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Associations between Timing of Palliative Care Consults and Family Evaluation of Care for Veterans Who Die in a Hospice/Palliative Care Unit

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Abstract

Background: Palliative care consultations (PCC) improve end-of-life (EOL) care, although they may occur too late in an illness to effect the best outcomes. Evidence about the optimal timing of PCC is limited.
Objective: To examine the associations between PCC timing and bereaved families' evaluation of care.
Methods: A retrospective, cross-sectional analysis of data collected between October 2011 and September 2014 was conducted with 5,592 patients who died in a Veterans Affairs inpatient hospice/palliative care unit. The independent measure was the date of first documented PCC within 180 days of death. Outcomes came from the validated Bereaved Family Survey (BFS) and included one global and three subscale scores characterizing EOL care in the last month of life.
Results: After adjustment for patient and facility characteristics, family members of veterans whose first PCC occurred 91–180 days before death were more likely to rate overall care as ''excellent'' compared with those whose PCC occurred 0–7 days before death, 67.9% versus 62.1%, respectively (adjusted odds ratio = 1.37; confidence interval [95% CI] 1.08–1.73). Mean scores on two of the three subscales also were significantly higher for veterans receiving PCC 31–90 days before the veteran's death compared with those who had their first PCC 0–7 days before death: Respectful Care and Communication, 13.6 versus 13.4, respectively ($\beta = 0.26$; 95% CI 0.11–0.41), and Emotional and Spiritual Support, 7.6 versus 7.4, respectively ($\beta = 0.22$; 95% CI 0.03–0.41).
Conclusions: Earlier PCC is associated with greater family satisfaction with care. Strategies that are aimed at conducting PCC earlier in life-limiting illness are needed.

Keywords: communication; end-of-life care; palliative care; quality of healthcare; satisfaction; veterans

Background

Palliative care is an interdisciplinary approach that is used to alleviate symptoms and to improve the quality of life for people with serious, life-limiting illness and their families.[1] Over the past decade, palliative care has rapidly expanded within the United States. As of 2012, two thirds of hospitals with 50 or more beds report having a palliative care program, representing a 157% increase since 2001.[2] The Department of Veterans Affairs (VA) is the largest integrated healthcare system in the United States; palliative care consultation (PCC) teams are available in all VA facilities, which include acute care, nursing home, and inpatient hospice units.[3] Some VA medical centers (VAMC) also have outpatient palliative care clinics. The VA also is unique because veterans can access hospice services concurrently with curative therapies. Veterans also have access to 95 inpatient hospice/palliative care units throughout the United States.

Empirical evidence demonstrates multiple benefits of PCC teams. Patients report improved health-related quality of life, higher satisfaction with care, and better symptom management.[4–6] Caregivers report less burden and greater satisfaction with communication.[7,8] PCC teams are also associated with lower hospital costs and hospital readmission rates.[9–13] Despite

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the positive outcomes that are associated with PCC, in general, certain factors increase the effectiveness of PCC. For example, some evidence suggests that earlier referral to palliative care is associated with better preparation for end of life (EOL), greater satisfaction with healthcare providers, improved quality of life, and enhanced illness understanding and coping behaviors that are associated with longer survival.[14,15] In contrast, late consultations are associated with worse outcomes, including undertreated symptoms, higher emergency department and intensive care unit use, higher costs, and greater 30-day posthospital mortality rates compared with patients who receive early PCC.[16,17]

Similarly, bereaved family members who felt their loved one was referred ''too late'' to hospice care report a higher rate of concerns, unmet needs, and rated EOL care as less than excellent compared with those who are referred at a time that the family members felt was ''right.''[18,19] Specifically, bereaved families who perceived late hospice referral reported that pain, dyspnea, and emotional support were not managed well and that they needed more information about the illness, including how to manage symptoms and what to expect as the illness progressed.[19] Those who identified as referred ''too late'' also had shorter stays in hospice care.[18]

Previous research offers important insights about the relationship between the organization of EOL care (e.g., PCC and hospice timing and outcomes); however, studies are limited by an exclusive focus on specific populations (e.g., diseases such as cancer), use of data from a single institution, and outcomes that are limited to healthcare use.[16,20,21] Little is known about the timing of PCC and outcomes such as patient and family experiences of EOL care. Thus, the purpose of this study was to determine the association between the timing of PCC and bereaved families' evaluation of care in the last month of life for veterans who died in a hospice/palliative care unit. To our knowledge, this is the first national study to examine the associations between PCC timing and outcomes, including bereaved family satisfaction with EOL care.

Materials and Methods

Study design and data sources

We performed a retrospective, cross-sectional analysis of medical record and Bereaved Family Survey (BFS) data collected between October 2011 and September 2014 for veterans who died in one of 95 VAMC hospice/palliative care units nationwide. Data were collected as a part of ongoing activities of the Veterans Performance Reporting and Outcomes Measurement to Improve the Standard of Care at End-of-life Center (PROMISE) (www.cherp.research.va.gov/PROMISE/PROMISE_Methods.asp). PROMISE is a national VA quality improvement program that evaluates the quality of care of all veterans who die in VAMC facilities, including acute care inpatient units, hospice/palliative care units, and nursing home settings. For this analysis, we included only veterans who died in an inpatient hospice/palliative care unit at a VAMC because this setting provided a homogenous sample of veterans who had a longer interval between PCC and death. We determined death in a hospice/palliative care unit from electronic medical record reviews.

Human subjects' approval for this secondary analysis of existing PROMISE data was obtained from the Philadelphia VAMC institutional review board.

Study variables

Bereaved families' evaluation of care. The BFS is a validated instrument that contains 19 items: 17 individual forced-choice items that focus on specific aspects of care, as well as two open-ended questions soliciting comments about positive and negative aspects of care (these two items are not included in the present analysis).[22,23] Our primary outcome of interest was one item that reflects the next-of-kin's (NOK) global assessment of care during the veteran's last month of life. This item, known as the BFS Performance Measure (BFS-PM), is validated and endorsed by the National Quality Forum.[24–27] For this analysis, the BFS-PM was dichotomized into ''excellent'' versus all other responses (i.e., ''very good,'' ''good,'' ''fair,'' ''poor'').

Our secondary outcomes were the BFS-Factor Scores. These three distinct BFS Factor scores—Respectful Care and Communication, Emotional and Spiritual Support, and Death Benefits—were derived from our previous work validating the BFS.[24] The Respectful Care and Communication Factor includes five items (score range 0–15): Staff *(1) listened to concerns; (2) provided medical treatment patient wanted; (3) were kind, caring, and respectful; (4) kept family members informed about patient's condition and treatment*; and *(5) attended to personal care needs.* The Emotional and Spiritual Support Factor consists of three items (score range 0–9): Staff provided *(1) enough emotional support before death; (2) enough spiritual support;* and *(3) enough emotional support after death.* The Death Benefits Factor includes three items (score range 0–3): The VA provided *(1) enough information about the survivor's benefits; (2) enough information about burial and memorial benefits;* and *(3) enough help with funeral arrangements.*

The PROMISE Center attempts to reach NOK for any veteran who dies in a VAMC inpatient facility. The only exclusion criteria are: veterans who died within 24 hours of admission, unless they had a length of stay longer than 24 hours in a VAMC facility in the preceding month, and veterans who did not have an NOK listed in the medical record.

Between 2008 and 2012, the BFS was predominantly administered via a phone survey by trained PROMISE staff who conducted BFS interviews by using standardized approaches. An introductory letter was sent to the veteran's NOK approximately four weeks after their death. Two weeks later, staff made a maximum of three telephone calls to the NOK to administer the BFS. After 2012, the survey was administered via mail. The mail survey was collected within a similar time frame as the phone-administered survey. Four to six weeks after the patient's death, NOKs were mailed the BFS along with an introductory letter. Postcards reminding the NOK to complete the survey and return it were sent six to eight weeks after death. For those NOKs who did not return the survey by seven to nine weeks after the patient's death, a trained interviewer called to remind them to complete the survey. The interviewer also presented the NOK with the option of completing the survey over the phone. Surveys were sent with a self-addressed prepaid return envelope. Previous work demonstrates strong psychometric support and measurement invariance for the BFS across administration modes.[24]

Timing of first PCC. The first PCC was determined by codes for inpatient or outpatient PCC. Our definition of a PCC was an encounter stop code 351 (hospice consult) or 353 (palliative consult) and Current Procedural Terminology (CPT®)

code 99241-99245 or 99251-99255. All PCCs took place before a veteran's inpatient hospice admission and occurred within 180 days of the veteran's death. We categorized PCC timing into four categories: 0–7, 8–30, 31–90, and 91–180 days.

Key study covariates

Patient characteristics. Patient-level variables included age, race/ethnicity, sex, relationship of NOK, and diagnosis.

Facility characteristics. Three facility-level structural characteristics were also included: classification (rural/urban), geographic region (Northeast, South, Midwest, Mountain, and West) based on the Veteran Integrated Service Network (VISN) classification system, and facility complexity level. The VA facility complexity level is an internal administrative categorization based on a weighted consideration of several factors, including patient volume and risk, available clinical services, extent of teaching and training activities, and amount of research involvement. Facilities were categorized as high (level 1a, 1b, or 1c) or low (levels 2 and 3) complexity.

Similar characteristics have been associated with patient reported satisfaction in previous research.[28] We expected that they also could affect BFS ratings of EOL care. Therefore, we included both patient-level variables and facility-level structural characteristics as covariates in our multivariate regression models to account for their independent effects on study outcomes.[29,30]

All variables other than the BFS data were derived from the VA Corporate Data Warehouse (CDW), which integrates existing robust databases containing VA-specific clinical (electronic medical records), financial, and administrative information into one standardized collection that can be accessed for operational, research, and other purposes (www.hsrd.research.va.gov/for_researchers/vinci/cdw.cfm).

Statistical analysis

Descriptive statistics were calculated to describe veteran and facility characteristics of the sample. We used robust logistic regression models, clustered by facility and adjusted for veteran and facility characteristics, to examine the relationship between the timing of the first PCC and overall NOK satisfaction on the BFS-PM. We used robust linear regression models, also clustered by facility and adjusted for veteran and facility characteristics, to assess the relationships between PCC timing and NOK responses on the continuous BFS Factor scores. The reference category for comparison in all analyses was PCC between 0 and 7 days before death.

To reclaim cases with missing BFS Factor Score item-level data, we employed hot-deck imputation procedures for all multivariate analyses where values of missing items were imputed by randomly selecting values from a donor pool with complete information.[31]

We used STATA statistical software version 13.1 (StataCorp, CollegeStation, TX) for all analyses and set statistical significance level at $p < 0.05$.

Results

Sample characteristics

We identified 5592 veterans who died in a VAMC inpatient hospice/palliative care unit between October 2011 and September 2014, received a PCC before hospice/palliative care unit admission and in the last 180 days of life, and whose family members completed the BFS. Veteran and facility characteristics are provided in Table 1. Among total deaths in the sample, the average veteran age was 75.5 years. The sample consisted primarily of male veterans (98%). The majority of veterans were cared for in high-complexity facilities (84%),

TABLE 1. PATIENT AND FACILITY CHARACTERISTICS (N = 5592)

Sample characteristics	*Number*	*Percentage*
Patient characteristics		
Patient age, years		
≤59	427	7.6
60–69	1568	28.0
70–79	1119	20.0
80–89	1662	29.7
90+	816	14.6
Patient male sex	5470	97.8
Patient race/ethnicity		
Non-Hispanic white	4283	76.6
All other race/ethnicity	1309	23.4
NOK relationship		
Spouse	2271	40.6
Child	1734	31.0
Sibling	818	14.6
Other family	458	8.2
Other nonfamily	311	5.6
Elixhauser comorbidity diagnostic categories (those occurring in >10% of the sample)		
Hypertension, uncomplicated	3444	61.6
Malignancy	3290	58.8
Fluid and electrolyte disorders	3118	55.8
Chronic pulmonary disease	2281	40.8
Cardiac arrhythmias	2193	39.2
Diabetes, uncomplicated	1856	33.2
Renal failure	1756	31.4
Congestive heart failure	1660	29.7
Dementia	1460	26.1
Depression	1535	27.5
Weight loss	1319	23.6
Peripheral vascular disorder	934	16.7
Liver disease	909	16.3
Coagulopathy	843	15.1
Deficiency anemia	867	15.5
Hypothyroidism	765	13.7
Diabetes, complicated	668	12.0
Other neurological disorders	617	11.0
Valvular disease	615	11.0
Facility characteristics		
Facility complexity		
Level 1a, 1b, 1c	4674	83.6
Level 2, 3	918	16.4
Facility region		
Northeast	920	16.5
Midwest	917	16.4
South	2916	52.2
Mountain	371	6.6
West	468	8.4
VAMC urban/rural classification		
Urban	5366	96.0
Rural	226	4.0

NOK, next-of-kin's; VAMC, VA medical centers.

and 96% of patients died in urban VAMCs. More than 50% of the deaths occurred in VA facilities that were located in the Southern United States.

BFS-PM outcome

Unadjusted proportions, adjusted predictive probabilities, and odds ratios for BFS-PM outcomes are presented in Table 2. We calculated odds ratios based on number of days that the first PCC occurred before the veteran's death.

In both adjusted and unadjusted analyses, respondents were more likely to rate the overall EOL care as ''excellent'' if the first PCC occurred >7 days before death. After we controlled for patient and facility characteristics, this relationship appeared to be stronger when the veteran's first PCC occurred greater than 30 days before death (31–90 days adjusted odds ratio [AOR] = 1.37, confidence interval [95% CI] 1.13–1.66; 91–180 days AOR = 1.37, 95% CI 1.08–1.73) compared with 0–7 days.

BFS factor score results

Table 3 summarizes the unadjusted and adjusted results for the Factor scores. In unadjusted analyses, high ratings on the Respectful Care and Communication Factor and Emotional and Spiritual Support Factor were significantly more likely when the first PCC occurred 31–90 days before death, compared with 0–7 days before death. No statistically significant unadjusted differences were observed between the timing of PCC and satisfaction ratings on the Death Benefits Factor.

After we adjusted for patient and facility characteristics, when compared with those who received PCC 0–7 days before death, respondents were significantly more likely to be satisfied with care and staff communication as well as with emotional and spiritual support offered by staff (i.e., Respectful Care and Communication Factor and Emotional and Spiritual Support Factor) when the PCC occurred 31–90 days before death ($\beta = 0.26$, 95% CI = 0.11–0.41; $\beta = 0.22$; 95% CI = 0.03–0.41, respectively). However, respondents were significantly less likely to be satisfied with death benefits (i.e., Death Benefits Factor) when the PCC occurred 31–90 days before death ($\beta = -0.08$, 95% CI = –0.17 to –0.01).

Discussion

In this analysis of a national sample of patients who died in a VAMC inpatient hospice/palliative care unit, we found that veterans' bereaved family members perceived the overall quality of EOL care to be higher when a PCC occurred greater than one week before death. This association was even greater when the PCC occurred at a maximum of six months before death. Moreover, PCCs occurring more than one month before death were associated with higher ratings of respectful care and communication, and emotional and spiritual support.

Earlier research found that bereaved family members reported better overall satisfaction with care and emotional support at the EOL in a dedicated palliative care/hospice unit after PCC.[32,33] Our study is unique as we associated the timing of PCC and patient and family experience with care. Our findings build on previous research supporting the benefits of early versus late PCC on EOL care quality.[16,34] Our results provide important evidence that families rate their satisfaction higher with earlier versus later PCCs and suggest several areas for improvement.

First, these results bring attention to the value of early PCC. Late PCC referrals are typically associated with inpatient consultation when patients are sicker and closer to the end of life, resulting in less days and time with palliative care.[16] Criteria for identifying patients for PCC during hospitalization are associated with a crisis (e.g., life-threatening condition) and/or a decline during an existing serious illness (e.g., infection and weight loss with dementia).[35] In the case of progressive serious illness, to reach patients earlier, PCCs need to be initiated in the setting where patients and families live and receive regular outpatient or community healthcare services. When compared with hospitalized patients or those who never receive a PCC, earlier PCC in the outpatient setting results in improved EOL care quality (reduces hospitalizations and costs and increases hospice use).[36] Efforts have been underway to increase access to and sustainability of community palliative care, but barriers still exist.[37,38]

Second, bereaved families reported higher ratings on respectful care and communication with earlier versus later PCC. Previous studies have shown that family caregivers value elements of communication, including building rapport and connections, explaining goals of care and honoring

Table 2. Average Predictive Probability of the Bereaved Family Survey Performance Measure (Overall Rating of Care) by Number of Days with a Palliative Consult

Number of days between initial PCC and death	N[a]	*Unadjusted proportions, %*	*Unadjusted OR (95% CI)*[b]	*Adjusted predictive probability, %*	*Adjusted OR (95% CI)*[c,d]
0–7 days	1185	62.1	Reference Category	62.1	—
8–30 days	2121	66.4	1.21 (1.04–1.40)*	66.4	1.23 (1.04–1.44)*
31–90 days	1447	68.5	1.33 (1.13–1.56)*	68.5	1.37 (1.13–1.66)*
91–180 days	783	67.9	1.29 (1.10–1.56)*	67.9	1.37 (1.08–1.73)*

[a] Bereaved Family Survey-Performance Measure missing data $N = 56$ (1%).

[b] Logistic regression clustered by facility was used to analyze associations between the number of days with a palliative consult before death and the proportion of families who rated end-of-life care as ''excellent.''

[c] Models were adjusted for Veteran age, race/ethnicity, family relationship, gender, diagnoses and facility complexity, urban/rural classification, and region.

[d] Standard errors and 95% CIs estimated by using a bias-corrected bootstrap approach.[45]

*Indicates p-value <0.05.

CI, confidence interval; PCC, palliative care consultations.

Table 3. Average Predictive Mean for Each Bereaved Family Survey Factor by Number of Days with a Palliative Care Consult

Number of days between initial PCC and death	N	*Unadjusted mean factor score*[a]	*Unadjusted β-coefficient (95% CI)*	*Adjusted predictive mean*	*Adjusted β-coefficient (95% CI)*[b,c]
Communication factor* (range 0–15)					
0–7 days	1196	13.4	Reference category	13.4	—
8–30 days	2147	13.5	0.16 (–0.01 to 0.32)	13.5	0.15 (–0.01 to 0.30)
31–90 days	1463	13.6	0.25 (0.08–0.43)*	13.6	0.26 (0.11–0.41)*
91–180 days	786	13.6	0.22 (0.01–0.43)*	13.6	0.24 (–0.01 to 0.48)
Support factor* (range 0–9)					
0–7 days	1196	7.4	Reference category	7.4	—
8–30 days	2147	7.5	0.05 (–0.11 to 0.20)	7.5	0.08 (–0.10 to 0.25)
31–90 days	1463	7.6	0.17 (0.01–0.34)*	7.6	0.22 (0.03–0.41)*
91–180 days	786	7.5	0.09 (–0.11 to 0.28)	7.5	0.16 (–0.07 to 0.38)
Benefits factor* (range 0–3)					
0–7 days	1196	1.2	Reference category	1.2	—
8–30 days	2147	1.2	–0.01 (–0.09 to 0.07)	1.2	–0.02 (–0.10 to 0.05)
31–90 days	1463	1.1	–0.09 (–0.17 to 0.01)	1.1	–0.08 (–0.17 to 0.01)*
91–180 days	786	1.1	–0.07 (–0.17 to 0.04)	1.1	–0.08 (–0.21 to 0.04)

[a] Linear regression clustered by facility was used to analyze associations between the number of days with a palliative consult before death and the Factor Scores.

[b] Models were adjusted for Veteran age, race/ethnicity, family relationship, gender, diagnoses and facility complexity, urban/rural classification, and region.

[c] Standard errors and 95% CIs estimated by using a bias-corrected bootstrap approach.[45]

*Indicates *p*-value <0.05.

choices, staying informed, active listening, and discussing death (e.g., advance care planning).[39,40] Advance care planning and goals-of-care discussions hinge on regular interactive dialogue. This process not only keeps patients and their families informed about conditions but also creates opportunities for sharing care preferences. Advance care planning involves giving information about serious illness (e.g., prognostic information) as well as listening to patients (e.g., illness understanding, personal values, and goals) to help patients and their families make decisions about care.[41] Conversations early in the course of serious illness provide for more time to plan care that is consistent with stated goals and may be associated with less unwanted treatments. Attention to careful communication deepens connections to patients and their families and grows trust throughout the trajectory of illness.

Third, in our analysis, bereaved families who received early PCC reported feeling supported in spiritual and emotional care both before and after death. These findings are not surprising when one considers the roles of PCC teams. Teams are responsible for not only managing physical and psychological symptoms but also helping patients to identify personal goals, providing spiritual support, and assessing patients' support systems.[35] Those who receive emotional and spiritual support during terminal illness report better quality of life.[42] Receiving less spiritual support than desired is associated with depression at EOL.[43] We suspect that conducting a PCC early in the illness allows for more time to develop a therapeutic relationship, tend to spiritual care, and find meaning at EOL. Attending to spiritual care helps patients and their families cope with grief and attain spiritual well-being.

Lastly, families reported less satisfaction with receipt of information about death benefits, including survivor's benefits, burial and memorial benefits, and funeral arrangements. This is not unexpected as we suspect families were not ready to hear information related to practical issues and planning for after-death during a PCC early in the illness. In addition, families are likely to be more focused on other issues, such as symptom management, decision making, and coping with disease prognosis earlier in the trajectory of an illness. This finding highlights the importance of asking patients and their families how much and what kind of information they want or need during a PCC.

This study has important limitations. First, all decedents died in a hospice unit. It is unclear how death in this setting may have influenced bereaved family members during survey completion. Second, the results of our study rely primarily on the bereaved family members' perception of care retrospectively rather than on the patients' perceptions before death. Third, our sample is limited by the preponderance of men in the Veteran population. However, our earlier work documented similar outcomes for female Veterans.[29]

However, families are an important source of evaluation for EOL care as often it is not possible for patients to report.[44] The strengths of this study include the use of a national sample clustered by facility to account for variability between VA facilities and use of a validated and nationally endorsed quality measure.[24,27]

In conclusion, we found that bereaved families were more likely to report higher satisfaction with EOL care when PCC was conducted earlier during serious illness. Future research is needed to better identify criteria for PCC referral. Increased understanding may help healthcare systems to develop and implement strategies to conduct initial PCCs at the time that a serious illness is diagnosed. In addition, research should focus on the timing and number of PCC contacts (''dose'') and care processes on outcomes and bereaved family satisfaction with EOL. This may help to characterize the essential components of PCC and their effect on EOL care.

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Author Disclosure Statement

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