



HHS Public Access

Author manuscript

J Pain Symptom Manage. Author manuscript; available in PMC 2023 May 01.

Published in final edited form as:

J Pain Symptom Manage. 2022 May ; 63(5): 721–728. doi:10.1016/j.jpainsymman.2021.12.032.

Palliative and End-of-Life Care After Severe Stroke

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Abstract

Background and Objectives: The distinct illness trajectory after acute ischemic stroke demands a better understanding of the utilization of palliative care consultations (PCC) for this patient cohort. This study sought to determine the prevalence, predictors, and outcomes associated with PCC for patients hospitalized with severe ischemic stroke.

Methods: This multicenter cohort study was conducted at four hospitals (2 comprehensive and 2 primary stroke centers) between 01/2016 and 12/2019. We included all patients with a discharge diagnosis of ischemic stroke and an initial National Institutes of Health Stroke Scale (NIHSS) of 10 or greater. We compared patient sociodemographic, clinical and care characteristics as well as hospital outcomes between patients who did and did not receive PCC.

Results: The study included 1297 patients hospitalized with severe ischemic stroke. PCC occurred for 20% of all patients and this proportion varied across institutions from 11.9% to 43%. Less than half (43%) of patients who died in the hospital. In multivariable analysis, PCC was less likely in female patients (OR .76, 95% CI .59, .99, $p=.04$) but more likely in patients with higher NIHSS (OR 1.95, 95% CI 1.13, 3.37, $p=.02$). Patients with PCC had higher rates of moving to a plan focused on comfort measures (CMO) ($p < .01$) and removal of artificial nutrition as part of a move to CMO ($p < .01$). In a sub analysis of patients who died in the hospital and received PCC, patients who died on or before hospital day 3 were less likely to receive PCC than patients who died on or after hospital day 4 (24% v. 51%) ($p < .01$).

Conclusions: Most patients with severe stroke do not receive PCC, even among those who experience in-hospital death. The results of this study indicate there are missed opportunities for PCC to help reduce suffering after severe stroke.

Background

Stroke is a leading cause of mortality in the United States resulting in one death every four minutes (1). Among patients who experience a nonfatal stroke, the risk of all-cause mortality at 28 days, 1 year, and 5 years after stroke is 28%, 41%, and 60%, equating to an almost 5-fold increase in risk of death compared with the general population (2). Of the 795,000 strokes that occur each year, nearly 1 in 4 occur in people who have had a previous stroke (1). As the population ages, stroke prevalence, and mortality could potentially double (3). Patients who survive severe strokes have high levels of disability due to impaired cognitive and physical function (3–5). Given the high morbidity and mortality after stroke, the acuteness of stroke onset, and the difficult decisions about goals of care, use of life sustaining treatments, and end of life care, patients with stroke and their families may benefit from palliative care (6–9). However, the distinct illness trajectory of stroke, including the sudden onset, physical and cognitive disabilities and uncertain prognosis, suggest the possible need for a distinct approach to palliative care after stroke; perhaps specifically one that moves away from the traditional, historic approaches that were developed in a cancer setting (7, 10).

Palliative care is medical care for patients living with serious illness which focuses on improving the quality of life for patients and their caregivers, providing care that is consistent with preferences, and addressing pain and symptom relief (11). Additionally, palliative care focuses on social, emotional, and spiritual support. Palliative care may be provided with an increasing emphasis on comfort measures as illness progresses; when curative treatment is no longer a possibility, patients may transition to hospice. Palliative care may be provided by the patient's primary medical team (primary palliative care) or, in cases where the needs of patients or their families are more complex or difficult, specialty palliative care clinicians may be consulted (12).

In disease courses such as heart failure and cancer, palliative care interventions, including care provided by specialty trained palliative care physicians and nurses, may improve certain aspects of patient care such as quality of life, mood, and healthcare utilization (13–16). Although use of palliative care specialists is established in some life threatening and life ending diseases, little is known about optimal integration of palliative care specialists among the stroke population (4, 17–18). Additionally, few studies have explored the landscape of palliative care use among patients hospitalized for severe stroke (3,6,19–22). The need for further studies regarding palliative care after severe stroke was emphasized in an American Heart Association statement on palliative care and end-of-life care after stroke in 2014 (3). This study sought to fill gaps in the literature by describing the characteristics, predictors and current practice of palliative care consultation as well as outcomes associated with palliative care consultation among patients hospitalized with severe stroke.

Methods

Study Design and Population

We conducted a retrospective multicenter cohort study of patients suffering severe stroke between January 1, 2016 and December 31, 2019 at four hospitals in one city in the Midwestern United States, including a 1262-bed teaching hospital with a comprehensive stroke center certification, a 825-bed comprehensive stroke center, a 462-bed primary stroke center, and a 315-bed safety-net hospital with a primary stroke center certification. Stroke center certification denotes shown ability to deliver appropriate clinical rapid stroke assessment and care. At the time of data collection, three of the four hospitals offered thrombectomy. All hospitals admitted patients to the hospitalist team and utilized neurologists as consultants during stroke care delivery. Additionally, all hospitals had inpatient PCC services and none had a standard or protocol regarding when to consult palliative care. Institutional Review Board approval was obtained from Indiana University.

Eligible patients were identified by the clinical stroke coordinator, a specialized stroke nurse at each hospital. We included all patients with a severe ischemic stroke defined by: (1) a discharge diagnosis of ischemic stroke as identified by International Classification of Diseases, 10th Revision codes; and (2) an initial National Institutes of Stroke Scale Score (NIHSS) of 10 or greater. Patients with a discharge diagnosis of intracranial hemorrhage (ICH) were excluded, as were patients with a discharge diagnosis of transient ischemic attack (TIA) or ischemic stroke with an NIHSS of 9 or lower. Patients with ICH were excluded as ICH is distinct from ischemic stroke and this study focuses on one disease.

Outcome Measures

A standardized chart review tool was designed by the research team to collect patient information from the electronic medical record (EMR) including: 1) demographics (age, gender, race, ethnicity); 2) clinical characteristics (history of prior stroke, NIHSS score on admission, receipt of tissue plasminogen activator (tPA), thrombectomy, intensive care unit (ICU) utilization, mechanical ventilation); 3) palliative care specialist consultation (PCC); and 4) patient outcomes (length of hospital stay, use of a percutaneous gastrostomy feeding tube (PEG Tube) or tracheostomy, a change in code status, transition to comfort measures only, in-hospital mortality, hospice consultation). Patient race and ethnicity were collected because prior studies have shown differential use of palliative care in stroke care between races and ethnicities (21). Sixteen chart reviewers were trained in data abstraction and a kappa statistic was performed on twenty charts. The minimum of 80% agreement was met in order to ensure interrater reliability among chart reviewers. Data was deidentified upon extraction from the EMR and collected and stored in a REDCap database (23).

Statistical Analysis

Descriptive analysis was conducted to determine the prevalence of palliative care consultations following acute severe stroke. Logistic regression was conducted to describe patient and clinical characteristics associated with a palliative care consultation after severe ischemic stroke. Additionally, bivariate analysis was conducted to determine patient and clinical characteristics associated with early PCC (defined as PCC on or before hospital day 3) and late PCC (defined as PCC on or after hospital day 4). Outcomes associated with palliative care consultation after severe stroke, as well as outcomes associated with early and late PCC were analyzed using chi square analysis. Hospital location was adjusted for in this analysis, using hospital as a random effect. This allowed for the effect of hospital to be accounted for in the model, while understanding that the included hospitals are a random sample of possible hospitals. Multivariable analysis with receipt of PCC as the dependent variable was conducted using all variables from the bivariate analysis with a p-value .20 as well as variables selected a-priori including age, gender, and race. All statistical tests were performed using SAS Version 9.0 (Cary, North Carolina).

Results

Baseline Characteristics

The study included 1297 patients hospitalized with severe ischemic stroke (Table 1). The patients were 54% female, 81% white, and had a median age of 70 years old. The median NIHSS was 17. One in three (501, 39%) patients had a history of prior stroke. One-third of patients received intravenous (tPA) (n=430, 33%) and/ or mechanical thrombectomy (n=405, 32%), and 17% received both tPA and mechanical thrombectomy (n=223).

Characteristics of Patients with Palliative Care Specialist Consultation

Palliative care specialist consultation (PCC) was received by 20% (256) of patients (Table 2). The proportion of PCC varied across the four institutions from 11.9% of patients suffering severe stroke receiving palliative care to 43% of patients. At the time of PCC, 66%

(170) of patients were in the ICU, 31% (78) were receiving mechanical ventilation, and 2% (6) were receiving dialysis. Setting goals of care was indicated as the primary reason for the PCC (239, 93%). Median time from hospital admission to PCC was 4 days (IQR: 2–7), and PCCs were most frequently placed early during the hospitalization (39% occurring on or by hospital day 2) with declining frequency on each successive day (Figure 1). Approximately 25% of PCC occurred on or after hospital day 7. Among those who died in-hospital, the median day between PCC and death was 4 days (Table 2).

In bivariate analysis, compared to patients with stroke who did not receive PCC, those who received PCC were older (mean age 81 years vs. 68), had a higher mean NIHSS score (20 vs. 17), and had less often received tPA (13% vs. 87%) or thrombectomy (12% vs. 88%) (Table 3). After adjusting for potential confounders in multivariable analysis, only higher NIHSS (OR 2.17) and female gender (OR 0.76) remained significantly associated with PCC. Receipt of tPA or thrombectomy were no longer associated with PCC. We found no significant difference in race between patients receiving PCC and those not (Table 3).

Characteristics of Patients with Early versus Late Palliative Care Specialist Consultation

In bivariate analysis, compared to patients who received late PCC, those who received early PCC were more often female (54% v. 41% male), were older (mean age 85 years vs. 77) and less often received tPA or thrombectomy (Table 3). After multivariable analysis, only thrombectomy remained independently associated with the timing of PCC (OR 3.56 for patients receiving late compared to early PCC, $p < 0.01$) (Table 3).

Palliative Care Specialist Consultation and Outcomes

During the index hospitalization, 16% (212) of patients died and 186 of those (88%) died in the setting of comfort measures only (Table 4). In bivariate analysis, compared to patients who did not receive a PCC, patients with PCC were more likely to receive hospice consultation ($p < .01$); to be moved to comfort measures only (CMO) ($p < .01$); and undergo removal of artificial nutrition as part of a move to CMO ($p < .01$) (Table 4). PCC was also associated with longer length of hospital stay ($p < .01$), and longer ICU stay ($p < .01$).

PCC was associated with patients not dying in the hospital ($p < .01$) and with being discharged to hospice (either in-patient, $p < .01$ or home, $p < .01$). Compared to patients who received late PCC, patients who received early PCC were more likely to receive hospice consultation (58% v. 43%) ($p = .04$) (Table 4). In a sub analysis of patients who died in the hospital and received PCC, patients who died on or before hospital 3 were less likely to receive PCC than patients who died on or after hospital day 4 (24% v. 51%) ($p < .01$).

Compared to early PCC, late PCC was associated with tracheostomy utilization among patients who received PCC and tracheostomy (0% early v. 100% late) ($p < .01$) (Table 4). Among patients who received PEG Tube and PCC, late PCC was associated with PEG Tube (72% late PCC v. 28% early PCC) ($p < .01$) (Table 4). Among patients in the ICU who received PCC, the mean length of stay in the ICU for patients who received early PCC was 3 days, compared to 7 days for patients who received late PCC ($p < .01$) (Table 4).

Discussion

In this large multi-center retrospective study, palliative care specialists were consulted for one in five patients after severe stroke with a wide variation across hospitals. Palliative care consultation was associated with greater stroke severity, suggesting it is often reserved for the sickest patients. However, there may have been missed opportunities for PCC. Patients who had disability severe enough to require a percutaneous feeding were no more likely to receive a PCC, and among those patients, fewer than one in four received a PCC. PCC was significantly associated with use of tracheostomy for long-term ventilator support, but was still only received in fewer than half of cases. Patients and families with feeding or respiratory difficulties may have high distress and could benefit from PCC. Also, patients with severe stroke may benefit from PCC directed goals of care decisions when considering these interventions. Goals of care conversations include discussions related to the patient's values, goals, and treatment preferences (25). The variability in PCC consultation among our four hospitals suggests a lack of standardization of who receives PCC after severe stroke.

This study also found that PCC was overwhelmingly consulted regarding setting goals of care. Goals of care conversations should be a core competency for all neurologist who treat stroke patients (26). More research is needed on the quality of these conversations and the role of medical documentation for its assessment. Given the high hospital mortality of this patient group and the difficulty in accurate and consistent prediction of recovery early on, PCC may be appropriate to help patients set goals of care regarding interventions during the hospitalization (26–30). Evidence from the cancer literature suggests that having goals of care conversations early may help patients avoid the unwanted use of aggressive interventions and suffering at end-of-life (31–34). Although early goals of care conversations are optimal, approximately 25% of PCC occurred on or after hospital day 7 in this patient population suggesting the potential need for earlier PCC to set goals of care with patients suffering severe stroke.

After severe stroke, patients with a higher NIHSS who did not receive either tPA and/or thrombectomy had the highest prevalence of PCC. This occurred even when adjusting for decompensation within the first 48 hours of hospital admission. It is likely that the non-receipt of these evidence-based interventions is a marker of worse outcome and possibly more palliative care needs. Conversely, patients who receive tPA and thrombectomy may be less likely to receive PCC because once aggressive care has been initiated, patients, families, and clinicians may wish to give the patient more time to recover.

The majority of PCC occurred early; however, there was a substantial number (25%) of patients who received PCC late in their hospitalization. Among those with PCC, late consultation was associated with receipt of tPA, which may have been because of early hopes for recovery that were not met. Patients who died late during the hospitalization were five times more likely to receive PCC than patients who died early. In essence, the data shows that patients are either admitted with an apparent poor prognosis and receive PCC upon admission, or after some time in the hospital, they decline or do not show signs of recovery and receive PCC.

Limitations

This study has several limitations. First, the chart review was conducted at hospitals in one city and therefore, may not fully represent the practices in other regions or hospital settings. However, these hospitals do represent two different levels of stroke care, and differ in the presence of trainees. Second, due to the retrospective design of this study, the causal relationship between PCC and important outcomes cannot be assessed and should be explored in future prospective studies. One possibility for variation between hospitals is the structure of the palliative care services. Future research with prospective observations in a larger number of participating sites needs to be done to investigate these differences, potentially using mixed methods including interviews with practitioners and patient family members.

Conclusions

The proportion of patients who receive PCC varies widely across hospitals, suggesting there may be missed opportunities to provide palliative care support after severe stroke. Importantly, low rate of PCC, does not in and of itself necessarily mean a low rate of people being managed with appropriate palliative care principles as patients may have been managed using palliative care skills by stroke staff without the requirement for PCC. Interventions may be useful that promote PCC through the use of prompts, such as a checklist or trigger protocol for identifying situations when a PCC consultation may be valuable and promoting consultation earlier in the hospital course (7). There may be more opportunities for through both neurologists and PCC to optimize setting goals of care and to help reduce suffering after severe stroke. More research is needed to identify areas of missed opportunity to better determine the timing and role of PCC after severe stroke.

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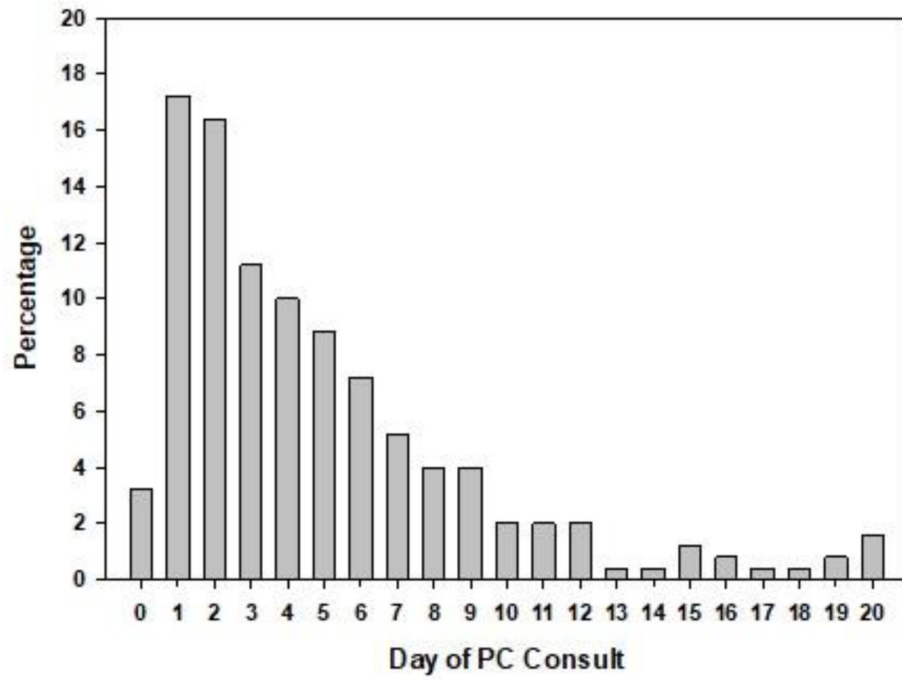


Figure 1.
Day of initial palliative care consultation and length of Hospital stay

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Table 1.

Patient Demographic and Clinical Characteristics

	All Patients (n=1297)
Gender	
Female	698 (53.9)
Male	597 (46.1)
Age	70.1 (58.1, 82.0)
Race	
White	1046 (81.2)
Black	192 (14.9)
Other/ Unknown	51 (4.0)
NIHSS (categorical)	
10 – 20	848 (65.4)
>=21	449 (34.6)
Prior CVA/TIA	
First Stroke (no prior)	789 (61.2)
Secondary Stroke (yes prior)	501 (38.8)
tPA	
Yes	430 (33.3)
No	863 (66.7)
Thrombectomy	
Yes	405 (31.6)
No	878 (68.4)

Table 2.

Palliative Care Utilization Following Acute Severe Stroke

	All Hospitals n (%)	Hospital 1 (n=106)	Hospital 2 (n=210)	Hospital 3 (n=563)	Hospital 4 (n=418)
Palliative care consultation	256 (19.7)	32 (30.2)	91 (43.3)	84 (14.9)	49 (11.7)
Median number of days between PCC and death	4 (2, 11); 125/256	9 (2, 53)	5 (1.5, 15)	3 (2, 6.5)	2 (1, 4)
Service ordering palliative care consultation					
Internal medicine	192 (77.4)	30 (100)	80 (87.9)	69 (86.3)	13 (27.7)
Neurology	43 (17.3)	0 (0)	5 (5.5)	7 (8.8)	31 (66.0)
Other	13 (5.2)	0 (0)	6 (6.6)	4 (5.0)	3 (6.4)
Reason for palliative care consultation					
Communication	20 (7.8)	0 (0)	2 (2.2)	2 (2.4)	16 (32.7)
Goals of care	239 (93.4)	30 (93.8)	86 (94.5)	77 (91.7)	46 (93.9)
Pain	3 (1.2)	0 (0)	1 (1.1)	1 (1.2)	1 (2.0)
Code status	53 (20.7)	3 (9.4)	28 (30.8)	5 (6.0)	17 (34.7)
Other	41 (16.0)	5 (15.6)	19 (20.9)	13 (15.5)	4 (8.2)
ICU Utilization at the time of PCC	170 (66.4)	28 (87.5)	48 (52.8)	66 (78.6)	28 (57.1)
Mechanical Ventilation at the time of PCC	78 (30.6)	15 (46.9)	14 (15.4)	33 (39.8)	16 (32.7)
Median days on vent	5 (2.5, 10)	11 (3, 15)	3.5 (2, 7)	4 (2, 8)	5 (3, 8.5)
Dialysis at time of PCC	6 (2.3)	0 (0)	2 (2.2)	2 (2.4)	2 (4.1)
Median (IQR) number of days until PCC from admission	4 (2, 7)	4.5 (2, 7)	2 (1, 4)	4 (2, 8)	6.5 (3, 10.5)

Table 3.

Bivariate and Multivariate Patient Characteristics Associated with Palliative Care Consultation after Severe Stroke

	No Palliative Care Consult (n=1041)*	Palliative Care Consult (n=256)*	p-value	Multivariate analysis Odds Ratio 95% CI p-value	Early PCC (n=125)	Late PCC (n=130)	p-value	Multivariate analysis Odds Ratio 95% CI p-value
Gender								
Female	548 (78.5)	150 (21.5)	.09	0.76 (0.59,0.99); p=.0419	82 (54.7)	68 (45.3)	.03	1.60 (0.91, 2.83); p=.1036
Male	491 (82.2)	106 (17.8)		reference	43 (41.0)	62 (59.1)		Reference
Age	67.6 (57.1,78.)	81.3 (67.1,88.6)	<.01	0.99 (0.99,1.00); p=.0773	84.8 (72.2, 90.1)	77.4 (63.8, 86.2)	<.00	1.02 (1.00, 1.04); p=.0728
Race							.67	
White	833 (79.6)	213 (20.4)	.38	Reference	107 (50.2)	106 (49.8)		Reference
Black	161 (83.9)	31 (16.2)		0.80 (0.55,1.16); p=.4837	13 (41.9)	18 (58.1)		0.67 (0.28, 1.61); p=.3284
Other/Unknown	40 (78.4)	11 (21.6)		0.90 (0.46,1.78); p=.9772	5 (45.5)	6 (54.6)		1.30 (0.32, 5.25); p=.5250
NIHSS (categorical)								
10 – 20	719 (84.8)	129 (15.2)	<.01	Reference	59 (45.7)	70 (54.3)	.29	Reference
>=21	322 (71.7)	127 (28.3)		2.17 (1.60,2.94); p<.0001	66 (52.4)	60 (47.6)		1.51 (0.88, 2.59); p=.1320
Prior CVA/TIA								
First Stroke (no prior)	639 (81.0)	150 (19.0)	.50	Reference	75 (50.3)	74 (49.7)	.56	Reference
Secondary Stroke (yes prior)	398 (79.4)	103 (20.6)		0.81 (0.2, 1.08); p=.1484	48 (46.6)	55 (53.4)		0.99 (0.57, 1.72); p=.9718
tPA								
Yes	376 (87.4)	54 (12.6)	<.01	1.07 (0.81,1.43); p=.6228	21 (38.9)	33 (61.1)	.09	1.21 (0.60, 2.44); p=.6016
No	661 (76.6)	202 (78.9)			104 (51.7)	97 (48.3)		
Thrombectomy								
Yes	355 (87.7)	50 (12.4)	<.01	1.00 (0.74,1.34); p=.9828	12 (24.5)	37 (75.5)	<.01	3.56 (1.65, 7.66); p=.0012
No	674 (76.8)	204 (23.2)			111 (54.4)	93 (45.6)		

Table 4.

Outcomes associated with Palliative Care Consultation after severe stroke

	All Patients (n=1297)	No Palliative Care Consult (n=1041)	Palliative Care Consult (n=256)	p- value	Early PCC (n=125)	Late PCC (n=130)	p- value
In Hospital Mortality	212 (16.4)	121 (57.1) 11.7%	91 (42.9) 35.8%	<.01	43 (47.8) 34.7%	47 (52.2) 36.4%	.77
Hospice Consultation	155 (12.0)	61 (39.4) 5.9%	94 (60.7) 36.7%	<.01	54 (57.5) 43.2%	40 (42.6) 30.8%	.04
Length of Hospital Stay	7 (4, 11)	7 (4, 11)	8 (5, 13)	.01	5 (3, 9)	11.5 (8, 18)	<.01
Length of stay in ICU	4 (2, 6)	4 (2, 6)	5 (3, 8)	<.01	3 (2, 5)	7 (4, 12)	<.01
PEG Tube	201 (15.6)	154 (76.6) 14.9%	47 (23.4) 18.4%	.17	13 (27.7) 10.4%	34 (72.3) 26.2%	<.01
TRACH	33 (2.6)	21 (63.6) 2.0%	12 (36.4) 4.7%	.01	0 (0) 0%	12 (100) 9.2%	<.01
Pt. moved to comfort measures	288 (22.4)	141 (49.0) 13.7%	147 (51.0) 57.7%	<.01	73 (50.0) 58.9%	73 (50.0) 56.2%	.66
Extubation as a part of move to comfort measures	136 (10.6)	85 (62.5) 8.3%	51 (37.5) 20.1%	<.01	19 (37.3) 15.3%	32 (62.8) 24.6%	.06
Withdrawal of artificial nutrition was part of a move to comfort measures	123 (9.6)	50 (40.7) 4.9%	73 (59.4) 28.7%	<.01	31 (43.1) 25.2%	41 (56.9) 31.5%	.26
Patient resuscitated during hospitalization	21 (1.6)	18 (85.7) 1.7%	3 (14.3) 1.2%	.53	1 (33.3) 0.8%	2 (66.7) 1.5%	>.99
Change in Code Status (yes)	337 (26.1)	183 (54.3) 17.7%	154 (45.7) 60.4%	<.01	63 (41.2) 50.8%	90 (58.8) 69.2%	<.01
Code Status change							
Full code	9 (2.7)	7 (77.8) 3.8%	2 (22.2) 1.3%	.06	0 (0) 0%	2 (100) 2.2%	.27
Partial code	22 (6.5)	16 (72.7) 8.7%	6 (27.3) 3.9%		1 (16.7) 1.6%	5 (83.3) 5.6%	
Do not resuscitate	306 (90.8)	160 (52.3) 87.4%	146 (47.7) 94.8%		62 (42.8) 98.4%	83 (57.2) 92.2%	
Discharge location							
Home	183 (16.8)	171 (93.4) 18.6%	12 (6.6) 7.0%	<.01	9 (75.0) 10.2%	3 (25.0) 3.6%	.15
Other Health Care Facility	514 (47.1)	476 (92.6) 51.7%	38 (7.4) 22.1%		16 (42.1) 18.2%	22 (57.9) 26.2%	
Acute Care Facility	273 (25.0)	218 (79.9) 23.7%	55 (20.2) 32.0%		24 (43.6) 27.3%	31 (56.4) 36.9%	
Inpatient Hospice	55 (5.0)	20 (36.4) 2.2%	35 (63.6) 20.4%		20 (57.1) 22.7%	15 (42.9) 17.9%	
Home Hospice	52 (4.8)	21 (40.4) 2.3%	31 (59.6) 18.0%		19 (61.3) 21.6%	12 (38.7) 14.3%	
D/C to another hospital	11 (1.0)	11 (100) 1.2%	0 (0) 0%		0 (0) 0%	0 (0) 0%	
Other	4 (0.4)	3 (75.0) 0.3%	1 (25.0) 0.6%		0 (0) 0%	1 (100) 1.2%	

Values are medians (IQRs) for continuous variables and frequencies (percentages for categorical variables are listed as row percentages in parentheses and column percentages with a %); p-values are from Wilcoxon and Chi-Square tests (verified with Fisher's Exact where necessary), respectively. Frequencies may not add to column totals due to missing data.

¥ indicates the category “N/A Due to Death” was removed from this one variable.

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