does not correspond to that presented in Table 2.)

We used two sources of data in this study: dataPACE (a secondary data source) and advance directives (a primary data source). The PACE data (also known as dataPACE) for these sites were collected under Health Care Financing Administration (HCFA) contract number 500-95-0035 through mid 1998. This is a comprehensive administrative database containing demographic, health, functional status, medical history, and service use (encounter) information on a person-

specific longitudinal basis. The following principles governed dataPACE collection.

- All sites collected the same set of variables (from each site's inception through mid-1998).
- A consistent set of guidelines for data collection was applied across all sites.
- All data collection training was performed and directed by On Lok, Inc. staff.
- HCFA and the sites were notified about the quality of data and corrective action was taken when needed.
- All sites had to incorporate changes to the data set.

Table 3. Mortality and Place of Death in Program of All-Inclusive Care for the Elderly (PACE): By Site

PACE Program	Number of Decedents*	Average LOS from Enrollment Until Death months	Mortality Rate [†]	Site of Death*		
				Hospital (n = 479)	Nursing Home (n = 765)	Home (n = 1,019)
				%		
All Sites	2,263	29.7	32	21.2	33.8	45.0
A		43.3	25	39.5	15.6	44.9
B		31.0	32	32.0	40.0	28.0
C		18.2	12	14.3	28.6	57.1
D		34.9	39	12.3	25.9	61.8
E		30.1	39	15.3	37.2	47.5
F		32.3	31	24.7	33.1	42.3
G		37.5	18	25.9	31.0	43.1
H		23.9	30	20.7	30.4	48.9
I		26.9	35	26.5	48.6	24.9
J		31.2	17	8.0	16.0	76.0
K		24.4	42	13.8	32.6	53.6
L		20.7	32	18.7	41.7	39.6

*To protect the confidentiality of the PACE sites, site names are coded and data on the number of decedents by site are not presented.

[†]Significant variations by PACE site ($P < .001$).

LOS = length of stay.

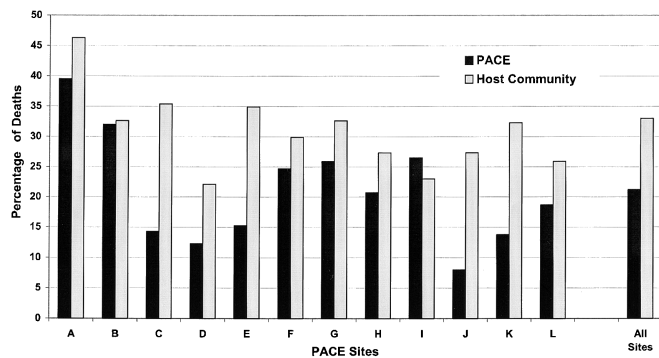


Figure 1. Percentage of hospital deaths by Program for All-Inclusive Care for the Elderly (PACE) site and host community.

- To increase data accuracy and interrater reliability, specific procedures were instituted and required of all sites.²³

Data on advance directives were obtained directly from the PACE sites, under a project supported by the Culpepper Foundation. Of the 12 PACE sites, 10 agreed to provide participant-specific data on advance directives for 5,377 people who were enrolled at these sites before mid-1998. Collectively, these 10 sites had 1,757 decedents during the period covered by the study. Advance directives are prior directives by the patient concerning his or her health care. They generally fall into two categories, those that have to do with instructions for medical care such as cardiopulmonary resuscitation (CPR) or artificial feeding, and those that have to do with designating a proxy for future decision-making.²⁷ Some PACE sites collect more-detailed advance directive data than others, but all collect information on CPR and most (7 out of 10) collect data on healthcare proxies and artificial feeding. A healthcare proxy is someone designated by the program participant (or chosen for the participant in case of cognitive impairment) to make medical decisions when the participant becomes unable to make such decisions. Artificial feeding refers to methods used to feed people who can no longer eat, such as insertion of a tube into the stomach or giving liquid nutrients through a vein catheter.²⁷

At each site, advance directives data were retrieved from patients' medical records by the designated program staff, usually in paper format, but, in the case of one site, in an electronic record format. Information on advance directives, site- and patient-specific identification numbers, and information on gender and date of birth were forwarded to the authors, who entered the information into a computer, edited it for accuracy, and linked it with dataPACE for each participant.

Methods

Outcome

The outcome variable, place of death, was identified as acute care hospital, nursing home, or home. Place of death is not a recorded variable in dataPACE and therefore had to be imputed based on services used, their dates, and the date of death. Deaths in acute care hospitals, in nursing homes, and in transitional housing (housing owned by

PACE and used as an alternative care site) were defined first, based on the participants' presence in these settings on the date of their death. All other deaths were defined as having occurred at home. Because only some PACE sites have transitional housing, we collapsed this category with nursing home based upon consultations with PACE providers (transitional housing being perceived as used mostly as an alternative to placing someone in a nursing home).

Independent Variables

Independent variables were obtained from dataPACE and from the advance directives data collected for this project. Those variables included age, gender, race, level of education attained, living arrangements, availability of an informal caregiver (coded as living with the participant or not), time from admission into the program until death, presence or absence of advance directives, self-assessed health status, functional status, cognitive status, incontinence, need for skilled care, and medical diagnosis. Also included was the variable indicating the PACE site where the participant was enrolled. This variable allowed us to assess the effect of site on place of death. The site variable captures local practice styles, availability of local resources (e.g., nursing home beds), and possibly participant characteristics not explicitly included in the regression model that are also correlated with the site. Given the richness of participant-level information included in dataPACE, it is unlikely that important participant risks are omitted from our analyses and therefore unlikely that they are captured in the site coefficient.

An informal caregiver may be a spouse, child, other relative, or friend. Advance directives were grouped into three categories: CPR with do not resuscitate (DNR), or full code; healthcare proxy (present or absent); and feeding tube (refused or not). Functional status was measured using an index of ADLs. The ADLs included in dataPACE are bathing, dressing, grooming, toileting, walking, and feeding. For each ADL, a score of 1 was assigned if a person was independent, a score of 2 if some help or supervision was required, and a score of 3 in cases of total dependence on human assistance. The scores were then summed. Cognitive status was measured using a mental status questionnaire (a 10-item instrument used to measure cognitive status) that has been validated in numerous other studies; a score of less than 3 was used to define absence of impairment.²⁸ Skilled care needs were coded as 1 if the participant received care from any source and as 0 if skilled care was not provided.

Statistical Analysis

The associations between the independent variables and the sites of death—hospital, nursing home, home—were assessed in a bivariate analysis using the chi-square statistic. To determine the independent effect of each of the participant characteristics and the PACE site effect we also estimated multivariate models. Because the outcome of interest (place of death) could assume any of three different unordered values (hospital, nursing home, or home) we estimated multinomial logit models. This technique estimates simultaneously two regression models in which the dependent

variables are the logarithm of the odds ratio of each of the first two states to the third (i.e., the ratio of the odds of hospital to home and the ratio of the odds of nursing home to home). Both regressions include the same independent variables, but each can have different coefficients, such that the correlation between each risk factor and the odds ratio can differ for the two odd ratios. These two regression models, together with the restriction that the sum of the probabilities of death in the hospital, death in the nursing home, and death at home equal 1, completely identify the relationships between risk factors and place of death probabilities.

Due to data sparsity within strata, we could not estimate multinomial logit models with all of the independent variables that were significantly associated with place of death in the bivariate analyses. Therefore, we first estimated logistic models of pair-wise comparisons of place of death. For example, we estimated logistic models predicting the probability of death in the hospital versus death in the home, models predicting probability of death in the nursing home versus home, etc. Independent variables that were significantly associated with place of death in at least one of these models (with P -values $\leq .10$) were included in the multinomial logit models. We did not use a more conservative cutoff for significance (e.g., .25) because the data could not support additional variables. However, because we were particularly interested in testing the hypothesis that site effects, in addition to individual participant characteristics, are significant predictors, we included all sites in the multinomial logit model, even if their effect was not significant at the .10 level in the logistic models.

The logistic models we estimated included not only statistically significant participant characteristics but also significant site-fixed effects. Therefore, in addition to the participant characteristics, the final multinomial logit models include indicator variables for each site. Because data sparsity led to violation of the underlying assumptions (more than 20% of the strata had fewer than five observations) we used bootstrapping techniques to estimate standard errors. In each iteration, we randomly chose, with replacement, a sample equal in size to the original sample and estimated the multinomial logit models. We then examined the distribution of estimated coefficients to determine the average and the 95% confidence interval for each coefficient and calculated the probabilities for each place of death. To determine the number of iterations required to provide stable and accurate coefficient estimates, we compared the average values of the coefficients from analyses based on increasing number of iterations. These values were the same within two decimal places for analyses based on 10,000 and 12,500 iterations. We therefore present results based on 12,500 iterations.

Because the advance directives data were available for only 10 of the 12 sites, we could not include them in the analyses of data for all 12 sites. This potentially subjects the results of the analysis to omitted variable bias; that is, a model omitting advance directives may attribute the association between place of death and advance directives to another variable that is correlated with advance directives. For example, older participants are more likely to have DNR orders. In a model that omits the DNR variable, the age coefficient would reflect not only the effect of age but

also the effect of DNR orders. It would bias the age coefficient and might lead to erroneous conclusions about the association between age and place of death. We therefore re-estimated the original model, excluding advance directives, on the 10-site data subset. We then added the advance directives variables and re-estimated the model again on the 10-site data. The results of the model with and without the advance directives variables were similar. This indicates that the models excluding advance directives estimated over the full data set (12 sites) were not biased by the omission of these variables.

The goodness of fit in these models was evaluated by comparing the predicted and the observed (unadjusted) place of death probabilities for a participant with the average characteristics. The correspondence between these probabilities was very good for all models, as is discussed in the results section.

Because the coefficients of a multinomial logit regression do not have an intuitive interpretation, we report instead the predicted place of death probabilities for the average participant. These were calculated using the estimated multinomial logit model by setting all variables to their average value in our sample. To evaluate the independent effect of each participant and site effect, we calculated site-of-death probabilities with and without the specific characteristic while keeping all other variables at the average participant values. We then calculated the difference in probabilities with and without the characteristic to determine the independent effect of the variable.

RESULTS

There were 2,263 decedents in the sample population. Table 3 provides descriptive statistics about each site's mortality rate and place of death distribution. On average, the annual mortality rate in PACE is high, 32% compared with about 8% for the Medicare population at large,²⁹ reflecting both the age and the frailty of its enrollees. The mortality rate varies significantly ($P < .001$) by site, from a low of 17% in site J to a high of 42% in site K. Similarly, there is a broad range of variation in the place of death between these PACE sites. Deaths occurring at home vary from a low of 24.9% in site I to a high of 76.0% in site J, whereas deaths in the hospitals were the lowest in site J (8%) and the highest in site A (39.5%).

Recent national statistics on place of death, by age of decedents, are not generally available, making it difficult to compare the PACE population to some reasonable national benchmark. Older national data show that 14% of the oldest (aged 85 or older) Medicare beneficiaries died at home, and another 10.6% died in other settings, including on the way to the hospital.³⁰ By comparison, more than twice as many, or 45%, of the PACE participants (average age 80) died at home.

PACE Participant-Specific Characteristics and the Place of Death

The characteristics of the PACE decedents and their choices regarding advance directives, by place of death, are presented in Tables 4 and 5, respectively. Overall, 21.2% of the decedents died in the hospital, 33.8% in nursing homes, and 45.0% at home.

The chance of dying at home increases significantly ($P < .001$) with age, from 41.7% among those younger than 80 to 47% among those aged 80 and older. Women are also significantly ($P < .013$) more likely to die at home (47.2%) than men (40.7%). Although the proportion of whites and blacks who died at home is almost equal (47.5% and 46.0%, respectively), the proportion of Hispanics (41.5%) and Asians (35.9%) is substantially lower ($P < .001$).

Living in a group or a foster home substantially increases the probability of dying at home: 69.7%, versus 43.4% of those who live alone. Education or having an informal caregiver (not living with a PACE participant) does not seem to have a statistically significant impact on the place of death. Alternatively, living with an informal caregiver appears to significantly ($P < .007$) increase the probability of dying in a hospital—23.8% for those with a caregiver as compared with 18.6% of those without.

Those who are in PACE for at least 2 years are significantly ($P < .001$) less likely to die in a hospital than those with less than 1 year in the program (17.9% vs 24.9%, respectively). Self-perceived health status also appears to significantly ($P < .007$) affect the probability of home deaths—47.5% for those who are in good to excellent health versus 41.5% for those in poor health. Similarly, limitations in ADLs, incontinence, skilled care needs, and medical diagnosis are all statistically significantly associated with the place of death.

The bivariate analysis on advance directives data was performed on a subset of information provided by 10 of 12 PACE sites. The relationships between the three types of advance directives—CPR, healthcare proxy, and artificial feeding—and the place of death were examined (Table 5). As expected, those who chose CPR were 70% more likely to have died in a hospital and 11% less likely to have died at home ($P < .001$), compared with those who chose DNR. Having a healthcare proxy significantly ($P < .017$) increases the probability of dying at home—49.6% for those with a proxy, compared with 41.3% for those without. The relationship between artificial feeding and the place of death was not found to be statistically significant ($P < .929$).

Impact of PACE Participants' and Sites' Characteristics on Place of Death

The bivariate analysis provides insights into the relative importance of each covariate relative to the place of death, but it is the multinomial logit regression that allows us to risk adjust for both the personal and site characteristics to better understand factors predictive of the place of death. Based on the logistic models, only a small number of variables were found to be important predictors of the place of death. These variables included two of the three advance directives (CPR and proxy), age, place of residence, presence of an informal caregiver, ADLs, and the PACE site in which the participant was enrolled.

Tables 6 and 7 report the predicted (and actual) probabilities of dying, by place of death, attributed to each risk factor and their statistical significance.

For the subset of PACE plans for which advance directives data were available, risk-adjusted and actual site-of-death probabilities for an average enrollee were not sta-

tistically different (Table 6). The predicted probability of death in the hospital for the average participant with a DNR order is 16.3% compared with 23.7% for a participant with full code (DNR). The incremental effect of having a DNR order is the difference between the two, a decrease in probability of death in the hospital of 7.4 percentage points ($P < .10$ in a one-tailed test of significance). We did not find other relationships between advance directives and the place of death to be statistically significant. Because the estimated associations between site and participant characteristics and place of death were similar in the full data set (12 sites) and the subset of 10 sites with advance directive information, we report and discuss only the results based on data for all 12 sites (Table 7). Age was a significant ($P < .05$) factor in predicting both hospital and home deaths, but not death in a nursing care facility. Individuals younger than 80 had an 8.6% greater probability of dying in a hospital than persons who were older but a 6.2% lower probability of dying at home, all other factors being equal. Living arrangement was also a significant predictor of deaths in all settings. Persons living in the community had a 13.3% higher probability of dying in a hospital and a 49.7% higher probability of dying at home than those who resided in nursing homes. Alternatively, they had a 63% lower probability of dying in a nursing home.

Other person-specific characteristics predictive of the site of death are live-in informal caregiver and ADL dependence. PACE participants who have a live-in informal caregiver are 10.3% less likely to die at home than are those without an informal live-in caregiver. Deaths in hospitals or nursing homes are not affected by the presence of an informal caregiver. The opposite is true of ADLs as predictors of the place of death. Although ADL dependence is not significantly predictive of death at home or in a nursing care facility, less-disabled participants are 8.1% more likely than those with a greater level of disability to die in a hospital, all else being equal.

PACE Site-Specific Variations in Place of Death

When all of the participant characteristics were accounted for, there remained significant variations in the place of death by PACE plan.

The predicted probability of dying in the hospital ranged from a low of 0.3% in site J to a high of 38.5% in site A (Table 7). The predicted probability of dying in a nursing home ranged from 8.1% in site J to 48.1% in site L; the probability of death at home was as low as 24.4% in site I and as high as 91.6% in site J. Many of the sites had probabilities significantly different from the average.

Overall, we found the least amount of site-specific variation in home being the place of death. In 8 of the 12 PACE sites (70%), the probability of dying at home was not statistically different from that of an average participant. Only two of the 12 plans (17%) had statistically higher, and another two statistically lower, than average probability of death at home. A somewhat greater variation between plans was observed in deaths occurring in a nursing home, with 50% of the plans clustering around the mean and 17% having statistically greater and 33% statistically lower probability than the mean for all PACE plans. The greatest amount of variation between plans oc-

Table 4. Characteristics of Decedents at Program of All-Inclusive Care for the Elderly By Site of Death

Participant Characteristics	Hospital 21.2% (n = 479)	Nursing Home* 33.8% (n = 765)	Home 45.0% (n = 1,019)	P-Value†
Age				.001
<80	27.0	31.4	41.7	
80+	17.8	35.2	47.0	
Gender				.013
Female	20.4	32.4	47.2	
Male	22.8	36.5	40.7	
Race				.001
White	20.8	31.6	47.5	
Black	19.5	34.5	46.0	
Hispanic	32.1	26.4	41.5	
Asian	18.7	45.4	35.9	
Education				.657
≤12	19.9	35.0	45.2	
>12	21.7	33.3	45.0	
Living arrangement				.001
Home alone	28.7	27.9	43.4	
Home w/others	24.7	27.4	48.0	
Other (group, foster)	13.5	16.8	69.7	
Nursing home	8.3	86.2	5.5	
Informal caregiver (any)				.18
No	18.6	32.3	49.1	
Yes	21.1	35.2	43.7	
Informal caregiver (not at home)				.13
No	21.3	31.9	46.8	
Yes	20.4	36.2	43.4	
Informal caregiver (at home)				.007
No	18.6	36.6	44.8	
Yes	23.8	31.8	44.4	
Length of time in program				.001
<1 year	24.9	29.1	46.0	
≥1 but <2 years	21.0	35.0	43.9	
≥2 years	17.9	37.2	44.9	
Health status				.007
Good to excellent	20.9	31.6	47.5	
Fair	26.6	27.7	45.7	
Poor	20.0	38.5	41.5	
ADL score				.001
Highest quartile	12.5	45.2	42.4	
2nd quartile	19.1	33.6	47.3	
3rd quartile	24.3	28.7	47.0	
4th quartile	29.7	27.4	42.9	
MSQ score				.557
<3	20.3	35.4	44.4	
≥3	21.7	32.9	45.4	
Incontinence				.001
No	27.4	29.9	42.7	
Yes	18.2	35.9	45.9	
Skilled care needs				.007
No	24.4	33.3	42.4	
Yes	18.2	34.9	47.0	
Medical diagnosis				.001
Dementia	16.7	38.3	45.1	
Vascular disease	25.0	30.5	44.5	
Heart disease	30.1	22.9	47.0	

*Includes transitional care.

†P-value for the rest of the bivariate association between place of death and participant characteristics.

ADL = activities of daily living; MSQ = Mental Status Quotient.

Table 5. Site of Death in PACE: By Advance Directives Chosen

Advance Directives	Hospital 17.9% (n = 204)	Nursing Home* 36.5% (n = 428)	Home 45.6% (n = 516)	P-Value†
CPR				
DNR	15.9	38.3	45.8	.001
Full Code	27.0	32.1	40.8	
Healthcare proxy				
Yes	16.9	33.5	49.6	.017
No	18.4	40.3	41.3	
Feeding tube				
Yes	16.7	39.4	43.9	.929
No	17.8	37.2	45.0	

Note: Advance directives data were available on 1,757 decedents from 10 PACE sites.

Because only seven of the 10 sites collected data on cardiopulmonary resuscitation healthcare proxies, and artificial feeding, the number of decedents for whom all of these advance directives were available was 1,148.

*Includes transitional care.

†P-value for the test of the bivariate association between place of death and participant characteristics.

DNR = do not resuscitate; CPR = cardiopulmonary resuscitation.

curred in hospital deaths. One-third of all PACE plans clustered around the mean, another one-third experienced statistically higher than the mean probability, and the remaining one-third had statistically lower than the mean probability of deaths in hospitals.

Prior research has shown that hospital deaths are closely correlated with hospital acute bed availability.¹³ Overall, 21.2% of PACE participants died in hospitals. By comparison, 33% of all Medicare traditional program enrollees die in hospitals.²⁹ In an effort to understand the impact of the PACE model on place of death, we examined the extent to which the observed proportions of hospitalized deaths in PACE mirrored place-of-death practice patterns in the host communities of these program sites. Host community is defined as the metropolitan area within which a PACE site is located. Hospital deaths in a host community are based on the Medicare program data presented in the Dartmouth Atlas.²⁹ Because these exclude information for Medicare risk programs (health maintenance organizations), which tend to enroll a younger and less frail population, the data presented in the Dartmouth Atlas may be more similar in terms of age and frailty to the PACE population than one may expect of the general Medicare population. Figure 1 depicts the proportion of hospital deaths in each PACE site and that observed in each host community. In all but one PACE site, the proportion of deaths occurring in hospitals was lower than that observed for the host community. On average, PACE sites experienced 30% fewer hospital deaths than did their host communities. Four of the 12 PACE sites had more than 50% fewer hospital deaths than the host communities. Because the PACE population is older and frailer than the average Medicare beneficiary population, it can not be concluded from these data alone that PACE sites have significantly different risk-adjusted place-of-death patterns than those observed in their host communities. Nevertheless, age and frailty alone also cannot account for the magnitude of the differences between PACE and their host communities.

To assess how much of the variation in hospital deaths across PACE sites can be attributed to practice

styles and hospital resources in their local communities, we regressed the percentage of hospital deaths in PACE against the percentage of hospital deaths in the host community. The R^2 of this regression suggests that 26% of the variation in PACE hospital deaths can be explained by practice styles predominant in the host communities.

DISCUSSION

It is not a priori obvious that dying at home equates to “better” death, but it is clear that honoring individuals’ preference for a place of death is important in delivering quality end-of-life care. Although our study does not contain information on specific preferences of PACE participants for the place of death, numerous other studies provide

Table 6. Impact of Advance Directives on Place of Death: Probabilities Estimated for the Average Enrollee Based on Multinomial Models

Advance Directives	Place of Death		
	Hospital	Nursing Home	Home
Probability for average enrollee			
Actual	17.9	36.5	45.6
Predicted	17.2	37.4	45.4
Do not resuscitate	16.3	37.9	45.8
CPR	23.7	33.8	42.5
Incremental effect*	-7.4†	4.1	3.3
Healthcare proxy	15.4	36.8	47.8
No healthcare proxy	19.4	37.9	42.7
Incremental effect*	-4.0	-1.1	5.1

†Incremental effect is the difference in the probability of dying in a given place for a participant with and without the characteristic. For example, the incremental effect of having a DNR order on probability of death in the hospital is 16.3 - 23.7 = -7.4; the incremental effect of a health care proxy is -4.0.

*P ≤ .10 one-tailed test.

CPR = cardiopulmonary resuscitation.

important insights into this question for frail populations, showing that, although most seriously ill patients prefer to die at home, few do so.¹¹ Some studies have shown that person-specific characteristics are important predictors of the place of death, whereas others have shown that regional variations in practice patterns and health-services use determine the place of death, particularly in the hospital. Our study provides some additional insight into this discussion by examining the place of death determinants of the participants of an innovative program such as PACE. The experience of these PACE decedents suggests that the characteristics both of the individuals and of the programs in which they are enrolled are important in predicting the place of death.

Study Limitations

There are several potential limitations to our analyses. First, we do not have data on patient preferences for the place of death. PACE dedicates substantial organizational commitment of time and resources to routine discussions of advance planning with participants and their families. Therefore, one could assume that the participants' wishes regarding their preferred place of death are known to physicians and other clinicians and are accordingly implemented.²² Second, although we show that program sites are important, in this study we were not able to test hypotheses about specific site characteristics that may influence place of death, except to suggest that local practice style may explain some (but not all) of the variations across PACE sites.

Participant Characteristics and Place of Death

Overall, the proportions of persons dying in the hospital or at home in this study population are almost mirror images of what has been observed to date for populations of older (aged 65 and older) decedents. Compared with the general population of older decedents, where 20% died at home and 44% in hospitals,⁶ 21% of the participants in PACE died in hospitals and 45% at home.

Although many person-specific characteristics were significantly associated with place of death in bivariate analyses, only five—age, living situation, live-in informal caregiver, ADLs, and CPR orders—had an independent statistically significant effect in multivariate analyses. As expected, older (≥ 80) PACE participants are significantly less likely than those who are younger to die in the hospital and more likely to die at home. Participant's age is not a significant predictor of death in a nursing home. This may suggest that younger (under age 80) participants may be treated more aggressively at the end of life either because the medical professionals believe that such treatment will improve their quality of life or because the individuals and their family members insist on more aggressive treatment, or perhaps both.

There have been virtually no studies examining the relationship between functional impairment and place of death, although this is an important issue in evaluating the appropriateness of care provided to older, terminally ill patients. The results of this study show that, in PACE, functional status is significantly associated with place of death. Participants experiencing higher level of functional impairment were 8% less likely than average to die in the

Table 7. Patient and Site Characteristics Predictive of Place of Death. Probabilities Estimated for the Average Enrollee Based on Multinomial Models

Characteristic	Place of Death		
	Hospital	Nursing Home	Home
	%		
Probability for average enrollee			
Actual	21.2	33.8	45.0
Predicted	20.3	35.6	44.2
Being older (age ≥ 80)	17.4	36.3	46.3
Being younger (age < 80)	26.0	33.9	40.1
Incremental effect [†]	-8.6*	2.4 ^{NS}	6.2*
Living in community	20.3	25.5	54.2
Living in nursing home	7.0	88.4	4.5
Incremental effect [†]	13.3*	-62.9*	49.7*
Live-in informal caregiver	20.7	36.8	42.5
No live-in informal caregiver	17.8	29.5	52.8
Incremental effect [†]	3.0 ^{NS}	7.3 ^{NS}	-10.3*
High ADL dependence	17.0	36.6	46.4
Lower ADL dependence	25.1	33.9	41.0
Incremental effect [†]	-8.1*	2.6 ^{NS}	5.5 ^{NS}
Site A	38.5	21.9	39.6
Incremental effect w/ average [‡]	18.2*	-13.7*	-4.6 ^{NS}
Site B	33.5	40.5	26.0
Incremental effect w/ average [‡]	13.2*	4.9 ^{NS}	-18.2*
Site C	4.3	38.4	57.3
Incremental effect w/ average [‡]	-16.0 ^{NS}	2.8 ^{NS}	13.1 ^{NS}
Site D	14.1	30.2	55.7
Incremental effect w/ average [‡]	-6.2*	-5.4 ^{NS}	11.5*
Site E	11.0	38.1	50.9
Incremental effect w/ average [‡]	-9.3*	2.5 ^{NS}	6.7 ^{NS}
Site F	30.9	21.3	47.8
Incremental effect w/ average [‡]	10.6*	-14.3*	3.6 ^{NS}
Site G	29.2	20.2	49.9
Incremental effect w/ average [‡]	8.9 ^{NS}	-15.4*	5.7 ^{NS}
Site H	21.3	35.8	42.9
Incremental effect w/ average [‡]	1.0 ^{NS}	0.2 ^{NS}	-1.3 ^{NS}
Site I	28.8	46.8	24.4
Incremental effect w/ average [‡]	8.5*	11.2*	-19.8*
Site J		8.1	91.6
Incremental effect w/ average [‡]	-20.0*	-27.5*	47.4*
Site K	14.0	36.1	49.8
Incremental effect w/ average [‡]	-6.3*	0.5 ^{NS}	5.6 ^{NS}
Site L	16.9	48.1	35.0
Incremental effect w/ average [‡]	-3.4 ^{NS}	12.5*	-9.2 ^{NS}

* $P \leq 0.05$.

[†]Incremental effect is the difference in the probability of dying in a given place for a participant with and without the characteristic. For example, the incremental effect of being older on probability of death in the hospital is $17.4 - 26.0 = -8.6$.

[‡]For example, for participants in site A, the incremental effect for dying in the hospital is $38.5 - 20.3 = 18.2$.

ADL = activity of daily living; NS = not significant at .05.

hospital, all other characteristics being equal. The differences in functional status between those who died in nursing homes and those who died at home were not statistically significant. One explanation may be that those who are more disabled are also longer-term disabled and may

have had more time to consider the end-of-life treatment options, focusing more on comfort care than on curative treatments. To answer this in greater detail, additional research focusing on those experiencing rapid late decline in ADLs versus those experiencing early functional loss would need to be performed.

The availability of social support or the presence of caregivers is often discussed in the literature as being associated with dying at home, although these are rarely shown to be statistically significant in multivariate analyses.^{2,31} Contrary to expectations based on prior studies, PACE participants with a live-in informal caregiver are significantly less likely to die at home than are those without this form of social support. A small proportion of the PACE participants live with spouses who are also quite old, often have their own medical problems, and may not be able to cope with the demands of caring at home for a dying person. Other family members may also experience substantial stress and conflict in trying to provide terminal care at home, making it difficult to allow people to die in their homes.

Studies focused on advance planning have made it quite clear that advance directives have not been explicit enough to guide medical decision-making for the seriously ill patients,³² nor have they been shown to reduce the use of hospital care.³³ In this study, we found that, in PACE, having expressed a written preference for DNR status results in a significantly lower probability ($P < .10$) of dying in a hospital. We found no statistically significant association between DNR and other sites of death. In PACE, discussions about CPR and other advance directives generally occur shortly after enrollment, are reassessed on a regular basis, and are revised if sentinel events such as strokes or heart attacks prompt the participants to change their healthcare preferences. A program where participants have a close and on-going relationship with their primary care physician and with other program staff and caregivers may create an environment that encourages addressing sensitive issues such as end-of-life treatment options and acting on them at an appropriate time and place.

Site-Specific Variations in Place of Death: Opportunities for Improvement

The PACE model has evolved from a single local initiative into a healthcare program being replicated across the country. The program is based on a specific model of care delivery, integrated financing, and a mission of serving a very frail older population. Despite the many similarities between the PACE sites, studies have shown that there is a significant amount of variation in health outcomes across the sites.²³ Indeed, in this study we also found significant variation in the place of death between the PACE plans. The greatest amount of site-specific variation was observed for deaths occurring in hospitals.

Nationally, hospital deaths in the Medicare population have been shown to vary widely depending on geographic location and to be very closely associated with the rate of hospital beds per 1,000 population. Perhaps it is therefore not surprising that we find 26% of the variation in PACE hospital deaths to be related to the practice styles predominant in the host communities. The observed site-specific variations, particularly with respect to hospital

deaths, suggest that an opportunity for narrowing the gap between the PACE sites exists and that it may be consistent with improving the quality of care for the dying.

Public Policy Implications

In the early 1900s, most Americans died at home, and it was the role of the physician to care for them by prognosticating, dispensing medication, and providing comfort. Today, we have better diagnostics, better pharmacology, and interdisciplinary teams, and most people die in hospital settings. The low rate of home deaths has prompted some to assert that “it is unlikely that we will, as a society, decide to take our dying older people back into our homes.”³⁴ The results of this PACE study cannot contradict this statement for the nation as a whole but do show that it is possible in substantial measure to reverse this trend and to allow people to die where they wish.

The high rate of home deaths in PACE may be a reflection of the program serving a specialized population, of its commitment to advance care planning, of close and on-going relationships between the participants and the care providers, and of the capitated payment model in which plans’ incentives for the least restrictive and least expensive care modality may be aligned with those of patients who prefer home to hospital as the place of death.

There is no doubt that end-of-life care, aside from the simple human dimensions, attracts much attention because of the perceived financial burden associated with almost half of all deaths occurring in hospitals. Dying in hospitals is expensive, and the care provided to people who die there is publicly financed—almost exclusively by Medicare (83% of U.S. residents who die are covered by Medicare).⁶ In any given year, healthcare spending in the last year of life averages roughly 28% of Medicare’s annual expenditures,³⁵ with 50% being spent on hospital care. The hospice program that was developed as an alternative to dying in hospitals has grown dramatically in the 1990s but still accounts for just 1% of all Medicare spending. Hospice programs generally serve restricted populations such as patients with cancer and acquired immunodeficiency syndrome, principally because the admission criteria require that only palliative care be provided and that the expected length of service use be no longer than 6 months. For most people at the end of life, their prognosis is not that clear-cut. For example, for patients with heart failure “the median prognosis [on the day before death] is still a 50% chance to live 6 more months.”³⁶ Furthermore, the amount of care provided under a hospice program does not generally give sufficient relief to informal caregivers, who must often be able to afford private duty nurses. If hospital deaths are expensive to society, deaths at home tend to be expensive to individuals, particularly in the fee-for-service Medicare system that provides no alternative at-home support (other than hospice) for the chronically ill who may be dying. Furthermore, the cost of medications may also be an impediment to home deaths, with Medicare paying for drugs administered to patients who die in hospitals but not to those who die at home. Thus, it appears that the Medicare fee-for-service payment system may in some measure be responsible for what has been termed the “high cost of dying.” This begs the question whether dying at home is a “luxury” reserved only for

those who can afford it. The experience from PACE suggests that it does not need to be so.

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REFERENCES

- Pritchard RS, Fisher ES, Teno JM et al. Influence of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc* 1998;46:1242–1250.
- Fried TR, O'Leary JR, Drickamer MA. Older persons' preferences for site of terminal care. *Ann Intern Med* 1999;131:109–112.
- Groth-Juncker A, McCusker J. Where do elderly patients prefer to die? Place of death and patient characteristics of 100 elderly patients under the care of a home health care team. *J Am Geriatr Soc* 1983;31:457–461.
- Leff B, Kaffenbarger KP, Remsburg R. Prevalence, effectiveness, and predictors of planning the place of death among older persons followed in community-based long term care. *J Am Geriatr Soc* 2000;48:943–948.
- Gallup GH Jr. *Spiritual Beliefs and the Dying Process: A Report on a National Survey*. The Nathan Cummings Foundation and Fetzer Institute, Available: http://www.ncf.org/reports/rpt_Fetzer_contents.html, 2000.
- Hogan C, Lynn J, Gabel J et al. *Medicare Beneficiaries' Cost and Use of Care in the Last Year of Life*. Washington, DC: Medicare Payment Advisory Commission, 2000.
- Brink S. The American way of dying. *U.S. News and World Report* December 4, 1995;70–75.
- Moyers B. *On Our Own Terms: Moyers on Dying in America*. Public Broadcasting System, 2000.
- Scitovsky A. "The High Cost of Dying" Revisited. *Milbank Q* 1994;72:561–591.
- Cohen GD. Journalistic elder abuse: It's time to get rid of fictions, get down to facts. *Gerontologist* 1994;34:399–401.
- The SUPPORT Principal Investigators for the SUPPORT Project. A controlled trial to improve care for the seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). *JAMA* 1995;274:1591–1598.
- Sager M, Easterling D, Kindig D et al. Changes in the location of death after passage of Medicare's prospective payment system. *N Engl J Med* 1989;320:433–439.
- Wennberg JE, Freeman JL, Shelton RM et al. Hospital use and mortality among medicare beneficiaries in Boston and New Haven. *N Engl J Med* 1989;321:1168–1173.
- Experton B, Ozminkowski RJ, Branch LG et al. A comparison by payor/provider type of the cost of dying among frail older adults. *J Am Geriatr Soc* 1996;44:1098–1107.
- Cher DJ, Lenert LA. Method of Medicare reimbursement and the rate of potentially ineffective care of critically ill patients. *JAMA* 1997;278:1001–1007.
- McCusker J. Where cancer patients die: An epidemiologic study. *Public Health Rep* 1983;98:170–176.
- Mor V, Hiris J. Determinants of site of death among hospice cancer patients. *J Health Soc Behav* 1983;24:375–385.
- Moinpour CM, Polissar L. Factors affecting place of death of hospice and non-hospice cancer patients. *Am J Public Health* 1989;79:1549–1551.
- Fried TR, Pollack DM, Drickamer MA et al. Who dies at home? Determinants of site of death for community-based long-term care patients. *J Am Geriatr Soc* 1999;47:25–29.
- Eng C, Pedulla J, Eleazer PG et al. Program of all-inclusive care for the elderly (PACE): An innovative model of integrated geriatric care and financing. *J Am Geriatr Soc* 1997;45:223–232.
- Eleazer GP, Hornung CA, Egbert CB et al. The relationship between ethnicity and advance directives in a frail older population. *J Am Geriatr Soc* 1996;44:938–943.
- Lee MA, Brummel-Smith K, Meyer J et al. Physician orders for life-sustaining treatment (POLST): Outcomes in a PACE program. *J Am Geriatr Soc* 2000;48:1219–1225.
- Mukamel DB, Temkin-Greener H, Clark ML. Stability of disability among PACE enrollees: Financial and programmatic implications. *Health Care Finance Rev* 1998;19:83–100.
- Lee W, Eng C, Fox N et al. PACE: A model for integrated care of frail older patients. Program of All-inclusive Care for the Elderly. *Geriatrics* 1998;53:62–74.
- Rich ML. The PACE model: Description and impressions of a capitated model of long-term care for the elderly. *Care Manage J* 1999;1:62–70.
- Wieland D, Lamb V, Wang H et al. Participants in the Program of All-Inclusive Care for the Elderly (PACE) Demonstration: Developing disease-impairment-disability profiles. *Gerontologist* 2001;40:218–227.
- Pace B, Glass RM. Decisions about end-of-life care. *JAMA* 2000;284:2550.
- Khan RL, Goldfarb AI, Pollack M et al. Brief objective measures for the determination of mental status in the aged. *Am J Psychiatry* 1960;117:326–328.
- Wennberg J. *Dartmouth Atlas of Health Care 1999*. Chicago, IL: American Hospital Publishing, Inc., 1999.
- McMillan A, Mentnech RM, Lubitz J et al. Trends and patterns in place of death for Medicare enrollees. *Health Care Finance Rev* 1990;12:1–7.
- McWhinney IR, Bass MJ, Orr VS. Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *Can Med Assoc J* 1995;152:361–367.
- Teno JM, Licks S, Lynn J et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment [see comments]. *J Am Geriatr Soc* 1997;45:508–512.
- Teno JM, Lynn J, Connors AF et al. The illusion of end-of-life resource savings with advance directives. *J Am Geriatr Soc* 1997;45:513–518.
- McCue JD. The naturalness of dying. *JAMA* 1995;273:1039–1043.
- Lubitz JD, Riley GF. Trends in Medicare payments in the last year of life. *N Engl J Med* 1993;328:1092–1096.
- Lynn J. Learning to care for people with chronic illness facing the end of life. *JAMA* 2000;284:2508–2511.