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Disparities in Palliative Care Utilization Among Hospitalized People With Huntington Disease: A National Cross-Sectional Study

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Abstract

Background: People with Huntington’s disease (HD) often become institutionalized and more frequently die away from the home setting. The reasons behind differences in end-of-life care are poorly understood. Less than 5% of people with HD report utilization of palliative care (PC) or hospice services, regardless of the lack of curative therapies for this neurodegenerative disease. It is unknown what factors are associated with in-patient specialty PC consultation in this population and how PC might be related to discharge disposition.

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Authors’ Note

Leonard L. Sokol conceived the project, wrote the I.R.B., wrote the first draft, devised the research questions, interpreted the work, revised the manuscript for valuable intellectual content, and approved the final draft. Danny Bega, Benzi M. Kluger, and Hillary D. Lum oversaw the work, conception, and design, drafted the work for important intellectual content, and approved the final draft. The Institutional Review Board of Northwestern University approved the study.

Supplemental Material

Supplemental material for this article is available online.

Objectives: To determine what HD-specific (e.g., psychosis) and serious illness-specific factors (e.g., resuscitation preferences) are associated with PC encounters in people with HD and explore how PC encounters are associated with discharge disposition.

Design: We analyzed factors associated with PC consultation for people with HD using discharge data from the National Inpatient Sample and the Nationwide Inpatient Sample (NIS), Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality. An anonymized, cross-sectional, and stratified sample of 20% of United States hospitalizations from 2007 through 2014 were included using ICD-9 codes.

Results: 8521 patients with HD were admitted to the hospital. Of those, 321 (3.8%) received specialty PC. Payer type, (specifically private insurer or other insurer as compared to Medicare), income, (specifically the top quartile as compared to the bottom quartile), mortality risk, D.N.R., aspiration pneumonia, and depression were significantly associated with PC in a multivariate model. Among those who received PC, the odds ratio (OR) of discharge to a facility was 0.43 (95% CI, 0.32–0.58), whereas the OR of discharge to home with services was 2.25 (95% CI 1.57–3.23), even after adjusting for possible confounders.

Conclusions: Among patients with HD, economic factors, depression, and serious illness-specific factors were associated with PC, and PC was associated with discharge disposition. These findings have implications for the adaptation of inpatient PC models to meet the needs of persons with HD.

Keywords

palliative care; neuropalliative care; Huntington disease; end-of-life

Introduction

Huntington's disease (HD) is an autosomal dominant neurodegenerative disease caused by the mutant *huntingtin* protein.¹ People with the HD gene have an almost 100% penetrance of motor symptoms, which often arise in the third to fifth decade of life. Sometimes years before motor symptoms appear, people will often exhibit apathy, impulsivity, depression, and anxiety.² Once the motor manifestations appear, life expectancy is around 15 to 20 years with an inexorable decline in all domains, including cognitive, psychiatric, and motor.³ No disease-modifying agent or cure has been discovered. There remain few evidence-based therapies to improve the health-related quality of life (HRQOL) in HD.³ Therefore, the management of HD remains inherently supportive.⁴ Yet, fewer than 5% of people with the HD gene mutation report receiving palliative care (PC), and approximately 57% reported little thought to these services in a recent large multi-center cross-sectional study.⁵

Nationally, people with HD often die in the hospital (29.8%) or at a skilled nursing facility (SNF) (19.8%), with 23.9% dying at home.^{6,7} Fewer than 5% die with hospice care.^{6,7} These findings are in stark contrast to other dementias, where a majority (66.9%) die at SNFs.⁸ Given the high rates of in-hospital deaths for people with HD, a specific evaluation of patient characteristics and the nature of the hospitalizations that persons with HD experience are essential for understanding their potential influence on the relative under-utilization of PC.^{9–13}

With the underutilization of PC services⁵ among people with HD and high institutionalization rates as the disease progresses, we sought to understand what factors were associated with PC utilization and to determine if PC encounters corresponded with discharge location from the in-patient setting. First, we examined the factors associated with PC encounters among hospitalized persons with HD.¹⁴ Similar to the disparities of PC during hospitalization for other chronic illnesses,¹⁵ we hypothesized that those who received PC encounters would likely arise from a higher median household income zip codes and exhibit depression, a prevalent co-morbidity of HD. Second, we explored how PC encounters affected discharge location. We hypothesized that even when accounting for the relevant patient, hospital-level, and serious illness-related confounders, persons with HD who had PC encounters, compared to those who did not receive PC, would have a) higher in-hospital mortality, b) higher discharge to home with services, and c) lower rates of SNF discharge.

Methods

Study Design and Participants

This cross-sectional analysis used data from the National Inpatient Sample (N.I.S.) database from the Healthcare Cost and Utilization Project.¹⁶ As the largest in-patient hospital admission database, N.I.S. includes an anonymized cross-section of approximately 20% of the hospitalizations nationwide.¹⁶ We adhered to similar design approaches¹⁵ and combined data from 2007–2014 and used the *International Classifications of Diseases, Ninth Revision* diagnostic codes. We identified persons with HD using the ICD-9 code 333.4 and includes individuals who survived hospital discharge. Missing data was less than 5% unless otherwise noted. The Northwestern University IRB approved this study.

Definition of Study Variables

The primary outcome for our first aim was PC encounter among people with HD. The options for this variable were binary (yes/no). We utilized V66.7, which was shown to be 99.1% specific for specialty PC consultation, based on a retrospective review of approximately more than 100,000 admissions in a large academic medical center in the United States between August 2013 and 2015.¹⁷ Independent variables were selected based on the presence of factors associated with hospitalization and institutionalization for HD (aspiration pneumonia, respiratory failure, and depression)¹⁸ as well as factors associated with PC consultation in chronic diseases (e.g., primary payer, median household income, risk of mortality subclass, the presence of a do-not-resuscitate order, bed size).¹⁴ Primary payers included Medicare, Medicaid, private insurance, self-pay, no charge, or other (e.g., workers compensation or Veterans Affairs). The median household income for a patient's zip code included 4 quartiles (0 to 25th percentile, 25th to 50th percentile, 50th to 75th percentile, and greater than 75th percentile), and was based on demographic data obtained from Claritas.¹⁹ The risk of mortality subclass was calculated using the 3 M Health Information Systems Software using the All-Patient Refined Version 20 Methodology Booklet.²⁰ The mortality classes included “no likelihood of dying, minor likelihood of dying, moderate likelihood of dying, major likelihood of dying, and extreme likelihood of dying.” Bed size was based on location and teaching status of the hospital;

these metadata were obtained from AHA Annual Survey of Hospitals.²¹ Other diagnoses related to admission and co-morbidities used the Clinical Classification Software and AHRQ Comorbidity Index respectively (Supplementary Material). For our second aim, the primary outcome of interest was disposition location. These included routine (e.g., home or self-care), facility (e.g., SNF, intermediate care facility, or another type of facility), home health care, and death in the hospital.

Statistical Analysis

Descriptive statistics were used to summarize hospitalized persons with HD who received and did not receive PC. Mean and standard deviation was used to illustrate the distribution of continuous variables. N with percentages was used for categorical variables. We used weighted logistic regression incorporating complex survey sample designs to estimate the relationship between PC encounter and variables of interest. We included either HCUP hospital identification number before 2012 or N.I.S. hospital number after 2012 as cluster effect, stratum used to post-stratify hospital as stratification effect, and weights assigned to each discharge. Tukey's test was used to make a pairwise comparison for posthoc analysis. To determine the final multivariable model, any covariable with a p-value <0.10 was initially included in the multivariable model. By comparing type 3 p-value and backward elimination, the final model includes primary payer, median household income, risk of mortality subclass, do-not-resuscitate order, aspiration pneumonia, respiratory failure, and depression as predictors. A similar model was performed to examine the association between PC encounter and discharge location while adjusting for the primary payer, median household income, risk of mortality subclass, do-not-resuscitate order, aspiration pneumonia, respiratory failure, and depression. Since we did not have a large portion of missingness and PROC SURVEYLOGISTIC has already accounted for the setting, we did not consider imputation. Any missing values were excluded from the analyses. P-values less than 0.05 were considered significant.

Results

Between 2007–2014, there were 8521 hospitalizations among persons with HD with a mean (standard deviation) age of 55.6 (14.8) years. Only 321 (3.8%) admissions received PC consultation. Of those who received PC consultation, Table 1 describes patient sociodemographic factors, characteristics of the hospitalization, and hospital discharge locations by PC encounter.

Hypothesis 1: Disparities Will Exist Among Persons With HD Who Receive PC

In bivariate analyses, gender, race, and hospital size were not associated with PC. However, primary expected payer ($p = 0.01$) and median household income ($p < 0.01$) were significantly correlated with PC (Table 2). Several other hospitalization-related factors were associated, including mortality class, D.N.R. status, sepsis, and others. In the multivariate model, after adjusting for all other variables (Table 3), the factors that remained associated with PC encounter were primary payer, with a private insurer as compared to Medicare (OR 1.86, 95% CI, 1.06–3.27), median household income, specifically the top quartile of income as compared to the bottom quartile (OR 1.77, 95% CI, 1.06–2.95), mortality class,

specifically the extreme likelihood of dying as compared to the minor likelihood of dying (OR 4.73, 95% CI, 2.36–9.46), D.N.R. order (OR 8.75, 95% CI, 6.67–11.47), aspiration pneumonia (OR 1.43, 95% CI, 1.07–1.92), respiratory failure (OR 1.46, 95% CI, 1.03–2.08), and depression (OR 0.70, 95% CI, 0.50–0.98).

Hypothesis 2: PC Will be Associated With Discharge Location, Even When Accounting for Other Factors

The analysis of disposition is found in Table 4. The odds of being discharged to a facility for those people with HD who received PC was 0.43 (95% CI 0.32–0.58) times the odds of being discharged to a facility for those patients who did not receive PC, after adjusting for the primary payer, median household income, risk of mortality subclass, D.N.R., aspiration pneumonia, respiratory failure, and depression. Similarly, the odds of being discharged to home with services for these people with HD who received PC were 2.25 (95% CI 1.57–3.23) times the odds of being discharged to home with home health care for those who did not receive PC after adjusting for other factors. Finally, upon adjusting for the same factors, the odds of in-hospital mortality for those who received PC was 7.56 (95% CI 5.25–10.88).

Discussion

This is the first nationally representative study of PC encounters among hospitalized people with HD. These data demonstrate an economic and psychosocial disparity among persons with HD who receive PC and those who do not. Our results suggest that people with HD who live in areas where the median household income is in the bottom quartile had a lower odds of receiving PC during hospitalization, which may reflect a lack of availability of PC services or other unmeasured factors. These findings build upon work in other serious illnesses, such as heart failure, where zip codes with higher median household income were positively associated with PC encounters.¹⁵ We also found that comorbid depression, a highly prevalent symptom in HD, was associated with lower PC use. Further study is needed to understand any barriers or implicit biases that may impact the use of PC.

Our analysis indicates that inpatient PC encounters were associated with discharge location. PC was significantly associated with fewer discharges to a facility and more discharges with home health care services, even when adjusting for other factors. These home health care services could include home hospice, though the N.I.S. does not include hospice enrollment or patient outcomes (e.g., death) after discharge. Notably, inpatient PC encounters were also associated with a high odds of in-hospital death, independent of the risk of mortality subclass, suggesting other potential contributing factors (e.g., the inpatient hospitalization itself may serve as a trigger point to refine goals of care with the assistance of specialty PC consultation). Though only 11% of persons with HD have thought about their death location, and fewer than 10% have established home care services, existing reports suggest home as advantageous to receiving dignified end-of-life care in those with serious illness,²² including people with HD.¹⁴

These data also build on a retrospective study with 59 people hospitalized with HD. It compared clinical and demographic factors associated with discharge disposition (SNF vs. home).²³ It found that (1) male gender; (2) longer in-patient stays; (3) psychosocial

difficulties (e.g., dissolution of financial and support networks); and (4) behavioral issues (e.g., impulsivity) were associated with discharge to a SNF. Caregiver distress was a fifth associated factor; however, it did not remain significant after adjusting for multiple comparisons.

Our study was limited because the data do not account for repeated hospitalizations, suicidality, initial location before hospital admission, patient values and preferences for care, HD staging and functional level, family (caregiver) distress/experience with HD, the primary reason for admission, or hospice use. Causality also cannot be inferred based on this data and no information is available on the initiating recipient (e.g., patient, care partner, or physician) of the consultation. Therefore, future work might prospectively examine how these additional factors influence discharge disposition, including hospice use and place of death. Further, additional work might explore the utility of primary neuropalliative assessments, including symptom assessments or the use of the “surprise question” to trigger PC consultation and support goalconcordant care in this population.²⁴ Since there are no evidence-based PC models in existence for this population in the outpatient setting,^{5,25,26} where most care resides, efforts are, therefore, warranted to adapt and pilot PC models (e.g., meaning-centered) to people with the HD genetic mutation, which could be interchangeable among various environments (e.g., outpatient and inpatient), and stages of illness (prodromal, early, and late).²⁷

In conclusion, these data are a compelling first step showcasing sociodemographic and psychosocial factors were associated with PC utilization among hospitalized persons with HD. People whose household resides in the bottom income quartile, even independent of the hospital’s size or location, were negatively associated with PC encounters. Similarly, Medicare and the presence of co-morbid depression were also inversely correlated. Inpatient PC was positively associated with discharge to home with services (potentially including home hospice) and negatively associated with discharge to a facility. Taken together, our findings can direct efforts to offer PC interventions for this population equitably.²⁸

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Descriptive Characteristics.

	All	Palliative care	
		No	Yes
In-patient admissions	N (%) 8521 (100.00)	8200 (96.23)	321 (3.77)
Age in years at admission (mean, S.D.)	N 8517	8196	321
	Mean (SD) 55.6 (14.8)	55.5 (14.7)	58.9 (14.9)
Length of stay (mean, S.D.)	N 8518	8197	321
	Mean (SD) 7.80 (13.21)	7.73 (12.44)	9.51 (25.98)
Gender			
Male	N (%) 4004 (47.02)	3842 (46.88)	162 (50.47)
Female	N (%) 4512 (52.98)	4353 (53.12)	159 (49.53)
Race [†]			
White	N (%) 5737 (77.92)	5512 (77.95)	225 (77.05)
Black	N (%) 729 (9.90)	701 (9.91)	28 (9.59)
Hispanic	N (%) 575 (7.81)	550 (7.78)	25 (8.56)
Asian or Pacific Islander/ Native American/ Other	N (%) 322 (4.37)	308 (4.36)	14 (4.79)
Disposition of patient			
Routine	N (%) 2741 (32.17)	2725 (33.23)	16 (4.98)
Facility	N (%) 4431 (52.00)	4300 (52.44)	131 (40.81)
Home health care	N (%) 1048 (12.30)	977 (11.91)	71 (22.12)
Died	N (%) 301 (3.53)	198 (2.41)	103 (32.09)
Primary expected payer			
Medicare	N (%) 5104 (60.00)	4914 (60.04)	190 (59.19)
Medicaid	N (%) 1750 (20.57)	1700 (20.77)	50 (15.58)
Private insurer	N (%) 1244 (14.62)	1185 (14.48)	59 (18.38)
Self-pay/ No charge/ Other	N (%) 408 (4.80)	386 (4.72)	22 (6.85)
Bed size of hospital			
Small	N (%) 1316 (15.55)	1271 (15.61)	45 (14.11)
Medium	N (%) 2185 (25.82)	2116 (25.99)	69 (21.63)
Large	N (%) 4960 (58.62)	4755 (58.40)	205 (64.26)

	N (%)	Palliative care	
		All	Yes
Median household income national quartile for patient ZIP Code			
0 to 25th percentile	N (%)	2569 (30.81)	2492 (31.06)
26th to 50th percentile	N (%)	2365 (28.36)	2283 (28.46)
51st to 75th percentile	N (%)	1877 (22.51)	1810 (22.56)
76th to 100th percentile	N (%)	1527 (18.31)	1438 (17.92)
All Patient Refined D.R.G.: Risk of Mortality Subclass			
Minor likelihood of dying*	N (%)	3030 (35.56)	2987 (36.43)
Moderate likelihood of dying	N (%)	3082 (36.17)	3012 (36.73)
Major likelihood of dying	N (%)	1716 (20.14)	1605 (19.57)
Extreme likelihood of dying	N (%)	693 (8.13)	596 (7.27)
DNR order			
No	N (%)	7956 (93.37)	7767 (94.72)
Yes	N (%)	565 (6.63)	433 (5.28)
Pneumonia (except caused by T.B. or S.T.I.s)			
No	N (%)	7582 (88.98)	7321 (89.28)
Yes	N (%)	939 (11.02)	879 (10.72)
Aspiration pneumonia			
No	N (%)	7366 (86.45)	7154 (87.24)
Yes	N (%)	1155 (13.55)	1046 (12.76)
Respiratory failure			
No	N (%)	7629 (89.53)	7415 (90.43)
Yes	N (%)	892 (10.47)	785 (9.57)
Septicemia (excludes labor)			
No	N (%)	7339 (86.13)	7116 (86.78)
Yes	N (%)	1182 (13.87)	1084 (13.22)
Urinary tract infection			
No	N (%)	6862 (80.53)	6597 (80.45)
Yes	N (%)	1659 (19.47)	1603 (19.55)
Fall			
No	N (%)	7857 (92.21)	7558 (92.17)
Yes	N (%)	265 (3.09)	265 (3.09)

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	Palliative care		
	All	No	Yes
Yes	N (%)	642 (7.83)	22 (6.85)
AHRQ co-morbidity measure: Depression			
No	N (%)	6580 (80.24)	271 (84.42)
Yes	N (%)	1620 (19.76)	50 (15.58)
AHRQ co-morbidity measure: Psychoses			
No	N (%)	7117 (86.79)	288 (89.72)
Yes	N (%)	1083 (13.21)	33 (10.28)

[†]There are 1158 (13.59%) subjects missing in race.

^{*} 4 (0.05%) subjects classified as "No class specified" were incorporated into the category: Minor likelihood of dying.

Table 2.
Bivariate Model of Factors Associated With P.C. Encounter for People With H.I.D.

Predictor	Group	N used	p-value	Odds ratio	95% CI	
					Lower	Upper
Age in years at admission		8517	<0.001	1.017	1.008	1.025
Length of Stay (Days)		8518	0.063	1.006	1.000	1.013
Gender (Reference: Male)	Female	8516	0.216	0.857	0.671	1.094
Race (Reference: White)	Black	7363	0.979	0.988	0.532	1.838
	Hispanic			1.105	0.564	2.167
	Asian or Pacific Islander			0.917	0.154	5.469
	Native American			1.776	0.179	17.638
Primary expected payer (Reference: Medicare)	Other			1.110	0.399	3.087
	Medicaid	8506	0.008	0.761	0.471	1.229
	Private insurer			1.327	0.809	2.177
	Self-pay			0.561	0.129	2.443
	No charge			1.558	0.099	24.644
	Other			2.399	1.033	5.574
			8338	<0.001	1.148	0.721
Median household income (Reference: 0 to 25th percentile)	26th to 50th percentile			1.156	0.709	1.884
	51st to 75th percentile			1.969	1.249	3.103
	76th to 100th percentile			0.865	0.532	1.406
Bed size of hospital (Reference: Large)	Small	8461	0.173	0.752	0.523	1.080
	Medium			1.612	0.904	2.872
Risk of Mortality Subclass (Reference: Minor likelihood of dying)	Moderate likelihood of dying	8521	<0.001	4.783	2.715	8.425
	Major likelihood of dying			11.219	6.363	19.778
	Extreme likelihood of dying			12.461	9.694	16.019
DNR (Reference: No)	Yes	8521	<0.001	1.930	1.426	2.612
Pneumonia (Reference: No)	Yes	8521	<0.001	3.514	2.757	4.479
Aspiration pneumonia (Reference: No)	Yes	8521	<0.001	4.719	3.678	6.054
Respiratory failure(Reference: No)	Yes	8521	<0.001	2.899	2.238	3.756
Septicemia (excludes labor) (Reference: No)	Yes	8521	<0.001	0.856	0.622	1.178
Urinary tract infection (Reference: No)	Yes	8521	0.341			

Predictor	Group	N used	p-value	Odds ratio	95% CI	
					Lower	Upper
Fracture of neck of femur (hip) (Reference: No)	Yes	8521	0.115	0.204	0.028	1.472
Fall (Reference: No)	Yes	8521	0.487	0.853	0.545	1.335
Depression (Reference: No)	Yes	8521	0.069	0.746	0.544	1.023
Psychoses (Reference: No)	Yes	8521	0.125	0.755	0.526	1.082

Example interpretation: Risk of mortality subclass is significantly correlated to palliative care with p-value <0.0001. The estimated odds of receiving palliative care for a person with H.D. who is major likelihood of dying is 4.783 (95% CI 2.715–8.425) times compared to patients who is a minor likelihood of dying.

Table 3.
Multivariate Model for Factors Associated With P.C. Encounter for People With H.D.

Predictor	Group	Odds ratio	95% CI		p-value
			Lower	Upper	
Primary expected payer (Reference: Medicare)	Medicaid	1.064	0.627	1.805	0.001
	Private insurer	1.862	1.062	3.266	
	Self-pay	1.005	0.212	4.773	
	No charge	4.993	0.291	85.560	
	Other	3.389	1.377	8.338	
Median household income (Reference: 0 to 25th percentile)	26th to 50th percentile	1.118	0.670	1.863	0.004
	51st to 75th percentile	1.009	0.592	1.720	
	76th to 100th percentile	1.771	1.063	2.951	
Risk of Mortality Subclass (Reference: Minor likelihood of dying)	Moderate likelihood of dying	1.388	0.769	2.505	<0.001
	Major likelihood of dying	2.994	1.649	5.435	
	Extreme likelihood of dying	4.726	2.361	9.458	
DNR (Reference: No)	Yes	8.749	6.674	11.471	<0.001
Aspiration pneumonia (Reference: No)	Yes	1.431	1.068	1.917	0.016
Respiratory failure (Reference: No)	Yes	1.464	1.032	2.077	0.033
Depression (Reference: No)	Yes	0.696	0.496	0.975	0.035

Table 4. Adjusted Analysis of Hospital Disposition Among People With H.D. Who Received Palliative Care Consultation.

Outcome	Predictor	N	P-value	Odds ratio	95% CI	
					Lower	Upper
Discharge Home	Palliative Care	8323	<.001	0.175	0.099	0.307
Discharge to Facility		8323	<.001	0.432	0.323	0.579
Discharge Home with Home Care		8323	<.001	2.250	1.567	3.229
Death in Hospital		8323	<.001	7.557	5.251	10.875

Example interpretation: The odds of death for those patients who received palliative care referral is 7.56 (95% CI 5.25–10.88) times the odds of death for those patients who did not receive palliative care referral with a p-value <0.001 after controlling for primary expected payer, median household income, risk of mortality subclass, D.N.R., aspiration pneumonia, respiratory failure, and depression.