

UCSF

UC San Francisco Previously Published Works

Title

Inpatients with neurologic disease referred for palliative care consultation.

Permalink

<https://escholarship.org/uc/item/84r9w7xx>

Journal

Neurology, 92(17)

Authors

Taylor, Breana
ORiordan, David
Pantilat, Steven
[et al.](#)

Publication Date

2019-04-23

DOI

10.1212/WNL.0000000000007364

Peer reviewed

Inpatients with neurologic disease referred for palliative care consultation

Breana L. Taylor, MD, David L. O'Riordan, PhD, Steven Z. Pantilat, MD, and Claire J. Creutzfeldt, MD

Neurology® 2019;92:e1975-e1981. doi:10.1212/WNL.0000000000007364

Correspondence

Dr. Taylor
btaylor6@uw.edu

Abstract

Objectives

To compare characteristics and needs of inpatients with neurologic disease to those with cancer referred for palliative care (PC) consultation.

Methods

This prospective cohort study used data collected by the Palliative Care Quality Network from January 2013 until December 2016. We compared demographics, reasons for consultation, discharge disposition, Palliative Performance Scale (PPS) score, and outcomes of care among patients with a primary diagnosis of neurologic disease vs cancer.

Results

The most common reason for PC consultation in all patients was assistance with goals of care and advanced care planning. PC consultation was less often requested for pain and symptom management in patients with neurologic disease compared to patients with cancer (13.7% vs 43%, odds ratio 0.3) and more often for assistance with transition to comfort measures only and withdrawal of life-sustaining treatment (19.1% vs 7.1%, odds ratio 1.3). Patients with cancer had higher PPS scores (42.1% vs 23.4%) and were more likely to be discharged home from the hospital, while patients with neurologic disease were more likely to die in hospital.

Conclusions

Patients with neurologic disease as a reason for PC consultation are more in need of end-of-life care planning and more likely to die in the hospital than those with cancer, suggesting that targeted approaches may best address the needs of each patient population. Our results can direct further research and education in neuropalliative care.

RELATED ARTICLE

Editorial

Palliative care and inpatient neurology: Where to next?

Page 784

From the Department of Neurology (B.L.T., C.J.C.), University of Washington, Seattle; and Department of Medicine (D.L.O., S.Z.P.), Division of Palliative Medicine, University of California San Francisco.

Go to [Neurology.org/N](https://www.neurology.org/N) for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

Glossary

ACP = advanced care planning; CI = confidence interval; OR = odds ratio; PC = palliative care; PCQN = Palliative Care Quality Network; PPS = Palliative Performance Scale.

Palliative care (PC) focuses on addressing pain and other symptoms, providing support to patients and families, and improving communication on goals of care and quality of life for patients with serious illness. The benefit of early introduction to PC specialists has been demonstrated for patients with cancer^{1–3} and heart failure,⁴ which has correlated with an increase in the availability of PC services in US hospitals.⁵ Neurologic disease is the second most common reason for inpatient PC consultations after cancer,^{6,7} yet the PC needs of patients affected by these 2 disease groups may be distinct.

One in 6 acute hospital admissions is due to neurologic diseases.⁸ Some neurologic diagnoses such as stroke require emergency hospitalization, while others, for example, pneumonia in patients with neuromuscular disease, more typically lead to hospitalization due to complications of neurologic disease. A large proportion of patients with neurologic diseases die in the hospital. This statistic is as true for chronic neurologic diseases such as Parkinson disease and motor neuron disease⁹ as it is for acute brain injury such as stroke.¹⁰

Previous studies have examined the characteristics of patients with neurologic disease receiving PC consultation in a single center compared to patients not receiving PC consultation.^{6,7} The goal of this study was to use a large multicenter database of PC consultations¹¹ to undertake an in-depth comparison of the characteristics and needs of patients hospitalized with neurologic disease and those with cancer receiving PC consultation to identify specific needs and opportunities to improve care and to guide future research.

Methods

Study population

The Palliative Care Quality Network (PCQN) is a national quality improvement initiative of interdisciplinary PC teams across the United States that collects standardized data on all patients seen with the goal of establishing best practices.¹¹ As of December 2016, the PCQN included 78 PC teams across 11 states in both academic and community hospitals entering patient-level data into the PCQN database.

Dataset

The PCQN dataset has previously been described in detail.¹¹ The 23-item PCQN core dataset documents patient characteristics, processes of care provided by PC teams, and patient-level outcomes. Patient characteristics include age, sex, primary diagnosis, and functional status assessed with the Palliative Performance Scale (PPS).¹⁰ Processes of care include reason(s) for the PC consult (e.g., advanced care planning [ACP],

pain management, comfort care). The primary diagnosis leading to the PC consult is recorded by checking 1 of 16 categories of diseases. The neurologic categories are neurologic/stroke/neurodegenerative and dementia. This distinction was made during the development phase of the PCQN as a result of the feedback from PC teams that patients with dementia had characteristics and needs that were distinct from those with other neurologic diseases, including a substantially older age. Patients with neurologic cancers are categorized as having cancer. Assessments by the PC teams for the PCQN dataset include information about care planning such as code status or presence of advance directives, presence and severity of patient-reported symptoms, and functional status assessed with the PPS score.¹² Symptoms include pain, dyspnea, nausea, and anxiety and are scored from 0 (none) to 3 (severe). Patients who are unable to self-report are given a 9 in the database. While clinicians assess and treat pain and discomfort in nonverbal patients, the clinician's subjective assessment was not included in the PCQN dataset. The PPS, scored 100% (normal activity, independent, and fully conscious) to 0% (death), is assessed for every patient. The PPS is a widely used tool for evaluating functional status across many conditions and can help assess prognosis and identify and track potential care needs of patients.^{12,13}

The data for this project include the records of patients who received PC consultation between January 1, 2013, and December 31, 2016.

Standard protocol approvals, registrations, and patient consents

This study was reviewed and approved by the University of California San Francisco Institutional Review Board (No. 16-18596). Medical record numbers are excluded from the dataset, and only aggregated data are reported, minimizing the risk of identifying individual patients. Because it represents an ongoing quality improvement project, patient consent was not required or obtained.

Data preparation and statistical analysis

Our primary goal was to compare clinical characteristics among patients who received PC consultation between those with neurologic disease and those with cancer because patients with cancer account for the highest percentage of patients who receive PC consultation. Using the PCQN identification, we therefore had 2 primary disease categories: patients with a primary diagnosis of neurologic/stroke/neurodegenerative disease and patients with a primary diagnosis of cancer (solid tumor). Because the focus of this study was on patients with neurologic disease overall, we decided not to include the group of patients with a primary diagnosis of dementia, who

had previously been identified as a distinct group. In an exploratory analysis, we examined certain characteristics in the dementia group to confirm and better understand the distinct features of this group.

Descriptive statistics, including frequencies and means (95% confidence interval [CI]), were used to examine the distribution of measures. We used χ^2 analysis to examine bivariate associations between categorical variables and analysis of variance to examine associations between categorical and continuous variables. A value of $\alpha \leq 0.05$ was used to determine statistical significance. We examined factors independently associated with patients with neurologic disease compared to those with cancer using multivariate logistic regression, adjusting for patient age, sex, referral location (critical care vs noncritical care), and PC team. The categorical variable of PC team was included in the model to adjust for potential variation among the PC teams across different hospitals. There was no adjustment or imputation for missing data. Analyses were performed only for patients for whom data were available for each specific data element, resulting in different n values for each analysis. The Statistical Package for the Social Sciences (SPSS Inc, Chicago, IL) for Mac (version 23) was used to conduct all analyses.

Data availability

PCQN data elements have been described previously.¹¹ PCQN member teams own their data and have access to them. Aggregated data for analysis are available only to members through the PCQN. Further information on these data is available on request from the authors.

Results

Patient characteristics

Primary diagnosis was documented for 70,655 PC consultations, of which 10.0% (n = 7,082) had neurologic disease and 33% (n = 23,296) had cancer. Over the years, the proportion of PC consultations for patients with neurologic disease remained stable ($p = 0.6$), while that for patients with cancer decreased (from 38% to 29%, $p < 0.0001$). Basic characteristics of these patients are listed in table 1. Overall, patients had a mean age of 71.8 (median = 74.0, range: 18–115) years; half of them were female (51.4%, n = 37,631); and 23.0% (n = 15,869) had advance directives documented at the time of PC consultation. The presence of advance directives suggests that a conversation about treatment values has taken place most likely before hospitalization. The main reason given by the referring providers for the initial PC consult was goals of care and ACP in three-quarters of patients with neurologic disease and in two-thirds of patients with cancer. The second most common reason for PC consultation was pain and other symptom management in patients with cancer (43.4% vs 13.7% in patients with neurologic disease) and assistance with transitioning to comfort measures only or withdrawal of life-sustaining treatment in patients with neurologic disease (19% vs 7.1% in patients with cancer). At the time of the PC

consultation, a larger proportion of patients with neurologic disease had a code status requesting “do not attempt resuscitation” (46.8%) compared to patients with cancer (34.1%) as distinct from advance directives.

In the subgroup of patients who had a pain assessment documented (total n = 24,012, 32.8%), most patients with neurologic disease were unable to report symptoms (64.5%) compared to only 1 in 5 (19.8%) patients with cancer. Among those able to report pain, moderate to severe pain was present in 15% of patients with neurologic disease compared to 41% of patients with cancer (33.2%). Patients with neurologic disease were in hospital 4.9 days before referral; patients with cancer, 3.8 days ($p < 0.0001$).

After adjustment for patient age, sex, referral location, and PC team, multivariate logistic regression (table 2) showed that patients with neurologic disease were 70% less likely to be referred to PC for symptom management (odds ratio [OR] 0.3, 95% CI 0.3–0.4), and 30% were more likely to be referred for transition to comfort measures only and withdrawal of life-sustaining treatment (OR 1.3, 95% CI 1.2–1.5), yet 20% were less likely to have discussions regarding hospice referral (OR 0.8, 95% CI 0.7–0.8).

Palliative Performance Scale

The mean PPS score at the time of PC consultation was 34.9% for all patients and lower among patients with neurologic disease (mean 23.4%) compared to those with cancer (mean 42.1%, table 1). Figure A illustrates the distribution of the PPS scores in patients who received PC consultation. The group of patients with neurologic disease is functionally more impaired than the group with cancer: two-thirds (68.5%) of patients with neurologic disease vs only 1 in 6 (16.9%) of patients with cancer have a PPS score ≤ 20 , meaning they are totally bed bound, require assistance with total care, and have minimal to no oral intake. After adjustment for patient age, sex, referral location, and PC team, patients with neurologic disease still had increased odds of having a PPS in the total care and totally bed bound category of 10% to 30% (OR 7.4, 95% CI 6.0–9.0, table 2). In addition, the mortality risk per PPS stage differs by disease category (figure B): while the majority (73%) of patients who die with neurologic disease do so at a PPS score of 10%, deaths in the cancer populations are more evenly distributed across the lower PPS scores (31% at PPS score of 10%, 20% at PPS score of 20%, 20% at PPS score of 30%, 15% at PPS score of 40%).

Hospital outcome

Overall, 77.5% (n = 54,171) of patients who received PC consultation were discharged alive. Patients with cancer were more likely ($p < 0.0001$) to be discharged alive (82.6%, 18,724 of 22,668) than patients with neurologic disease (69.0%, 4,724 of 6,844). Among survivors, patients with cancer were more likely ($p < 0.001$) to be discharged home (64.8%, 11,994 of 18,498) than those with neurologic disease

Table 1 Patient characteristics at time of referral to palliative care consultation by disease status

	Primary diagnosis		p Value
	Neurological (not dementia)	Cancer	
Age, n	7,082	23,296	
Mean (95% CI), y	75.4 (75.1–75.8)	65.4 (65.3, 65.6)	<0.0001
Female sex, n	7,087	23,309	<0.0001
% (n)	52.4 (3,716)	51.4 (11,978)	
Referral location, n	7,059	23,175	<0.0001
Medical/surgical, % (n)	28.2 (1,990)	55.6 (12,887)	
Critical care, % (n)	38.0 (2,682)	12.5 (2,894)	
Telemetry/stepdown, % (n)	22.7 (1,604)	19.5 (4,524)	
Other, % (n)	11.1 (783)	12.4 (2,870)	
Reason for referral, n	7,043	23,117	
GoC/ACP, % (n)	75.4 (5,313)	66.9 (15,472)	<0.0001
Symptom management, % (n)	13.7 (964)	43.4 (10,043)	<0.0001
Hospice referral/discussion, % (n)	17.4 (1,224)	18.7 (4,319)	<0.0001
CMO/withdrawal of LST, % (n)	19.0 (1,338)	7.1 (1,652)	<0.0001
Support for patient/family, n	7,045	23,123	
% (n)	23.1 (1,625)	20.2 (4,672)	<0.0001
Advance directives, n ^a	6,900	22,471	
% (n)	22.6 (1,562)	19.8 (4,442)	<0.0001
Code status, n ^a	6,888	22,696	<0.0001
Full, % (n)	45.6 (3,142)	61.5 (13,956)	
Partial, % (n)	7.6 (525)	4.4 (1,004)	
DNR/DNI, % (n)	46.8 (3,221)	34.1 (7,736)	
Symptom scores at first assessment			
Pain, n	5,265	18,747	<0.0001
Unable to report, % (n)	64.5% (3,393)	19.8% (3,705)	
Able to report, % (n)	1,872	15,042	
None, % (n)	68.2 (1,276)	36.6 (5,356)	
Mild, % (n)	16.4 (307)	23.0 (3,458)	
Moderate/severe, % (n)	15.4 (289)	41.4 (6,228)	
Anxiety, n	5,272	18,747	<0.0001

Table 1 Patient characteristics at time of referral to palliative care consultation by disease status (continued)

	Primary diagnosis		p Value
	Neurological (not dementia)	Cancer	
Unable to report, % (n)	67.4 (3,552)	25.4 (4,755)	
Able to report, % (n)	1,720	13,992	
None, % (n)	23.1 (1,217)	59.2 (8,286)	
Mild, % (n)	6.1 (319)	25.2 (3,520)	
Moderate/severe, % (n)	3.5 (184)	15.6 (2,186)	
Nausea, n	5,262	18,712	<0.0001
Unable to report, % (n)	65.9 (3,466)	21.1 (3,944)	
Able to report, % (n)	N = 1,796	N = 14,768	
None, % (n)	94.2 (1,691)	77.1 (11,391)	
Mild, % (n)	3.9 (70)	13.3 (1,971)	
Moderate/severe, % (n)	1.9 (35)	9.5 (1,406)	
Dyspnea, n	5,277	18,748	<0.0001
Unable to report, % (n)	65.2 (3,442)	20.8 (3,899)	
Able to report, % (n)	1,835	14,849	
None, % (n)	28.4 (1,499)	75.4 (11,189)	
Mild, % (n)	4.3 (227)	14.5 (2,158)	
Moderate/severe, % (n)	2.1 (109)	10.0 (1,493)	
PPS score, n	6,238	20,765	
Mean (95% CI)	23.4 (23.0–23.8)	42.1 (41.8, 42.3)	<0.0001

Abbreviations: ACP = advanced care planning; CI = confidence interval; CMO = comfort measures only; DNR/DNI = do not resuscitate/do not intubate; GoC = goals of care; LST = life-sustaining therapy; PPS = Palliative Performance Scale.

^a Presence of advance directives (AD) suggests that a patient has had a conversation, most likely before hospitalization, about future treatment preferences and/or a durable power of attorney. Distinct from AD, code status refers only to the level of medical interventions that will be done if the patient's heart or breathing stops.

(27.4%, 1,323 of 4,658), whereas patients with neurologic disease were more likely to be discharged to a long-term or extended-care facility (34.4%, 1,604 of 4,658) than those with cancer (15.7%, 2,913 of 18,498). Among patients discharged from the hospital, there was no difference ($\chi^2 = 0.2, p = 0.6$) in hospice referral between patients with neurologic disease (38.5%, 1,613 of 4,187) and those with cancer (38.9%, 6,768 of 17,381).

Table 2 Logistic regression examining characteristics associated with patients referred to PC with neurologic illnesses compared to those with cancer with cancer as the reference

Characteristics	Adjusted OR for patients with neurologic disease (95% CI) ^a	p Value
Reason for referral		
GoC/ACP	1.1 (1.0–1.2)	0.04
Management of pain and other symptoms	0.3 (0.2–0.3)	<0.0001
Hospice referral discussion	0.8 (0.7–0.8)	<0.0001
CMO/withdrawal of intervention	2.4 (2.1–2.8)	<0.0001
Support for patient/family	1.1 (1.0–1.2)	0.01
PPS score, %		
70–100	1.0	
40–60	1.5 (1.2–1.8)	0.0001
10–30	7.4 (6.0–9.0)	<0.0001

Abbreviation: ACP = advanced care planning; CI = confidence interval; CMO = Comfort Measures only; GoC = goals of care; OR = odds ratio; PC = palliative care; PPS = Palliative Performance Scale.

^a Adjusted for age, sex, referral location, and PC teams.

Discussion

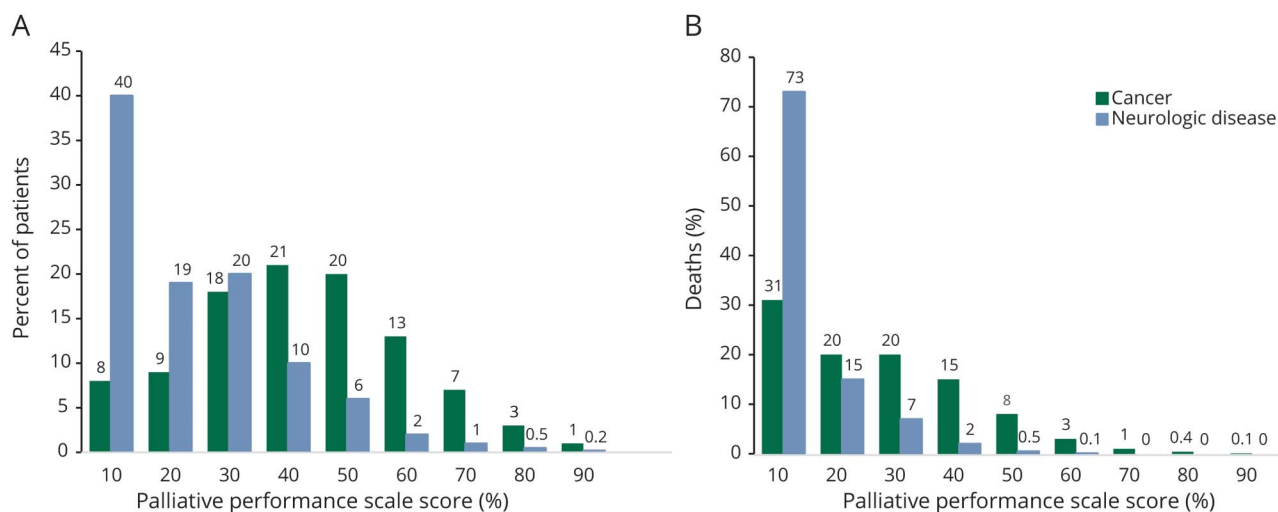
The large, prospective PCQN dataset provides a unique opportunity to undertake an in-depth comparison between hospitalized patients with neurologic disease and patients with cancer who were referred for PC consultation. While ACP and

goals-of-care discussions represented the most common reason for PC consultation and only 1 in 5 patients had advance directives in both disease categories, we found substantial variation in the illness severity at the time of PC consultation, the need for symptom management, and end-of-life care planning.

Effective communication about goals of care is fundamental in the care of all patients with a serious illness. Discussing the patient's goals and values is a specific skill that all clinicians need to learn, and a hospitalization represents an important opportunity and need to engage in such a conversation.¹⁴ This need may be especially true for hospitalized patients with neurologic disease, who, compared to patients with cancer, were more commonly referred to PC for transitions to comfort measures only and withdrawal of life-sustaining treatment and had a higher in-hospital mortality. This finding is consistent with previous studies suggesting that most in-hospital deaths in patients with neurologic disease occur after a decision is made to withdraw life-sustaining treatment.^{15–19}

While addressing goals of care is a core skill for PC specialists, our findings highlight the importance of skilled communication for neurologists, especially concerning prognosis and end-of-life treatment decisions, as well as hospital-based social and family support. Teaching effective communication to clinicians and trainees is finally finding its way into medical schools and residencies across the United States,^{20–22} yet many still feel uncomfortable having potentially emotionally charged conversations with patients or families about their treatment options.²³ Because neurologists care for many patients with serious illness in the inpatient and outpatient settings, we need to prioritize efforts to teach communication skills to neurology trainees and research to help us adjust what we know to be

Figure PPS scores among patients with neurologic disease vs those with cancer and proportion of deaths by PPS score



(A) Distribution of Palliative Performance Scale (PPS) scores among patients with neurologic disease and patients with cancer who received a palliative care (PC) consultation. (B) Percentage of deaths for each PPS score, as assessed at time of PC consultation, for patients with cancer vs those with neurologic disease who died during hospitalization.

effective for communicating with patients with cancer to match the challenges we face for patients with neurologic disease.²⁴

Overall, we found that hospitalized patients with neurologic disease seen by PC teams are sicker compared to those hospitalized with cancer. They had lower PPS scores, were more likely to be in the intensive care unit, and had a higher mortality. This observation may be driven by a higher proportion of acute, devastating conditions in the group of patients with neurologic diseases compared to those with cancer, although our data do not allow this distinction. For patients with acute neurologic injuries such as stroke or other acute brain injury, engagement with PC teams at a point of high mortality and critical illness would be expected because most of these patients were unlikely to be seriously ill before the acute event. However, for patients with progressive neurologic illness such as amyotrophic lateral sclerosis, Parkinson disease, or multiple sclerosis, late engagement with PC teams in the intensive care unit represents a missed opportunity to clarify goals of care and potentially to avoid unwanted intensive care and death in the hospital. Additional specificity about the exact neurologic condition would help to distinguish between these patient populations and would be a useful data point for the PCQN and other quality measurement and improvement collaboratives to collect. Such information would help PC teams better target interventions, especially in the outpatient setting.

Pain management and symptom management have been important considerations in the PC approach and a cornerstone of PC training and education, making up almost half of the content of the current hospice and palliative medicine board examinations (45%).²⁵ Our study found that pain and symptom management was a reason for PC consultations in only 1 in 7 patients with neurologic disease, although the vast majority of patients with neurologic disease overall were unable to verbally report their pain. Patients with neurologic impairment are at high risk for undertreatment of symptoms due to cognitive or communication impairment. For example, patients with aphasia are less likely to receive pain medications, both scheduled and as needed, than patients with intact language.²⁶ Given the potential challenges to verbal communication, clinicians must stay alert to potential pain, and special attention should be paid to nonverbal signs of discomfort when caring for patients with neurologic disease.^{27,28}

Finally, our findings question the use of the PPS score to predict mortality in patients with neurologic disease: The PPS score is designed in part to provide prognostic information, with lower scores indicating a higher mortality. While patients with neurologic disorders had both a lower mean PPS score and an overall higher inpatient mortality, with any given PPS score, patients with neurologic disorders had a lower mortality than their counterparts with cancer, except for those with a PPS score of 10%. The higher mortality in the group of patients with neurologic disease and a PPS of 10% may be due to a large proportion of patients with severe acute brain injury, although this information is not available from the dataset.

The discrepancy found between the actual mortality of patients with neurologic disease and patients with cancer with the same PPS scores suggests that the PPS may overestimate mortality among patients with neurologic disease.

Interpretation of our findings should be tempered by the following limitations, some of which have been described previously.^{29–31} First, data were collected by interdisciplinary PC teams prospectively in the course of patient care. The advantage of this approach is that the data directly reflect the teams' process of care rather than their chart documentation. For such an approach to be clinically feasible, the PCQN dataset can include only data elements that are considered to be useful for ongoing clinical care, quality reporting, and improvement. Second, for this reason, the PCQN dataset collects categorical diagnostic groups and does not specify individual diagnoses. The benefit of this standardized method is that it allows aggregation of data and comparisons across PC teams. The limitation is that it does not allow finer distinctions between diagnostic groups. This limitation is true for neurologic diseases and for cancer because the PCQN dataset does not include data on location and stage of cancer. Given these limitations, it is possible that PCQN teams may choose to collect more detailed, standardized diagnosis information, at least for a limited period of time, to explore differences between patients within the same broader category of diagnosis. The group that we focused on in this study was therefore a somewhat heterogeneous group of both chronic and acute neurologic illnesses and therefore the conclusions are about patients with neurologic disease overall. Third, to focus on our primary research question and to simplify the analysis and reporting of our findings, we limited our analysis to neurologic illness and excluded patients with dementia. Our exploratory analysis of the cohort with dementia confirmed that this cohort differs significantly from those analyzed here in a variety of characteristics (e.g., median age 85 years [95% CI 85.2–85.8]; referral from critical care unit in 8%; code status do not resuscitate/do not intubate in 62%; all $p < 0.05$ compared to patients with neurologic disease and cancer). Fourth, our dataset did not provide information on the type of medical team that referred the patient to PC. It is therefore not clear what proportion of patients with neurologic disease who received a PC consultation were actually cared for by neurologists. Finally, the dataset includes only those patients who underwent PC consultation. Because we are unable to compare this cohort to patients who did not receive PC consultation, we cannot identify specific predictors for PC consultation. The availability of data from a large number of PC teams across the United States and the standardization of data collection provide a broader and deeper picture of hospitalized patients cared for by PC teams and allow analysis of a cohort of patients that would be impossible at any 1 site or even small group of sites over many years. Given the large sample size in our study, we used caution in interpreting the results because statistical significance may not translate to clinical relevance.

The large number of PC consultations across multiple hospitals and regions in the United States adds substantial evidence to

the literature about this important cohort of PC consultations for patients with neurologic disease. The unique characteristics of patients with these conditions call for continued research to determine the best ways to meet the PC needs of patients with neurologic disease and to refine the neuropalliative care approach. Such research endeavors need to include both quantitative and qualitative studies (1) to determine the needs and characteristics of patients with individual diseases, including a more specific distinction between patients with acute and chronic neurologic diseases; (2) to determine needs specific to the clinician teams who are consulting PC such as neurology, medicine, or different intensive care units because this specification would help target educational or hospital policy-based interventions; (3) to better assess pain and discomfort through reliable, nonverbal methods that are ideally not dependent on the clinician because different clinicians may rate the same symptoms differently; and (4) to examine disease-specific severity scales and how they may be more appropriately used than the PPS for neurologic diseases for prognosis, needs assessment, or hospice eligibility.

Author contributions

B.L. Taylor: drafting of the manuscript, critical revision of the manuscript for important intellectual content. D.L. O’Riordan: study design and data collection, data analysis, statistical analysis, critical revision of the manuscript for important intellectual content. S.Z. Pantilat: study design and data collection, critical revision of the manuscript for important intellectual content. C.J. Creutzfeldt: study design and concept, critical revision of the manuscript for important intellectual content.

Study funding

We acknowledge the foundations that have generously supported the PCQN, including the California HealthCare Foundation, the UniHealth Foundation, the Archstone Foundation, the Kettering Family Foundation, the James Irvine Foundation, and the Stupski Foundation.

Disclosure

B. Taylor, D. O’Riordan, and S. Pantilat report no disclosures relevant to the manuscript. C. Creutzfeldt receives funding from the NIH–National Institutes of Neurological Disease and Stroke (K23 NS099421). Go to Neurology.org/N for full disclosures.

Publication history

Received by *Neurology* July 29, 2018. Accepted in final form January 3, 2019.

References

- Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014;383:1721–1730.

- Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA* 2009;302:741–749.
- Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733–742.
- Rogers JG, Patel CB, Mentz RJ, et al. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol* 2017;70:331–341.
- Center to Advance Palliative Care CAPC. America’s care of serious illness. 2015. Available at: reportcard.capc.org/. Accessed January 1, 2018.
- Chahine LM, Malik B, Davis M. Palliative care needs of patients with neurologic or neurosurgical conditions. *Eur J Neurol* 2008;15:1265–1272.
- Liu Y, Kline D, Aerts S, et al. Inpatient palliative care for neurological disorders: lessons from a large retrospective series. *J Palliat Med* 2017;20:59–64.
- Weatherall MW. Acute neurology in a twenty-first century district general hospital. *J R Coll Physicians Edinb* 2006;36:196–200.
- Sleeman KE, Ho YK, Verne J, et al. Place of death, and its relation with underlying cause of death, in Parkinson’s disease, motor neurone disease, and multiple sclerosis: a population-based study. *Palliat Med* 2013;27:840–846.
- Robinson MT, Vickrey BG, Holloway RG, et al. The lack of documentation of preferences in a cohort of adults who died after ischemic stroke. *Neurology* 2016;86:2056–2062.
- Pantilat SZ, Marks AK, Bischoff KE, Bragg AR, O’Riordan DL. The Palliative Care Quality Network: improving the quality of caring. *J Palliat Med* 2017;20:862–868.
- Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): a new tool. *J Palliat Care* 1996;12:5–11.
- Lau F, Downing M, Lesperance M, Karlson N, Kuziemyk C, Yang J. Using the Palliative Performance Scale to provide meaningful survival estimates. *J Pain Symptom Manage* 2009;38:134–144.
- You JJ, Fowler RA, Heyland DK; Canadian Researchers at the End of Life Network (CARENET). Just ask: discussing goals of care with patients in hospital with serious illness. *CMAJ* 2014;186:425–432.
- Creutzfeldt CJ, Engelberg RA, Healey L, et al. Palliative care needs in the neuro-ICU. *Crit Care Med* 2015;43:1677–1684.
- Frontera JA, Curtis JR, Nelson JE, et al. Integrating palliative care into the care of neurocritically ill patients: a report from the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care. *Crit Care Med* 2015;43:1964–1977.
- Zurasky JA, Aiyagari V, Zazulia AR, Shackelford A, Diringner MN. Early mortality following spontaneous intracerebral hemorrhage. *Neurology* 2005;64:725–727.
- Turgeon AF, Lauzier F, Simard JF, et al. Mortality associated with withdrawal of life-sustaining therapy for patients with severe traumatic brain injury: a Canadian multicentre cohort study. *CMAJ* 2011;183:1581–1588.
- Creutzfeldt CJ, Wunsch H, Curtis JR, Hua M. Prevalence and outcomes of patients meeting palliative care consultation triggers in neurological intensive care units. *Neurocrit Care* 2015;23:14–21.
- Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014;174:1994–2003.
- VitalTalk. 2018. Available at: vitaltalk.org/courses/. Accessed April 2, 2018.
- Center to Advance Palliative Care CAPC. Communication Skills Curriculum. 2018. Available at: capc.org/providers/courses/communication-skills-34/. Accessed April 30, 2018.
- Schmit JM, Meyer LE, Duff JM, Dai Y, Zou F, Close JL. Perspectives on death and dying: a study of resident comfort with end-of-life care. *BMC Med Educ* 2016;16:297.
- Creutzfeldt CJ, Kluger B, Kelly AG, et al. Neuropalliative care: priorities to move the field forward. *Neurology* 2018, 91:217–226.
- American Board of Internal Medicine. Hospice and Palliative Medicine Certification Examination Blueprint. 2018. Available at: abim.org/~media/ABIM Public/Files/pdf/exam-blueprints/certification/hospice-palliative-medicine.pdf. Accessed March 15, 2018.
- Kehayia E, Korner-Bitensky N, Singer F, et al. Differences in pain medication use in stroke patients with aphasia and without aphasia. *Stroke* 1997;28:1867–1870.
- Gélinas C, Puntillo KA, Levin P, Azoulay E. The Behavior Pain Assessment Tool for critically ill adults: a validation study in 28 countries. *Pain* 2017;158:811–821.
- McGuire DB, Kaiser KS, Haisfield-Wolfe ME, Iyamu F. Pain assessment in non-communicative adult palliative care patients. *Nurs Clin North Am* 2016;51:397–431.
- Bischoff K, O’Riordan DL, Marks AK, Sudore R, Pantilat SZ. Care planning for inpatients referred for palliative care consultation. *JAMA Intern Med* 2018;178:48–54.
- Bischoff KE, O’Riordan DL, Fazzalero K, Kinderman A, Pantilat SZ. Identifying opportunities to improve pain among patients with serious illness. *J Pain Symptom Manage* 2018;55:881–889.
- Grubbs V, O’Riordan D, Pantilat S. Characteristics and outcomes of in-hospital palliative care consultation among patients with renal disease versus other serious illnesses. *Clin J Am Soc Nephrol* 2017;12:1085–1089.