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Original Article

Family Involvement at the End-of-Life and Receipt of Quality Care

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Abstract

Context. Most patients will lose decision-making capacity at the end of life. Little is known about the quality of care received by patients who have family involved in their care.

Objectives. To evaluate differences in the receipt of quality end-of-life care for patients who died with and without family involvement.

Methods. We retrospectively reviewed the charts of 34,290 decedents from 146 acute and long-term care Veterans Affairs facilities between 2010 and 2011. Outcomes included: 1) palliative care consult, 2) chaplain visit, and 3) death in an inpatient hospice or palliative care unit. We also assessed "do not resuscitate" (DNR) orders. Family involvement was defined as documented discussions with the health care team in the last month of life. We used logistic regression adjusted for demographics, comorbidity, and clustered by facility. For chaplain visit, hospice or palliative care unit death, and DNR, we additionally adjusted for palliative care consults.

Results. Mean (SD) age was 74 ($\pm$12) years, 98% were men, and 19% were nonwhite. Most decedents (94.2%) had involved family. Veterans with involved family were more likely to have had a palliative care consult, adjusted odds ratio (AOR) 4.31 (95% CI 3.90–4.76); a chaplain visit, AOR 1.18 (95% CI 1.07–1.31); and a DNR order, AOR 4.59 (95% CI 4.08–5.16) but not more likely to die in a hospice or palliative care unit.

Conclusion. Family involvement at the end of life is associated with receipt of palliative care consultation and a chaplain visit and a higher likelihood of a DNR order. Clinicians should support early advance care planning for vulnerable patients who may lack family or friends.   J Pain Symptom Manage 2014;48:1108–1116. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

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Introduction

It is estimated that 25%−75% of seriously ill patients lose capacity to make some or all their medical decisions at the end of life.[1−3] In such cases, it is the ethical and legal standard to have close family or friends (henceforth referred to as family) serve as surrogate decision makers.[4] Ideally, family members work with the patient's clinical team to help interpret advance directives and prior goals of care conversations, when available, and to make medical decisions that align with patients' preferences.[5,6] Even when patients retain the ability to make their own medical decisions, the added support of close family and friends who can help advocate for the patient may relieve stress and provide comfort at the end of life.[1]

However, many patients, up to 25% in some studies, lack a surrogate decision maker[7,8] either because they have no close friends or family members or because suitable surrogates cannot be reached during a crisis.[9,10] For instance, studies in intensive care units have shown that up to one quarter of patients lack both a surrogate decision maker and an advance directive to help guide treatment decisions.[11,12] For patients who lack a family member who can serve as a surrogate, medical decisions are often made with the support of third parties like hospital ethics committees or the courts.[13]

There are concerns that patients without an involved family member who can advocate for the patient may not receive high-quality care at the end of life, such as receipt of a palliative care consultation, visits by a chaplain, and receipt of care that is consistent with patients' goals and preferences.[14−16] However, for a family member to advocate for needed services, he or she must be involved in the patient's care and not just named on a legal document. For instance, Silveira et al.[1] found that a documented durable power of attorney (DPOA) for health care was associated with death outside a hospital and less aggressive care. However, approximately 10% of the actual decision makers for these incapacitated patients were not the documented DPOA.[1] In addition, other studies demonstrate physician frustration in finding the documented DPOA during a medical crisis.[9] What may be more important is not whether a patient has a documented DPOA but whether the patient has involved family who can advocate for the patient and who is actually involved in caring for and helping that person make decisions at the end of life.

Little is known about whether family involvement in health care decisions affects the quality of care that patients receive near the end of life. This is important because many patients who lack involved family may be at risk for poor-quality end-of-life care. Therefore, this study compared the quality of the end-of-life care between patients who had family involved in health care decision making at the end of life vs. those who did not. We hypothesized that patients with involved family members would receive better quality end-of-life care than patients without involved family.

Methods

Setting and Participants

This investigation was part of the Performance Reporting and Outcomes Measurement to Improve the Standard of Care at the End-of-life (PROMISE) Center, an ongoing quality improvement initiative to optimize end-of-life care at 146 Veterans Affairs Medical Centers that had palliative care teams.[17] All Veterans Affairs (VA) facilities with palliative care consultations participate in the PROMISE program and are included in this analysis. The facilities are a mix of acute care and long-term inpatient facilities, including intensive care units, nursing homes, and inpatient hospice units. This study only included veterans who died after >24 hours in a VA inpatient facility between January 2010 and September 2011. Veterans were excluded if they did not have a next of kin documented in the electronic medical record (EMR) or if they died by suicide or outside a VA inpatient facility. Inpatient deaths were retrieved from national VA databases derived from the EMR; this method identifies >95% of decedents.[16,17] Approximately 2% of decedents were selected at random from the largest VA

facility (San Juan, Puerto Rico, which averages 646 inpatient deaths per year) for exclusion to manage staff workload of chart abstraction.

Measures

To measure the main outcome of quality of end-of-life care, we used three processes of care obtained from chart review: 1) receipt of a palliative care consult within the last month of life, 2) one or more documented contacts between the veteran and a chaplain within the last month of life, and 3) death in a designated VA hospice or palliative care unit rather than an inpatient hospital ward. These factors have been shown to be associated with higher ratings of care and satisfaction by bereaved family members.[16,18]

We also ascertained whether there was a "do not resuscitate" (DNR) order at the time of death. Prior analyses in this VA cohort showed an association between DNR orders and family members' satisfaction with care quality.[18] A DNR order may be a proxy measure for more in-depth "goals of care" conversations between the care team and patients or families and/or an acknowledgment and understanding that the veteran had a life-limiting illness.

The independent variable was whether there was documentation in the EMR that family members were involved in the veteran's medical care and/or decision making during the last month of life. Family refers to anyone (family or a friend, excluding VA staff) who was documented in the EMR to be involved on the patient's behalf. To be considered a veteran with involved family, the EMR had to contain one or more notes documenting a discussion about the veteran's medical care or medical decision making between medical staff and a family member or friend during the last month of the veteran's life.

We also collected veteran age, gender, and race/ethnicity from Veterans Health Administration databases. Race and ethnicity were obtained through veteran self-report and grouped into reporting categories defined by the National Institutes of Health.[19] Comorbidity was measured using the Deyo adaptation of the Charlson Comorbidity Index,[20] using active diagnoses that were listed in the EMR. This variable was coded into three categories: best health (i.e., no comorbid conditions), average health (1−3 comorbid conditions), and worst health (≥4 health conditions).[21] To obtain veteran income and education, we linked the

veterans' zip code information and date of birth to the (2000) U.S. census data.[22] VA inpatient facility location was also dichotomized into rural (defined as a population density <1000 people per square mile) or urban (defined as at least 1000 people per square mile).[23] We also collected information about primary diagnoses at death, which we defined as all *International Classification of Diseases, Ninth Revision,* diagnosis codes listed in the EMR in the last week of life. We report the top five causes of death identified by the Centers for Disease Control for individuals 65 years and older (cardiovascular disease, cancer, cerebrovascular disease, respiratory disease, and diabetes).[24] We did not have information on whether the involved family member was the documented DPOA or was the next of kin. However, the PROMISE Center does collect information about the documented next of kin. In 94% of cases, the next of kin, who most often is involved in the veteran's care, is a spouse, adult child, sibling, or other family.

All data derived from the EMR, including the three quality indicators, the DNR order, and the presence of involved family, were collected by trained staff using standardized protocols. Staff were required to meet a minimal level of agreement and accuracy before collecting data independently, and supervisors conducted regular data quality audits. Twenty-five research coordinators reviewed an average of 200 medical charts each quarter. Two quality assurance managers checked a 10% random sample of all chart extractions each quarter, and the error rate was <3%. Human subjects approval was obtained from the Philadelphia VA Medical Center Institutional Review Board.

Statistical Analysis

Veteran characteristics were described with means (±SD) and percentages. To compare veteran characteristics by family involvement status, we used Wilcoxon rank-sum tests for continuous variables and Pearson Chi-square tests for categorical variables. To assess the unadjusted association between binary quality of end-of-life care measures and family involvement, we fit logistic regression models for each outcome and included a random facility intercept to account for clustering within facilities. In adjusted analyses, we included age, race/ethnicity, veteran education, veteran income, and Charlson comorbidity score into the models. Covariates

were chosen based on the literature and factors that have been found to be associated with care received at the end of life.[25–28] Because palliative care consultation may result in more chaplain visits, more deaths on a hospice or palliative care unit, and more documentation of code status, for these outcomes, we also adjusted for receipt of a palliative care consult. For multivariable analysis assessing whether a veteran died in an inpatient hospice or palliative care unit, we truncated our sample to include only veterans who died in a VA facility with these inpatient units (98 of the 146 facilities [68%]). In addition, because an unexpected death would not allow time for a discussion with the medical team or a palliative care consultation and could bias our results, we conducted sensitivity excluding all individuals who died after only two days or less in the hospital.

Twenty-nine percent of the sample had missing data for one or more covariates, primarily because of zip code match failures for census data for education and income. Although we expect that these data are missing completely at random,[29] we performed our analyses in two ways to assess the sensitivity of our analyses to this assumption. For the primary analysis, we used multiple imputations to create 10 complete data sets by imputing values for missing covariates with the Markov Chain Monte Carlo method as implemented in SAS PROC MI. We analyzed each imputed complete data set and then applied Rubin's rules[30] to combine the results and produce a single estimate with adjusted SEs for each outcome measure. We confirmed that 10 imputations were adequate by checking the relative efficiency of our imputation procedure,[30] which was 0.97 or greater for all imputed variables.[29] We compared these results against analyses using only those decedents with complete covariate data. Results were very similar for both sets of analyses, with a mean difference under 5%. Therefore, we present the results using the entire sample using multiple imputations for missing values. All analyses were conducted using SAS, version 9.3 (SAS Institute, Inc., Cary, NC).

Results

Medical record review identified 36,722 veterans who died in one of 146 participating VA facilities between January 2010 and September 2011. Of these, 1761 veterans were ineligible because they spent <24 hours as an inpatient during the last month of life ($n = 1605$), did not have a next of kin (NOK) listed in the patient record ($n = 121$), or committed suicide ($n = 35$). Six hundred seventy-one veterans were selected at random from the San Juan, Puerto Rico VA for exclusion to manage staff workload. The remaining 34,290 veterans were included in the analysis.

The mean (SD) age of the cohort was 74 ($\pm$12) years, 98% were men, and 19% were nonwhite (Table 1). Most veteran decedents (94.2%) had involved family with at least one documented conversation between this individual and the health care team in the last month of life, yet 1972 veterans (5.8%) did not. Decedents who did not have involved family were younger than those who did (71.2 years [$\pm$11.9] vs. 74.2 [$\pm$12.0], $P < 0.001$).

In unadjusted analysis, veterans with involved family were more likely to have received a palliative care consultation (odds ratio [OR] 4.32; 95% CI 3.91–4.78), to have contact with a chaplain (OR 1.48; 95% CI 1.34–1.64), and to have died in an inpatient hospice unit (OR 2.24; 95% CI 1.96–2.56) (Table 2). Individuals with involved family members were also more likely to have a DNR order in the EMR than those who did not (OR 7.62; 95% CI 6.86–8.47). After adjusting for patient age, race/ethnicity, gender, education, income, and Charlson comorbidity and clustering by facility, veterans with involved family were more likely to have a palliative care consult before death than those who did not (adjusted odds ratio [AOR] 4.31; 95% CI 3.90–4.76). After additionally adjusting for receipt of a palliative care consult, veterans with involved family were more likely to have had a chaplain visit (AOR 1.18; 95% CI; 1.07–1.31) and to have had a documented DNR order (AOR 4.59; 95% CI 4.08–5.16); however, dying in an inpatient hospice or palliative care unit was no longer significant (AOR 1.07; 95% CI 0.91–1.26). After excluding 2022 veterans who died within 48 hours or less from admission, there were no significant differences in our results.

Discussion

To our knowledge, this is the first study to demonstrate the association of having

Table 1
Participant Characteristics[a]

Characteristic	All Veterans (n = 34,290)	Surrogate Involvement[a] (n = 32,318)	No Surrogate Involvement (n = 1972)	P-value[b]
Age, mean (SD)	74.0 (12.0)	74.2 (12.0)	71.2 (11.9)	<0.001
Gender, men, n (%)	33,557 (97.8)	31,632 (97.8)	1925 (97.6)	0.44
Race, n (%)				0.13
White/Caucasian	25,207 (73.5)	23,779 (73.5)	1424 (72.2)	
African American	5859 (17.0)	5478 (16.9)	378 (19.1)	
Asian	152 (0.4)	144 (0.4)	8 (0.4)	
Pacific Islander	223 (0.7)	213 (0.7)	10 (0.5)	
American Indian/Alaska Native	143 (0.4)	139 (0.4)	4 (0.2)	
Other	31 (0.09)	29 (0.09)	2 (0.1)	
Unknown	2675 (7.8)	2385 (7.3)	134 (6.7)	
Ethnicity, Hispanic, n (%)	1294 (3.7)	1231 (3.8)	63 (3.1)	0.17
Income, n (%)[b]				0.27
25th percentile (<$30,000)	9744 (28.4)	9167 (28.4)	577 (29.3)	
50th percentile ($30,000–$39,999)	7452 (21.7)	7017 (21.7)	435 (22.1)	
75th percentile (≥$40,000)	10,187 (29.7)	9635 (29.8)	552 (28.0)	
Education, n (%)[b]				0.51
Less than high school diploma	321 (0.9)	306 (0.9)	15 (0.8)	
High school diploma	17,826 (52.0)	16,796 (52.0)	1030 (52.2)	
Some to college degree	9235 (26.9)	8715 (27.0)	520 (26.4)	
Graduate degree	5 (0.01)	5 (0.02)	0 (0.0)	
Missing	6903 (20.1)	6496 (20.1)	407 (20.6)	
Charlson comorbidity, n (%)				0.01
0, Best health	6344 (18.5)	5944 (18.4)	400 (20.3)	
1–3, Average health	13,868 (40.4)	13,129 (40.6)	739 (37.5)	
≥4, Worst health	12,787 (37.3)	12,037 (37.2)	750 (38.0)	
Cause of death, n (%)[c]				
Cancer	16,579 (48.3)	15,646 (48.4)	933 (47.3)	0.45
Cerebrovascular disease	4754 (13.9)	4471 (13.8)	283 (14.4)	0.46
Cardiovascular disease	3340 (9.7)	3132 (9.7)	208 (10.5)	0.19
Respiratory disease	1077 (3.1)	1011 (3.1)	66 (3.3)	0.56
Diabetes	1106 (3.2)	1025 (3.2)	81 (4.1)	0.02
Facility setting, n (%)				0.04
Urban	31,361 (91.5)	29,541 (91.4)	1781 (90.3)	
Rural	2929 (8.5)	2777 (8.6)	191 (9.7)	

[a]Missing data: 20.1% of veterans and 19.1% of surrogates had missing data on income and education and 3.8% of veterans had missing *International Classification of Diseases, Ninth Revision*, code data for Charlson Comorbidity assessment.
[b]Differences between groups evaluated with *t*-tests for continuous variables and Chi-square for categorical variables.
[c]Only the top five causes of death are listed in the table identified by the Centers for Disease Control for individuals 65 years and older (cardiovascular disease, cancer, cerebrovascular disease, respiratory disease, and diabetes).[24]

documented involvement of family (defined as family or friends) at the end of life on process measures that are associated with quality of end-of-life care. Veterans who died in a VA facility with involved family were more likely to have received a palliative care consult and to have

Table 2
Quality of Care Indicators and DNR Orders Based on Surrogate Involvement

Outcome	Surrogate Involvement (n = 32,318), n (%)	No Surrogate Involvement (n = 1972), n (%)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio[a] (95% CI)
Quality of care indicator				
Received palliative consult	23,340 (72.2%)	765 (38.8%)	4.32 (3.91–4.78)	4.31 (3.90–4.76)
Chaplain/veteran contact[b]	21,039 (65.0%)	1120 (56.8%)	1.48 (1.34–1.64)	1.18 (1.07–1.31)
Died in an inpatient hospice unit[b,c]	10,317 (48.1%)	364 (29.7%)	2.24 (1.96–2.56)	1.07 (0.91–1.26)
DNR order				
Documented DNR order[b]	29,792 (92.2%)	1238 (62.8%)	7.62 (6.86–8.47)	4.59 (4.08–5.16)

[a]Adjusted odds ratios clustered by facility and adjusted for age (continuous), veteran race/ethnicity (white vs. all other races/ethnicities), veteran income (25th percentile vs. all other categories, imputed for missing data), veteran education (≤high school graduate vs. all other categories, imputed for missing data), and Charlson comorbidity category (best health vs. all other categories).
[b]Includes additional adjustment for receipt of a palliative care consult.
[c]Only includes veterans who died in a Veterans Affairs Medical Centers with an Inpatient Hospice Unit (surrogate involvement, n = 21,413; no surrogate involvement, n = 1223).

been visited by a chaplain. In addition, veterans with family involvement were more likely to have a DNR order, which may be a proxy measure for discussions between the patient, family, and the clinical team and/or family or patient acknowledgment that the veteran had a life-limiting illness. After adjustment for receipt of a palliative care consult, death within a VA hospice or palliative care unit instead of on an acute hospital ward was no longer statistically significant. This is likely because of the fact that palliative care teams initiated hospice or palliative care unit referrals.

In this cohort, there was a surprisingly large number of veterans (>90%) who had involved family at the end of life. These rates are much higher than reported rates of a documented durable power of attorney for health care (DPOAHC) in the community (~75%).[7,10,11] This may reflect the unique veteran patient population or the VA's attempts to document next-of-kin and emergency contacts. In addition, our definition of involved family was very inclusive and included any friend or family member who was involved in the veteran's care. Involvement was defined as having documentation of at least one discussion between the family and the health care team in the last month of life. It is possible, although our data do not allow us to confirm, that some of the involved family were not the documented DPOAHC or the documented next-of-kin/ emergency contacts listed in the EMR as has been shown in other studies.[1] This possible discrepancy may be because of a lack of discussion with the documented next of kin or DPOAHC about their role before documenting their name in the EMR or because of a lack of updating the EMR with changes in social situations, such as the death of a spouse.[31]

Other studies have demonstrated that family members play an important role in medical decision making at the end of life. Up to 76% of the time, patients are unable to make some or all their own medical decisions over the course of their illness and at the end of life.[1−3] In these cases, family support and involvement can be critical to the care that is received. For instance, one national study found that subjects with an assigned DPOAHC were less likely to die in the hospital or to receive aggressive care.[1] Our sample contained only veterans who died in an inpatient VA facility and yet having

involved family was associated with a higher likelihood of dying in a hospice or palliative care unit, as opposed to an acute or intensive care unit or a nursing home. Another smaller study demonstrated that the mere act of documenting a surrogate decision maker on admission to a neurology intensive care unit resulted in decreased hospital length of stay and costs.[32] Our sample was focused on process measures, and therefore, we do not have information on health care utilization. However, we found higher DNR orders for patients with involved family. This is consistent with other studies demonstrating less aggressive treatment received for patients with a documented surrogate[1,32] and with findings of another small study of increased DNR orders of patients who had a family member present at the time of death (a possible proxy for family involvement).[33]

The strengths of this study are the use of the EMR to define the process measures and family involvement instead of relying on potentially biased proxy reports. An additional strength is the large, national sample. However, this study has several limitations. The VA cares for a disproportionate number of men in an integrated health care system with an EMR. This may limit the generalizability of our findings. However, recent studies among mixed samples of veterans' and non-veterans' surrogates found no differences between the groups with regard to surrogates' roles, attitudes, or decision making.[31,34] Moreover, our national sample was composed of nearly 94% of all decedents who died at a VA facility during the study period and, thus, are representative of nonsuicide deaths. However, generalizability may be limited because we randomly excluded 2% of all deaths from our potential sample from only one large facility (San Juan VA in Puerto Rico) to manage workload. In addition, it is possible that the definition we used for noninvolved family (no EMR documentation of discussions between providers and family) may have been because of the clinician's lack of proper documentation rather than a lack of family involvement and resulted in misclassification bias. Furthermore, because this is a cross-sectional and not longitudinal study, we did not have information about the quality of communication, whether the involved family member was the documented DPOAHC or whether the veteran retained decision making

capacity and needed surrogate decision making. In addition, more involved family members may have been able to provide more support and help some veterans die at home. We could not capture veterans who did not die in an inpatient setting, and therefore, we are likely to have underestimated the full benefits of family involvement. There is concern for ascertainment bias as veterans who obtained a palliative care consult may have been more likely to have documented family involvement. Thus, we attempted to adjust for receipt of palliative care consultation for other outcomes, and our results suggest that receipt of a palliative care consult may explain all the association for inpatient hospice deaths and some, but not all, referrals to a chaplain and DNR orders. Furthermore, we do not have information concerning prior advance directives or documented advance care planning preferences and, therefore, cannot examine the association between patients' prior preferences with care received. We do not have information on health care utilization or data on the number of veterans who died outside a VA facility.

Despite the limitations, this study provides important information about family involvement and quality of end-of-life care. Moreover, our findings have several implications for clinical care. Although the actual percentage of veterans without involved family was low ($\sim 6\%$), this translates into large numbers of veterans across the nation who are left vulnerable without involved family. The number of nonveterans who are bereft of an involved surrogate decision maker in other studies where the patient had lost decision-making capacity is much higher (up to 25%). Because patients who lack involved family may be at risk of not receiving high-quality end-of-life care, efforts should focus on seeking out and involving family and close friends early on, where appropriate. Early advance care planning should be targeted to individuals without known family or friend contacts, and clinicians should help patients discuss and document their preferences for medical care.[13] There may also be implications for research focused on proxy reports of quality of medical care. If involved families, who ask for and receive higher quality care for their loved ones, are also more likely to respond to study surveys, there may be a potential to overestimate quality of care. Thus, studies that use data from bereaved family surveys as outcomes should adjust for nonresponse bias.[35,36]

In conclusion, involvement of family in medical decision making at the end of life is associated with the receipt of higher quality end-of-life care such as palliative care consultation and chaplain involvement. Family involvement is also associated with a higher prevalence of a DNR order. Future studies should examine the quantity and quality of family involvement that result in better patient care and whether involvement of a surrogate advocate results in care consistent with patients' previously stated goals.

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