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ORIGINAL REPORT

Which Hospice Patients With Cancer Are Able to Die in the Setting of Their Choice? Results of a Retrospective Cohort Study

Neha Jeurkar, Sue Farrington, Teresa R. Craig, Julie Slattery, Joan K. Harrold, Betty Oldanie, Joan M. Teno, and David J. Casarett

Neha Jeurkar and David J. Casarett, University of Pennsylvania Perelman School of Medicine, Philadelphia; Joan K. Harrold, Hospice of Lancaster County, Lancaster, PA; Sue Farrington and Teresa R. Craig, Suncoast Solutions; Betty Oldanie, Suncoast Hospice, Clearwater, FL; Julie Slattery, Agrace HospiceCare, Madison, WI; and Joan M. Teno, Brown University Warren Alpert School of Medicine, Providence, RI.

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Corresponding author: David J. Casarett, MD, MA, 3615 Chestnut St, Philadelphia, PA 19104, e-mail: casarett@mail.med.upenn.edu.

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ABSTRACT

Purpose
To determine which hospice patients with cancer prefer to die at home and to define factors associated with an increased likelihood of dying at home.

Methods
An electronic health record–based retrospective cohort study was conducted in three hospice programs in Florida, Pennsylvania, and Wisconsin. Main measures included preferred versus actual site of death.

Results
Of 7,391 patients, preferences regarding place of death were determined at admission for 5,837 (79%). After adjusting for other characteristics, patients who preferred to die at home were more likely to die at home (adjusted proportions, 56.5% *v* 37.0%; odds ratio [OR], 2.21; 95% CI, 1.77 to 2.76). Among those patients (n = 3,152) who preferred to die at home, in a multivariable logistic regression model, patients were more likely to die at home if they had at least one visit per day in the first 4 days of hospice care (adjusted proportions, 61% *v* 54%; OR, 1.23; 95% CI, 1.07 to 1.41), if they were married (63% *v* 54%; OR, 1.35; 95% CI, 1.10 to 1.44), and if they had an advance directive (65% *v* 50%; OR, 2.11; 95% CI, 1.54 to 2.65). Patients with moderate or severe pain were less likely to die at home (OR, 0.56; 95% CI, 0.45 to 0.64), as were patients with better functional status (higher Palliative Performance Scale score: < 40, 64.8%; 40 to 70, 50.2%; OR, 0.79; 95% CI, 0.67 to 0.93; > 70, 40.5%; OR, 0.53; 95% CI, 0.35 to 0.82).

Conclusion
Increased hospice visit frequency may increase the likelihood of patients being able to die in the setting of their choice.

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INTRODUCTION

Although most patients with cancer prefer to die at home, most will not.[1-9] One exception exists for patients who are enrolled in a hospice program. Many hospice patients or palliative home care patients are more likely to die at home than in other settings.[10,11] Indeed, this exception is often described as a benefit of hospice care.[12-14]

However, it is not known how often hospice patients in the United States who prefer to die at home will actually die at home. Nor is it known which patient characteristics are associated with an increased likelihood of death at home, among those patients who prefer to die at home. Finally, it is not known how hospice or palliative care is able to facilitate death at home.[15] For instance, physician visits may be associated with death at home, raising the possibility that among hospice patients, a greater intensity of nursing visits might have a similar effect.[16] Answers to these questions could help hospices to prospectively identify those patients who are at increased risk of dying in nonpreferred settings. Therefore, the goals of this study were to define the patient characteristics that are associated with death at home and to determine whether hospice visits increase the likelihood that a patient with cancer who prefers to die at home will be able to do so.

METHODS

Setting and Sample

This study was conducted in three hospices that volunteered to be pilot participants in the CHOICE (Coalition of Hospices Organized to Investigate Comparative Effectiveness) network. All hospices in the network use an electronic health record (EHR) developed by Suncoast Solutions (Clearwater, FL). The smallest cares for 400 patients per day and the largest for 2,700. They are located in Clearwater, Florida; Lancaster, Pennsylvania; and Madison, Wisconsin, and serve populations that include urban, suburban, and rural areas. All are not for profit, and all provide care in patients' homes, nursing homes, acute care settings, and hospice units. We limited this study to patients with cancer, because cancer is the single most common hospice diagnosis[10] and because a focus on a single diagnosis would limit variation in disease trajectory and rate of decline.

Data Collection

This study used data extracted from the hospice EHRs, which provide a common framework and uniform data definitions. Iterative data extraction, feedback, and validation were used to ensure data accuracy. Extracted data were then stripped of identifiers to create a Health Insurance Portability and Accountability Act–compliant limited data set and transferred as an encrypted file to the University of Pennsylvania (Philadelphia, PA) for analysis.

To determine preferences regarding site of death, we used a patient question embedded in the EHR admission form ("Where would you prefer to live out the rest of your life?"). The admitting nurse asks this question and enters the response directly into the EHR. We extracted additional data including basic demographic variables (age, sex, race, ethnicity), diagnoses, admitting cancer diagnosis, and site of care at the time of enrollment (home, long-term care facility, hospital, hospice inpatient unit). We also coded whether the patient's medical history was determined from the patient versus other sources. We coded patients as having moderate or severe pain if they had a numeric pain score of at least 4 on a 0 to 10 scale, in which higher numbers reflect worse pain, or if an assessment described pain as either moderate or severe. We also extracted each patient's Palliative Performance Scale (PPS) score at the time of hospice enrollment. The PPS is an 11-point scale of functional and cognitive status (scored from 0 to 100 in 10-point increments), in which a higher score reflects better function. We used the PPS scores in raw form and divided them into three categories (0 to 30, 40 to 60, and 70 to 100) based on previous research.[17-20]

We calculated the average number of visits per day that each patient received during the first 4 days of hospice care. We used the first 4 days of care, because Medicare hospice regulations require that a comprehensive care plan be developed by the fifth day. Therefore, it would be important to know whether that care planning process influences the likelihood that patient preferences are honored. We counted visits by registered nurses, licensed practical nurses, nurse practitioners, physicians, social workers, chaplains, volunteers, home health aides, speech therapists, occupational therapists, and physical therapists.

Data Analysis

To examine the association between preferred and actual sites of death, we restricted the sample to patients whose initial site of care was in the home. We reasoned that these patients would have the functional status, home environment, and resources to make death at home possible. In contrast, some patients who begin care in a hospital might not survive to discharge. Similarly, patients in a nursing home may lack the resources at home that would make death at home possible.

First, we compared patients for whom a preference regarding site of death was and was not recorded, using univariate and multivariable logistic regression with robust SEs to account for clustering within hospices. For this and all subsequent analyses, we included all variables in Table 1, because they were recorded at the time of hospice enrollment, using forward stepwise regression. When two or more models identified different sets of significant predictors, we selected the model with the best predictive power, defined as the optimal Bayes information criterion score.[21,22]

Second, we dichotomized patients' preferences for site of death as home versus other and used both bivariate and multivariable models to identify patient characteristics that were independently associated with a preference for dying at home. Third, of those patients whose first site of care was at home and who expressed a preference for remaining at home, we examined the proportion of patients who actually died at home. We created univariate and then multivariable logistic regression models, using the same criteria for variable inclusion described. Because a patient who survived for several months would be more likely to be transferred to another setting than a patient who survived for a day, we adjusted for length of stay in hospice.

To determine whether the available three-hospice sample was sufficient, we calculated that a sample of at least 21,000 patients would include at least 3,000 patients with cancer who received care at home at the time of hospice enrollment and who would have documented preferences for dying at home. We assumed that approximately 60% (1,800) would die at home, providing adequate power ($1-\beta = 0.90$) to detect a 5% increase (eg, between 40% and 50%) in deaths at home attributable to a single variable with a prevalence of 10% ($\alpha = 0.05$). A rough rule of thumb for logistic regression models is to allow at least 10 events for each variable under consideration.[23,24] Therefore, this sample would provide adequate power to detect modest effects of a candidate predictor variable on the likelihood of dying at home.

The University of Pennsylvania Institutional Review Board approved the use of secondary data for this study. STATA statistical software (STATA MP2 11.0 for Mac; STATA, College Station, TX) was used for all statistical analysis.

RESULTS

A total of 21,074 patients were admitted to the three hospices between October 1, 2008, and May 31, 2011. Hospices contributed 4,475 patients (Lancaster, PA), 4,021 patients (Madison, WI), and 12,578 patients (Clearwater, FL). Of these, 7,391 (35%) had a primary admitting diagnosis of cancer and were included in the analysis. Sample characteristics are listed in Table 1.

Of 7,391 patients with cancer, preferences regarding place of death were determined at admission for 5,837 (79%). In univariate analysis, several patient characteristics were associated with higher rates of documentation of preferences, including higher (better) PPS score, initial care at home, absence of a do-not-resuscitate order, and presence of an advance directive or moderate or severe pain (Table 1). In univariate analysis, there was also modest variation among the three hospices in the proportion of patients for whom preferences were documented (range, 77.7% to 83.4%).

In a logistic regression model that included PPS score, age, ability to provide a history, marital status, and presence of an advance directive, patients with higher (better function) PPS scores (0 to 100 scale in 10-point increments) were more likely to have preferences documented (odds ratio [OR], 1.03; 95% CI, 1.01 to 1.03; $P < .001$). There was an approximately two-fold variation in the adjusted proportions of patients with documented preferences across the range of PPS scores (0, 52.2%; 100, 92.3%). Patients who were able to provide a history were also more likely to have their preferences documented (adjusted proportions, 78.3% *v* 63.4%; OR, 2.13; 95% CI, 1.78 to 2.55; $P < .001$), as were married patients (adjusted proportions, 76.1% *v* 74.3%; OR, 1.19; 95% CI, 1.05 to 1.38; $P < .001$), younger patients (age < 65 years, 74.2% *v* age > 64 years, 66.3%; OR, 2.04; 95% CI, 1.70 to 2.48; $P < .001$), and those with an advance directive (adjusted proportions, 75.8% *v* 69.8%; OR, 1.36; 95% CI, 1.20 to 1.57; $P < .001$).

Among 5,837 patients for whom preferences were documented, 4,336 (74%) preferred to die at home. An additional 565 (9.7%) preferred to die in a nursing home, 254 (4.4%) preferred to die in a hospice unit, and 35 (0.60%) preferred to die in a hospital. The remaining 117 patients expressed a preference for dying in other settings (eg, group home, homeless shelter, or prison).

In a logistic regression model that included site of care, race, age, and hospice, married patients were more likely to want to die at home (adjusted proportions, 92.2% *v* 85.1%; OR, 2.21; 95% CI, 1.94 to 2.53;

Table 1. Patient Demographics and Clinical Characteristics (N = 7,391)

Characteristic	Total Patients No.	Total Patients %	Preferences Regarding Site of Death: Known (n = 5,837) No.	Known %	Preferences Regarding Site of Death: Unknown (n = 1,554) No.	Unknown %	Documentation of Preferences: Unadjusted OR	95% CI	*P*
Male sex	3,762	50.9	3,002	51.5	760	48.9	1.11	0.99 to 1.24	.069
Mean age, years	72.6		72.5		72.8		1.00	0.99 to 1.00	.447
White race	6,584	89.1	5,227	89.5	1,357	87.3	1.16	0.93 to 1.44	.184
Married	3,184	43.1	2,562	43.9	622	40.0	1.17	1.05 to 1.31	.006
Primary tumor site									
Breast	564	7.6	444	7.6	120	7.7	—	—	—
GI	1,827	24.7	1,438	24.6	389	25.0	1.00	0.79 to 1.26	.994
Genitourinary	1,169	15.8	932	16.0	237	15.3	1.06	0.83 to 1.36	.629
Larynx	48	0.7	41	0.7	7	0.5	1.58	0.69 to 3.62	.276
Leukemia	206	2.8	158	2.7	48	3.1	0.89	0.61 to 1.30	.547
Lung	2,066	28.0	1,671	28.6	395	25.4	1.14	0.91 to 1.44	.253
Lymphoma	232	3.1	182	3.1	50	3.2	0.98	0.68 to 1.43	.931
Melanoma	105	1.4	79	1.4	26	1.7	0.82	0.50 to 1.34	.428
Multiple myeloma	107	1.5	84	1.4	23	1.5	0.99	0.60 to 1.63	.960
Neuroendocrine	9	0.1	6	0.1	3	0.2	0.54	0.13 to 2.19	.389
Oropharynx	104	1.4	86	1.5	18	1.2	1.29	0.75 to 2.23	.359
Other	954	12.9	716	12.3	238	15.3	0.81	0.63 to 1.04	.104
Initial site of care									
Home	4,714	63.8	4,017	68.8	697	44.9	—	—	—
Hospital	1,393	18.9	903	15.5	490	31.5	0.32	0.28 to 0.37	< .001
Nursing home	928	12.6	613	10.5	315	20.3	0.34	0.29 to 0.40	< .001
Hospice unit	356	4.8	304	5.2	52	3.4	1.01	0.75 to 1.38	.927
Pain									
Any severity	5,198	70.3	4,261	73.0	937	60.3	1.78	1.58 to 2.00	< .001
Moderate or severe pain	1,594	21.6	1,295	22.2	299	19.2	1.20	1.04 to 1.38	.012
Average No. of visits per day of home care	1.07		1.13		1.05		0.85	0.78 to 0.94	.001
DNR order	4,847	65.6	3,781	64.8	1,066	68.6	0.84	0.75 to 0.95	.005
Advance directive	5,057	68.4	4,084	70.0	973	62.6	1.39	1.24 to 1.56	< .001
Pressure ulcer	705	9.5	562	9.6	143	9.2	1.05	0.87 to 1.27	.611
Mean Palliative Performance Scale score	41.0		42.1		36.9		1.03	1.03 to 1.04	< .001
Able to provide history	6,727	91.0	5,449	93.4	1,278	82.2	3.03	2.57 to 3.58	< .001

Abbreviations: DNR, do not resuscitate; OR, odds ratio.

$P < .001$), as were white patients (adjusted proportions, 92.2% *v* 85.1%; OR, 2.21; 95% CI, 1.94 to 2.53; $P < .001$). Conversely, older patients were less likely to want to die at home (OR, 0.97; 95% CI, 0.97 to 0.98; $P < .001$). For instance, 90.1% (adjusted proportion) of those age 45 year preferred to die at home compared with 89% of those age 65 years, 87.1% of those age 85 years, and 86.0% of those age 95 years. Finally, compared with the first hospice (reference group; adjusted proportion, 59.0%), patients in the second hospice were more likely to want to die at home (75.5%; OR, 2.17; 95% CI, 1.87 to 2.51; $P < .001$), as were patients in the third hospice (70.7%; OR, 1.69; 95% CI, 1.42 to 2.02; $P < .001$).

Among those patients who died during follow-up (3,561), 1,877 (53.3%) died at home, 245 (6.9%) died in a nursing home, 401 (11.3%) died in a hospital, 1,002 (28.1%) died in a hospice unit, and 48 (1.3%) died in another location. Those who preferred to die at home were more likely to die at home than other patients (1,735 of 3,153 [55.0%] *v* 142 of 408 [34.8%]; OR, 2.29; 95% CI, 1.85 to 2.84; $P < .001$). In a logistic regression model that included time to death, marital status, presence of an advance directive, pain, and hospice, a preference for dying at home was still an independent predictor of death at home (adjusted proportions, 56.5% *v* 37.0%; OR, 2.21; 95% CI, 1.77 to 2.76; $P < .001$). In the same model, patients who were married were also more likely to die at home (adjusted proportions, 52.1% *v* 45.0%; OR, 1.32; 95% CI, 1.16 to 1.52; $P < .001$), as were patients with an advance directive (adjusted proportions, 62.1% *v* 42.3%; OR, 1.82; 95% CI, 1.60 to 2.02; $P < .001$). However, patients with moderate or severe pain at the time of hospice enrollment were less likely to die at home (adjusted proportions, 43.1% *v* 56.9%; OR, 0.57; 95% CI, 0.42 to 0.66; $P < .001$). The hospice at which the patient received care was also independently associated with the likelihood of dying at home, with a higher likelihood at the second (OR, 1.38; 95% CI, 1.17 to 1.64; $P < .001$) and third hospices (OR, 1.24; 95% CI, 1.01 to 1.53; $P = .044$), compared with the first hospice (adjusted proportions, 41.7%, 50.0%, and 47.1%, respectively).

Next, we restricted the analysis to those patients (n = 3,153) who began their care at home and who preferred to die at home. In a multivariable logistic regression model that included length of stay in hospice (in days) and all variables in Table 2, patients were more likely to die at home if they had at least one visit per day in the first 4 days (adjusted proportions, 61% *v* 54%; OR, 1.23; 95% CI, 1.07 to 1.41;

Table 2. Factors Associated With Death at Home Among Hospice Patients Who Began Hospice Care at Home and Preferred to Die at Home

Characteristic	Adjusted Proportions of Patients Dying at Home (%)*	Adjusted OR*	95% CI	P
Moderate or severe pain	50 *v* 58	0.56	0.45 to 0.64	< .001
Married	63 *v* 54	1.35	1.10 to 1.44	.001
Advance directive	65 *v* 50	2.11	1.54 to 2.65	< .001
Visit frequency (≥ one visit per day *v* < one visit per day) in first 4 days	61 *v* 54	1.23	1.07 to 1.41	< .001
Hospices				
One	48	—	—	—
Two	63	1.58	1.28 to 1.96	< .001
Three	57	1.49	1.16 to 1.92	.002
PPS score†				
0-30	64.8	—	—	—
40-60	50.2	0.79	0.67 to 0.93	.005
70-100	40.5	0.53	0.35 to 0.82	.005
Length of stay, days	—	0.99	0.99 to 1.00	< .001

Abbreviations: OR, odds ratio; PPS, Palliative Performance Scale.
*ORs and proportions are adjusted for all variables in the final model (pain, marital status, advanced directive, visit frequency, site/hospice, PPS score).
†Adjusted proportions for the PPS score are for scores of 70 to 100 and < 0 to 30, respectively.

$P < .001$), if they were married (63% *v* 54%; OR, 1.35; 95% CI, 1.10 to 1.44; $P = .001$), and if they had an advance directive (65% *v* 50%; OR, 2.11; 95% CI, 1.54 to 2.65; $P < .001$). Patients with moderate or severe pain were less likely to die at home (OR, 0.56; 95% CI, 0.45 to 0.64; $P < .001$), as were patients with better functional status (PPS score 0 to 40, 64.8% (reference); 40 to 60, 50.2%; OR, 0.79; 95% CI, 0.67 to 0.93; $P = .005$; 60 to 100, 40.5%; OR, 0.53; 95% CI, 0.35 to 0.82; $P = .005$; Table 2). In addition, the likelihood that a patient who preferred to die at home would actually die at home also varied among the three hospices (adjusted proportions range, 48% to 63%; Table 2).

Because these variables were all present at the time of admission, it was possible that their effects were limited to those patients who died soon after hospice enrollment. Therefore, we examined interaction terms with length of stay in hospice (mean, 64 days; median, 25 days). None of the variables in the model had significant interaction terms, suggesting that their impact was not greater for patients who died close to the time of admission than it was for other patients.

DISCUSSION

Although most patients with advanced cancer prefer to spend their final days at home,[1-4] the majority will die in the hospital.[3,4,25,26] These results have four implications for the role that hospices can play in helping to ensure that patients with advanced cancer who prefer to die at home are able to do so. First, these results indicate that it is possible to integrate a question about preferred place of death into the hospice enrollment process. In fact, these three hospices were able to establish preferences for four of five newly admitted hospice patients with cancer. Moreover, these preferences seem to influence site of death for home care patients, although their effect for patients admitted to hospice from other settings (eg, nursing homes) is likely to be smaller. Future research is needed, however, to explore the influence of families' preferences, which were not included in this analysis.

Second, there were several patient characteristics associated with the likelihood that patients who preferred to remain at home would be able to do so. These associations were independent of length of stay in hospice and are consistent with the results of studies in other settings that have described the influence of patient and caregiver factors on site of death.[1,3,6,26-29] In addition, this study identified several variables that might be under the control of a hospice. For instance, although not all pain can be managed in a home care setting, some patients with moderate or severe pain might be able to remain at home with more effective pain management. Similarly, more attention paid to advance directives might also be useful in clarifying patients' goals and avoiding hospitalization. A better understanding of these and other variables could help hospices to identify those patients for whom additional planning and resources are needed.

Third, this study found that more hospice visits in the first 4 days are associated with an increased likelihood that patients who want to die at home will be able to do so. It is particularly noteworthy that this association seems to be independent of the time from admission to death. This is somewhat surprising, because one would expect that initial visit frequency would have affected the site of death for patients who died within the first several days of hospice care. However, it is plausible that increased visit frequency allows a more comprehensive evaluation of goals. More visits may also facilitate the development of a care plan and involvement of more family members in planning. Similarly, the finding that patients were more likely to remain at home if their pain was well controlled suggests that more effective pain management might help patients to stay at home. Finally, the association with advance directive completion offers the possibility that clear documentation of goals may help to prevent emergent acute care utilization.

Fourth, this study found significant variation among hospices in the proportion of patients who were able to die at home. The fact that this variation persisted after adjusting for patient characteristics, time in hospice, and initial visit frequency suggests that there may be other factors that influence the likelihood that patients who prefer to die at home will be able to do so. For instance, it is possible that there were differences in visit frequency later in each patient's hospice course. There might also be structural variables (eg, hospice staffing, policies about patient transfers) that were not measured in the current study. Research is needed to better define variation at the hospice level in the proportion of patients who are able to die at home, with particular attention paid to variables such as staffing or policies that might be modifiable.

This study has two limitations that should be noted. First, we only assessed preference for site of death at the time of admission. Therefore, it is possible that these preferences changed over the course of patients' hospice enrollment. However, we did not find an interaction between preference, site of death, and time, suggesting that preference at the time of admission predicts site of death equally well, whether death occurs in days or weeks. Second, these data are derived from only three hospices that volunteered to be pilot CHOICE sites. Although these hospices are administratively and geographically distinct, it is possible that their patterns of care are not nationally representative. However, their proportions of patients dying at home are similar to those of other hospices.[10]

The results of this study add to our understanding of the factors that facilitate death at home and highlight the importance of early visits by hospice team members. These findings are important for clinical practice. Nevertheless, further research is needed to better define the role that hospice interventions can play in helping to ensure that patients with cancer who want to die at home are able to do so.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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AUTHOR CONTRIBUTIONS

Conception and design: Neha Jeurkar, David J. Casarett
Financial support: David J. Casarett
Administrative support: Sue Farrington, David J. Casarett
Provision of study materials or patients: Julie Slattery, Joan K. Harrold, Betty Oldanie
Collection and assembly of data: Sue Farrington, Teresa R. Craig, David J. Casarett
Data analysis and interpretation: Julie Slattery, Joan K. Harrold, Betty Oldanie, Joan M. Teno, David J. Casarett
Manuscript writing: All authors
Final approval of manuscript: All authors

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