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Inpatient gastrostomy in Huntington's disease: Nationwide analysis of utilization and outcomes compared to amyotrophic lateral sclerosis



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ABSTRACT

Background: Huntington's disease (HD) causes dysphagia and dementia, both of which are risk factors for malnutrition. Gastrostomy is used to sustain enteral intake in neurodegenerative diseases and specifically improves outcomes in ALS, but its indications and outcomes in HD are understudied.

Objective: To explore the indications and outcomes for gastrostomy for HD.

Methods: We performed a retrospective cross-sectional analysis of all HD admissions in the National Inpatient Sample. Logistic regression models compared the patient- and hospital-level characteristics associated with gastrostomy placement in HD and the prevalence of associated diagnoses in HD vs. ALS gastrostomy patients. We also examined inhospital mortality, length of stay (LOS), and discharge status.

Results: Between 2000 and 2010, 5.12% (n = 1614) of HD admissions included gastrostomy tube placement. Gastrostomy patients were more likely to be Black (adjusted odds ratio [AOR] 1.55, 95% CI: 1.09–2.21) and have Medicare coverage (AOR 1.43, 95% CI: 1.0–2.05). The most common comorbidities were aspiration pneumonia (34.1%), dementia (31.3%), malnutrition (30.3%), and dysphagia (29.5%). Dementia and delirium were associated with discharge type but not LOS. Aspiration pneumonia, sepsis, and Elixhauser comorbidity index were associated with LOS but not discharge type. Compared to 7908 ALS gastrostomy patients, those with HD more frequently had aspiration pneumonia (34.1% vs. 20.5%, p < 0.0001), sepsis (28.1% vs. 13.7%, p < 0.0001), prolonged LOS (OR 1.14, 95% CI: 1.02–1.28), and skilled nursing facility discharge (p < 0.0001, Wald chi square test).

Conclusions: Gastrostomy is frequently performed in HD patients with dementia and aspiration pneumonia who are at increased risk for negative hospitalization outcomes.

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1. Introduction

Huntington's disease (HD) causes dysphagia and cognitive impairment in addition to typical motor manifestations of chorea and parkinsonism [1]. In neurologic disease, both dysphagia and dementia are risk factors for malnutrition and other downstream health consequences, and therefore many patients with stroke, motor neuron disease, or other neurodegenerative disorders undergo gastrostomy placement for enteral support [2]. However, the risks, benefits, and indications for gastrostomy vary dramatically depending on the neurologic disease in question. For example, in amyotrophic lateral

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sclerosis (ALS), there is evidence that gastrostomy prolongs survival and improves quality of life, resulting in its inclusion as part of bestpractice guidelines [3]. However, in advanced dementia, gastrostomy placement has *not* been shown to prevent aspiration pneumonia or improve survival or quality of life, and the American Geriatrics Society, American Academy of Hospice and Palliative Medicine, and American Board of Internal Medicine therefore recommend *against* its use in this population [4].

Dysphagia is common in HD [5], and gastrostomy is performed, but its frequency, timing, indications, and outcomes are unknown, as there are no data on current utilization patterns of enteral support in HD. A central question is whether feeding tube placement in HD occurs primarily in the setting of neuromuscular dysphagia (similar to ALS, which is associated with favorable outcomes following gastrostomy) or advanced dementia (which is not associated with improved

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outcomes). In this study, we examine the clinical and demographic characteristics and discharge outcomes of HD patients undergoing gastrostomy in the United States using the National Inpatient Sample (NIS), a national database of hospital discharge data.

2. Methods

2.1. Standard protocol approvals, registrations, and patient consents

This study was approved by the University of Pennsylvania Institutional Review Board.

2.2. Data

We used data from the National Inpatient Sample (NIS), which is the largest all-payer inpatient healthcare database in the United States and is made available through the Healthcare Cost and Utilization Project (HCUP) by the Agency for Healthcare Research and Quality (AHRQ) [6]. Before 2012, the NIS included all discharges from a 20% sample of U.S. hospitals. Beginning in 2012, the NIS estimates a 20% sample (>7 million hospitalizations annually) of discharges from all U.S. hospitals. The database contains deidentified encounter-level information on patient and hospital demographics, diagnoses and comorbidities, inpatient procedures, and healthcare costs and payer information. For our analysis, we pooled data from the years 2000–2010.

2.3. Data availability policy

The full dataset is publicly available through HCUP.

2.4. Population

We identified all inpatient admissions with HD using ICD-9 code 333.4. Gastrostomy placement was identified using AHRQ Clinical Classification Software (CCS) code 71, a validated algorithm developed by HCUP that aggregates multiple diagnostic and procedural codes to identify incident gastrostomy placement during an admission. This code only identifies new gastrostomy tube placement and is different from the code identifying the presence of a gastrostomy tube from a previous admission. However, the timing of gastrostomy placement within a given hospitalization cannot be determined. In addition to describing and comparing the clinical and demographic characteristics and outcomes of HD inpatients with and without gastrostomy as detailed below, we also compared inpatient gastrostomy for HD to amyotrophic lateral sclerosis (ALS), which was identified using ICD-9 codes 335.20 or 335.21. We selected ALS as a comparator because it is a neurodegenerative disease with evidence and best-practice guidelines supporting the use of gastrostomy to improve outcomes in this population [3], in contrast to other neurodegenerative diseases where evidence is either lacking or to the contrary.

2.5. Outcomes and covariates

Our primary outcomes were inpatient mortality, hospital length of stay (LOS), and disposition status. We also considered patient-level factors such as age group (18–39, 40–49, 50–59. 60–69, 70–79, \geq 80 years), race/ethnicity (White, Black, Hispanic, Asian or Pacific Islander, Native American, or other), gender, insurance provider (Medicare, Medicaid, private, selfpay, or no charge/other), and median income by ZIP code (\leq \$37,999, \$38,000–\$47,999, \$48,000–\$63,999, \geq \$64,000), as well as hospitallevel factors such as size (small, medium, or large as defined by HCUP), teaching status, and geographic region (Northeast, South, Midwest, or West). We recorded whether hospital admission was electively planned (as opposed to occurring via presentation to the emergency department or transfer from another hospital), though this not identify whether gastrostomy itself was elective or not. Severity of comorbid medical illness was quantified using the Elixhauser comorbidity index [7], which

incorporates a number of different diagnoses including diabetes, hypertension, and cardiopulmonary disease. Specific associated diagnoses were defined using diagnostic and procedural codes (Supplemental Table 1).

2.6. Statistical analysis

We summarized the patient and hospital-level characteristics of HD admissions with and without gastrostomy using descriptive statistics and compared them using single-variable and multivariable logistic regression (adjusted for age, race, gender, elective admission status, median income by ZIP, insurance payer, hospital size, hospital location, and teaching status). We also summarized the Elixhauser comorbidity index, frequency of associated diagnoses, hospital length of stay, and in-hospital mortality for inpatient HD gastrostomies and compared them to inpatient ALS gastrostomies using chi-square tests. We constructed separate logistic regression models for HD gastrostomies and ALS gastrostomies to determine the patient and hospital characteristics and comorbidities associated with non-routine discharge (defined as discharge to a short-term hospital, skilled nursing facility, or other institution). LOS was not normally distributed due to ceiling effects (specifically, all observations in the NIS dataset are terminated at 365 days such that individuals cannot be tracked across years), so LOS was logtransformed for linear regression, and regression coefficients were exponentiated and interpreted as the ratio of geometric mean LOS. Sampling weights were applied to account for the complex survey design of the NIS and ensure proper confidence intervals for both descriptive statistics and regression models. Statistical significance was defined at the p < 0.05 level.

3. Results

3.1. Clinical characteristics of HD gastrostomy patients

We identified 31,551 inpatient admissions with a diagnosis of HD during the study period, of which 1614 (5.12%) included gastrostomy tube placement. While we pooled data from 2000 to 2010, complete information on HD admissions was only available in NIS beginning in 2003. Fig. 1 illustrates the total number of HD admissions and the number of HD admissions with gastrostomy by year. The patient- and hospital-level characteristics of HD admissions with vs. without inpatient gastrostomy tube placement are summarized in Table 1. In both unadjusted and adjusted analyses, Native American (AOR 3.47, 95% CI: 1.21-9.95) or Black (adjusted odds ratio [AOR] 1.55, 95% CI: 1.09-2.21) ancestry was associated with gastrostomy, as compared to White. After adjusting for age, race, gender, elective admission status, median income by ZIP, and hospital characteristics, Medicare insurance was associated with gastrostomy compared to private insurance (AOR 1.43, 95% CI: 1.0-2.05). A similar proportion (12.5%) of hospitalizations for HD, either with or without gastrostomy, was elective. There were no significant differences between gastrostomy and non-gastrostomy HD admissions in terms of age, gender, median income by ZIP, or hospital size, location, or teaching status.

Next, we examined the medical comorbidities and associated diagnoses for HD patients who underwent inpatient gastrostomy (Table 2). The distribution of inpatient HD gastrostomy patients was skewed towards higher Elixhauser comorbidity scores. The most common associated diagnoses were aspiration pneumonia (34.1%), dementia (31.3%), malnutrition (30.3%), and dysphagia (29.5%). Dementia and delirium were both more common among HD patients undergoing gastrostomy than those who did not receive gastrostomy (p < 0.0001 and p = 0.003, respectively). Of those with dementia (weighted sample size = 515), 243 (47.2%) also had dysphagia, whereas 272 (52.8%) did not.

3.2. Outcomes associated with gastrostomy in HD

The median hospital length of stay for HD patients who underwent inpatient gastrostomy tube placement was 8.04 days (interquartile range: 4.34– 14.32 days). Thirty five patients (2.25%) died during hospitalization. Of the remaining 1574 patients who were discharged, the majority (n = 1201,



Fig. 1. Trend in hospitalization for Huntington's disease and gastrostomy utilization by year, National Inpatient Sample 2003–2010. Vertical bars denote 95% confidence intervals.

69.9%) were discharged to a skilled nursing facility or other facility. Of the 473 patients who were discharged home, 228 (48.2%) required home health services, and only 245 (15.2% of all discharges) were considered routine.

The patient- and hospital-level features associated with non-routine discharge and prolonged length of stay for HD inpatient gastrostomy are shown in in Table 3. Women had a lower odds of prolonged length of stay compared to men (OR 0.85, 95% CI: 0.73–1.0), as did those from the Midwest compared to the Northeast (OR 0.29, 95% CI: 0.09–0.97). Otherwise, there were no differences in outcome after gastrostomy between age, race, insurance payer, median income by ZIP, or hospital characteristics. Dementia (OR 3.27, 95% CI: 1.31–8.20) and delirium (OR 8.18, 95% CI: 1.35–49.66) were both strongly associated with non-routine discharge but not prolonged length of stay. Aspiration pneumonia (OR 1.39, 95% CI: 1.2–1.62), sepsis (OR 1.76, 95% CI: 1.81–2.05), and mechanical ventilation (OR 2.17, 95% CI: 1.72–2.73), and higher Elixhauser comorbidity scores were associated with prolonged length of stay but not with non-routine discharge.

3.3. Gastrostomy for HD versus ALS

Compared to inpatient gastrostomy patients with ALS, those with HD had significantly greater odds of aspiration pneumonia (34.1% vs. 20.5%, p < 0.0001) and sepsis (28.1% vs. 13.7%, p < 0.0001). Dementia and delirium were both much more common in HD than ALS admissions with gastrostomy (p < 0.0001). Mechanical ventilation was more common in ALS than HD. Compared to inpatient ALS gastrostomies, HD patients had longer length of stay (OR 1.14, 95% CI: 1.02–1.28) and greater skilled nursing facility discharge (p < 0.0001 for Wald chi square test) but less inhospital mortality (OR 0.35, 95% CI: 0.16–0.77).

4. Discussion

In this study of over 30,000 hospital admissions with HD in the U.S. over a 10-year period, 1614 (5.12%) were associated with gastrostomy tube placement. Black or Native American patients and Medicare beneficiaries were more likely to undergo gastrostomy placement during admission. Gastrostomy was associated with diagnoses of aspiration pneumonia, dementia, and delirium; prolonged hospital length of stay; and discharge to a skilled nursing facility. These outcomes were more frequent than a comparable group of ALS patients receiving inpatient gastrostomy.

The association between Medicare coverage and gastrostomy in HD patients is likely confounded by disease severity. Specifically, older adults in the U.S. automatically become eligible for Medicare at age 65, but individuals with disabling medical conditions can become eligible before age 65. Over 65% of admitted HD patients who underwent gastrostomy received Medicare coverage, yet <37% would have met eligibility criteria by age. We therefore suspect that the majority of Medicare beneficiaries with HD are eligible due to disability, and that even after adjusting for age, the greater disease duration and severity which result in disability increase the odds of gastrostomy.

The association between race or ethnicity and gastrostomy in HD is less clear. Previous studies have shown differences in HD incidence according to nationality or ethnic background [8-10], but these have not examined outcomes such as gastrostomy. It is possible that race is a proxy for socioeconomic status and that decreased access to resources such as speech therapy or home health aides for supervised oral feeding results in earlier initiation of enteral support. However, we did not find an association between median income by ZIP and gastrostomy in this population. Interestingly, an analysis of administrative claims data from the Veterans Health Administration also found a higher incidence of gastrostomy among Black veterans with dementia compared to White veterans with dementia, the reasons for which remain unclear but have been hypothesized to reflect differences in end-of-life healthcare decision-making [11]. Of note, the overall prevalence of Black and Hispanic HD patients in the National Inpatient Sample (10.1% and 6.8%, respectively) is lower than current U.S. Census estimates (13.4% and 18.3%, respectively) [12], especially for Hispanics. The reasons for this are also not clear. The prevalence of HD is generally reported to be higher in Northern European populations [13], possibly due to genetic founder effects, and multicenter HD cohorts have found even lower prevalences of Black and Hispanic patients of 1-2.5% [14,15]. However, the latter are limited by research recruitment and participation, and as referral for genetic testing is required for a diagnosis of HD, underascertainment among minority populations is also possible.

Over 30% of HD patients undergoing gastrostomy were diagnosed with dementia, an inevitable consequence of this disease, and over half of these patients did not carry a diagnosis of dysphagia. This suggests that dementia may have been the primary indication for gastrostomy placement in a significant proportion of the HD population. Current guidelines recommend against feeding tube placement for advanced dementia, suggesting that up to 30% of gastrostomies placed for HD are in conflict with best practice recommendations. However,

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Table 1

Patient- and hospital-level characteristics of hospital admissions for Huntington's disease patients with vs. without inpatient gastrostomy tube placement.

	Gastrostomy ($n = 1614$)	No gastrostomy (n = $29,937$)	OR, unadjusted (95% CI)	OR, adjusted ^a (95% CI)
Age				
18–39 years	188 (12%)	3666 (12.4%)	REF	REF
40-49 years	405 (25.8%)	6203 (20.9%)	1.28 (0.86-1.89)	1.2 (0.81-1.79)
50–59 years	383 (24.4%)	7971 (26.9%)	0.94 (0.64–1.37)	0.88 (0.6-1.3)
60–69 years	332 (21.1%)	6233 (21%)	1.04 (0.7–1.55)	0.95 (0.63-1.43)
70–79 years	191 (12.2%)	3927 (13.3%)	0.95 (0.61-1.49)	0.82 (0.51-1.33)
\geq 80 years	73 (4.6%)	1632 (5.5%)	0.87 (0.48-1.59)	0.75 (0.4–1.38)
Race				
White	1156 (71.6%)	23,766 (79.4%)	REF	REF
Black	232 (14.4%)	2967 (9.9%)	1.61 (1.16-2.23)	1.55 (1.09-2.21)
Hispanic	138 (8.6%)	1998 (6.7%)	1.42 (0.95-2.13)	1.32 (0.85-2.03)
Asian or Pacific Islander	20 (1.3%)	301 (1%)	1.39 (0.51–3.84)	1.35 (0.49–3.69)
Native American	12 (0.7%)	70 (0.2%)	3.45 (1.24–9.58)	3.47 (1.21-9.95)
Other	55 (3.4%)	840 (2.8%)	1.36 (0.75–2.46)	1.32 (0.7-2.47)
Gender				
Male	769 (47.7%)	13,680 (45.7%)	REF	REF
Female	845 (52.3%)	16,262 (54.3%)	0.92 (0.74-1.15)	0.94 (0.75–1.17)
Elective admission (no, %)				
No	1412 (87.5%)	26,199 (87.5%)	REF	REF
Yes	202 (12.5%)	3743 (12.5%)	1 (0.71–1.41)	0.99 (0.69–1.41)
Insurance				
Medicare	1055 (65.4%)	18,223 (60.9%)	1.29 (0.92–1.81)	1.43 (1-2.05)
Medicaid	318 (19.7%)	6034 (20.2%)	1.18 (0.8–1.73)	1.11 (0.73–1.69)
Private insurance	196 (12.2%)	4371 (14.6%)	REF	REF
Self-pay	13 (0.8%)	614 (2.1%)	0.48 (0.14–1.59)	0.48 (0.14-1.61)
No-charge/other	31 (1.9%)	700 (2.3%)	0.99 (0.43-2.27)	0.88 (0.36-2.19)
Median income by ZIP				
Lowest \$1-\$37,999	485 (30%)	9085 (30.3%)	1 (0.72–1.41)	0.89 (0.63–1.27)
\$38,000-\$47,999	414 (25.7%)	8469 (28.3%)	0.92 (0.66–1.29)	0.89 (0.63–1.26)
\$48,000-\$63,999	418 (25.9%)	6815 (22.8%)	1.15 (0.82–1.62)	1.15 (0.82–1.62)
Highest \$64,000 +	297 (18.4%)	5574 (18.6%)	REF	REF
Hospital size				
Small	171 (10.6%)	4401 (14.7%)	REF	REF
Medium	453 (28.1%)	7944 (26.5%)	1.47 (0.98–2.22)	1.49 (0.97–2.29)
Large	990 (61.3%)	17,598 (58.8%)	1.45 (0.99–2.14)	1.48 (0.99–2.21)
Teaching status				
No	951 (58.9%)	18,489 (61.8%)	REF	REF
Yes	663 (41.1%)	11,453 (38.2%)	0.89 (0.7–1.12)	0.92 (0.73–1.17)
Location				
Northeast	435 (27%)	7768 (25.9%)	REF	REF
South	240 (14.9%)	5673 (18.9%)	0.76 (0.51–1.12)	0.74 (0.49–1.11)
Midwest	610 (37.8%)	10,846 (36.2%)	1 (0.75–1.34)	1.01 (0.75–1.35)
West	329 (20.4%)	5655 (18.9%)	1.04 (0.74–1.45)	0.95 (0.68–1.33)

^a Adjusted for all variables in this table.

Table 2

Diagnoses and comorbidities associated with inpatient gastrostomy for Huntington's disease vs. amyotrophic lateral sclerosis.

	HD		ALS		
	Number (%) with gastrostomy	Number (%) without gastrostomy	Number (%) with gastrostomy	Number (%) without gastrostomy	p-Value (HD gastrostomy vs. ALS gastrostomy)
Elixhauser comorbidity index					0.01
0–1	195 (12.1%)	5229 (17.5%)	876 (11.1%)	8861 (15.3%)	
2	399 (24.7%)	8935 (29.8%)	1761 (22.3%)	14,080 (24.3%)	
3	512 (31.7%)	7601 (25.4%)	2019 (25.5%)	14,947 (25.8%)	
4+	507 (31.4%)	8172 (27.3%)	3253 (41.1%)	20,152 (34.7%)	
Aspiration pneumonia	550 (34.1%)	3463 (11.6%)	1620 (20.5%)	6778 (11.7%)	< 0.0001
Dementia	505 (31.3%)	7613 (25.4%)	374 (4.7%)	2527 (4.4%)	< 0.0001
Malnutrition	489 (30.3%)	1817 (6.1%)	2226 (28.2%)	3944 (6.8%)	0.48
Dysphagia	477 (29.6%)	1726 (5.8%)	2470 (31.2%)	5037 (8.7%)	0.59
Infection, sepsis	453 (28.1%)	5479 (18.3%)	1085 (13.7%)	10,388 (17.9%)	< 0.0001
Delirium, dementia, and amnestic and other cognitive	277 (17.2%)	4329 (14.5%)	244 (3.1%)	1633 (2.8%)	< 0.0001
disorders					
Mechanical ventilation	234 (14.5%)	1369 (4.6%)	2553 (32.3%)	16,525 (28.5%)	< 0.0001
Anorexia	33 (2.1%)	208 (0.7%)	133 (1.7%)	264 (0.5%)	0.67

these guidelines are based primarily on data from Alzheimer's disease and may not be generalizable to HD. Furthermore, "advanced dementia" is defined in these studies using scales such as the Functional Assessment staging tool or Clinical Dementia Rating scale, but the NIS does not contain information regarding dementia severity or associated defining features (e.g. incontinence, need for assistance with all

Table 3

Adjusted^a odds ratios for discharge outcomes as a function of patient- and hospitallevel characteristics and comorbidities for inpatient gastrostomy in Huntington's disease.

	Non-routine discharge	Prolonged length of stay				
Bace						
White	RFF	DEE				
Black	1 33 (0 47 - 3 72)	11(0.87-1.4)				
Hispanic	0.43(0.13-1.43)	1.08(0.79-1.4)				
Other	0.25 (0.06-1.05)	1.00(0.751.10) 1.37(0.87-2.14)				
Gender	0.20 (0.00 1.00)	1.07 (0.07 2.11)				
Male	REF	REF				
Female	0.69(0.34 - 1.42)	0.85(0.73-1)				
Age		0.00 (0.70 1)				
18–39 years	REF	REF				
40–49 years	1.79 (0.67-4.81)	0.98(0.7-1.38)				
50–59 years	2.11 (0.81-5.5)	1.04 (0.76–1.43)				
60–69 vears	2.88 (0.79–10.52)	0.85(0.61-1.17)				
70–79 years	3.06 (0.7-13.45)	1 07 (0 74–1 56)				
\geq 80 years	0.95 (0.16-5.65)	1.07(0.7 + 1.00) 1.1(0.7 - 1.72)				
Insurance		(0)				
Medicare	1.45 (0.55-3.82)	0.85(0.65 - 1.12)				
Medicaid	1.28 (0.43-3.79)	0.82 (0.59–1.13)				
Private insurance	REF	REF				
Self-pay, no-charge, or other	1.31 (0.2-8.7)	1.06 (0.63–1.78)				
Median income by ZIP		,				
\$1-\$37.999	0.95 (0.33-2.75)	0.91 (0.71-1.18)				
\$38.000-\$47.999	1 (0.37-2.7)	0.95 (0.75-1.21)				
\$48.000-\$63.999	2.37 (0.74-7.56)	0.97 (0.77-1.21)				
\$64,000 +	REF	REF				
Hospital size						
Small	REF	REF				
Medium	1.7 (0.56-5.14)	1.04 (0.81-1.34)				
Large	0.94 (0.36-2.46)	1 (0.8–1.25)				
Teaching status						
No	1.44 (0.72-2.89)	0.96 (0.81-1.14)				
Yes	REF	REF				
Location						
Northeast	REF	REF				
South	0.45 (0.13-1.53)	0.88 (0.68-1.14)				
Midwest	0.29 (0.09-0.96)	0.94 (0.76-1.17)				
West	1.06 (0.25-4.44)	0.88 (0.68-1.15)				
Elective admission	0 40 (0 17 1 0 4)					
(yes versus no)	0.42 (0.1/-1.04)	0.58 (0.45-0.75)				
Elixhauser comorbidity index (quartiles)						
0–1	REF	REF				
2	1.49 (0.55-4.04)	0.87 (0.64-1.16)				
3	1.23 (0.48-3.16)	1.03 (0.77-1.37)				
4+	1.59 (0.55-4.59)	1.19 (0.88–1.59)				
Diagnoses						
Aspiration pneumonia	0.71 (0.32-1.60)	1.39 (1.2-1.62)				
Dementia	3.27 (1.31-8.20)	0.98 (0.82-1.16)				
Malnutrition	0.94 (0.41-2.15)	0.84 (0.7-1.01)				
Dysphagia	0.53 (0.20-1.39)	0.84 (0.68-1.03)				
Infection, sepsis	0.75 (0.31-1.80)	1.76 (1.51-2.05)				
Delirium, dementia, and						
amnestic and other cognitive	8.18 (1.35-49.66)	0.92 (0.74-1.15)				
disorders						
Mechanical ventilation	1.81 (0.39-8.46)	2.17 (1.72–2.73)				

^a Adjusted for age, race, gender, insurance, median income by ZIP, hospital size and teaching status, geographic location, elective admission, Elixhauser comorbidity index, and year.

activities of daily living), so it is difficult to tell whether the HD patients undergoing gastrostomy in this cohort fall into this category or not.

Our primary outcome analyses revealed that gastrostomy among HD inpatients was associated with prolonged hospital length of stay and discharge to a skilled nursing facility or other facility rather than home. Previous NIS data have shown that inpatient admission for HD in general frequently results in discharge to a facility rather than home, regardless of gastrostomy [16]. This reflects the challenges in maintaining care at home in the presence of motor and cognitive disability.

In addition to providing national data on gastrostomy utilization and outcomes in HD, we also compared the indications and outcomes for gastrostomy between HD and ALS, a neuromuscular disorder for which gastrostomy has been demonstrated to improve survival and quality of life [3]. Inpatient gastrostomy for HD was frequently associated with diagnoses of dysphagia, malnutrition, and aspiration pneumonia, which are all common indications for enteral support in patients with neurologic disease. ALS inpatients receiving gastrostomy had a similar prevalence of dysphagia and malnutrition, but a significantly lower prevalence of aspiration pneumonia compared to HD. We believe this reflects the fact that gastrostomy is initiated earlier in ALS, often prior to an aspiration pneumonia or other sentinel decompensation event, than in HD, in accordance with clinical guidelines [3]. However, it is difficult to definitively ascertain from claims data whether aspiration pneumonia occurred before or after gastrostomy, and it is also possible that ALS patients receive earlier speech therapy and other non-surgical interventions to prevent aspiration compared to HD. Inpatient gastrostomy for HD was also associated with a greater odds of nonroutine discharge than inpatient gastrostomy for ALS, again reflecting the fact that other variables besides gastrostomy affect discharge outcomes. Given that dementia is a key driver of nursing home placement in the older adult population, especially in the setting of neurodegenerative disease, we hypothesize that the increased prevalence of dementia in HD compared to ALS at least partly explains this difference in discharge outcome.

Hospital length of stay and discharge outcomes are frequently grouped together for analysis in health services research, but we observed an important difference in their risk factors among HD inpatients with gastrostomy: intrinsic HD-related comorbidities (e.g. dementia, delirium) were associated with discharge outcome but not length of stay, whereas infectious complications and other medical comorbidities (e.g. aspiration pneumonia, sepsis, Elixhauser comorbidity index) were associated with length of stay but not discharge outcome. This has important implications for the potential benefits of future healthcare interventions. Specifically, interventions to prevent aspiration pneumonia or other infectious complications may reduce length of stay but may not determine the ultimate hospitalization outcome at discharge. Likewise, the presence of dementia may limit measures designed to increase the probability of home discharge.

Limitations of this study include its reliance on administrative claims coding of HD, which has not previously been validated [17], though we estimate misclassification of HD to be low as it is a discrete disorder with a single confirmatory genetic test rather than a purely clinical diagnosis without defined confirmatory testing. As the NIS dataset consists solely of inpatient data, we were unable to obtain information regarding genetic testing, symptom duration and treatment, or precise nutritional status (e.g. weight or body mass index). As neurologic severity and malnutrition are associated with both gastrostomy utilization and health outcomes, these could have confounded the associations between gastrostomy and outcomes such as LOS and discharge status. We are also unable to capture outpatient surgical encounter data, and the proportion of gastrostomies performed for HD on an inpatient vs. outpatient basis is unknown. Additionally, because the NIS is an encounter-level rather than patient-level database, it is possible that the same patient was admitted and counted more than once. Nevertheless, we were able to demonstrate important clinical and demographic factors associated with gastrostomy utilization and outcomes in HD and key differences from ALS using a nationally representative patient sample.

In summary, gastrostomy tube placement for HD frequently co-occurs with aspiration pneumonia, delirium, and dementia and is associated with prolonged LOS and discharge to skilled nursing facilities. Future studies of gastrostomy in HD care should examine the timing of gastrostomy with respect to dysphagia vs. dementia, the use of palliative care services, and patient-reported outcomes such as quality of life.

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CRediT authorship contribution statement

Ali G. Hamedani: Conceptualization, Funding acquisition, Methodology, Writing - original draft, Writing - review & editing. Meredith Pauly: Conceptualization, Writing - review & editing. Dylan P. Thibault: Data curation, Formal analysis, Methodology. Pedro Gonzalez-Alegre: Conceptualization, Writing - review & editing. Allison W. Willis: Conceptualization, Funding acquisition, Methodology, Writing - review & editing.

Declaration of competing interest

The authors report no conflicts of interest.

References

- C. Kay, M.R. Hayden, B.R. Leavitt, Epidemiology of Huntington disease, Handb. Clin. Neurol. 144 (2017) 31–46, https://doi.org/10.1016/B978-0-12-801893-4.00003-1.
- [2] T. Stavroulakis, C.J. McDermott, Enteral feeding in neurological disorders, Pract. Neurol. 16 (5) (2016) 352–361, https://doi.org/10.1136/practneurol-2016-001408.
- [3] R.G. Miller, C.E. Jackson, E.J. Kasarskis, et al., Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology, Neurology. 73 (15) (2009) 1218–1226, https://doi. org/10.1212/WNL0b013e3181bc0141.
- [4] American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, American Geriatrics Society feeding tubes in advanced dementia position

statement, J. Am. Geriatr. Soc. 62 (8) (2014) 1590–1593, https://doi.org/10.1111/jgs.12924.

- [5] A.-W. Heemskerk, R.A.C. Roos, Dysphagia in Huntington's disease: a review, Dysphagia. 26 (1) (2011) 62–66, https://doi.org/10.1007/s00455-010-9302-4.
- [6] Agency for Healthcare Research and Quality R MD, HCUP National Inpatient Sample (NIS), Healthcare Cost and Utilization Project (HCUP), 2012. www.hcup-us.ahrq.gov/ nisoverview.jsp.
- [7] B.J. Moore, S. White, R. Washington, N. Coenen, A. Elixhauser, Identifying increased risk of readmission and in-hospital mortality using hospital administrative data: the AHRQ Elixhauser Comorbidity index, Med. Care 55 (7) (2017) 698–705, https://doi. org/10.1097/MLR.00000000000735.
- [8] E. Bruzelius, J. Scarpa, Y. Zhao, S. Basu, J.H. Faghmous, A. Baum, Huntington's disease in the United States: variation by demographic and socioeconomic factors, Mov Disord Off J Mov Disord Soc. 34 (6) (2019) 858–865, https://doi.org/10.1002/mds.27653.
- [9] P.H. Gordon, J.M. Mehal, A.S. Rowland, J.E. Cheek, M.L. Bartholomew, Huntington disease among the Navajo: a population-based study in the Navajo Nation, Neurology. 86 (16) (2016) 1552–1553, https://doi.org/10.1212/WNL.00000000002486.
- [10] T. Pringsheim, K. Wiltshire, L. Day, J. Dykeman, T. Steeves, N. Jette, The incidence and prevalence of Huntington's disease: a systematic review and meta-analysis, Mov Disord Off J Mov Disord Soc. 27 (9) (2012) 1083–1091, https://doi.org/10. 1002/mds.25075.
- [11] U.K. Braun, L. Rabeneck, L.B. McCullough, et al., Decreasing use of percutaneous endoscopic gastrostomy tube feeding for veterans with dementia-racial differences remain, J. Am. Geriatr. Soc. 53 (2) (2005) 242–248, https://doi.org/10.1111/j.1532-5415.2005. 53109.x.
- U.S Census Bureau, QuickFacts, https://www.census.gov/quickfacts/fact/table/US/ PST045218, Accessed date: 19 December 2019.
- [13] M.D. Rawlins, N.S. Wexler, A.R. Wexler, et al., The prevalence of Huntington's disease, Neuroepidemiology. 46 (2) (2016) 144–153, https://doi.org/10.1159/000443738.
- [14] Huntington Study Group PHAROS Investigators, At risk for Huntington disease: the PHAROS (Prospective Huntington At Risk Observational Study) cohort enrolled, Arch. Neurol. 63 (7) (2006) 991–996, https://doi.org/10.1001/archneur.63.7.991.
- [15] G.B. Landwehrmeyer, C.J. Fitzer-Attas, J.D. Giuliano, et al., Data analytics from enroll-HD, a global clinical research platform for Huntington's disease, Mov Disord Clin Pract. 4 (2) (2017) 212–224, https://doi.org/10.1002/mdc3.12388.
- [16] R.M. Dubinsky, No going home for hospitalized Huntington's disease patients, Mov Disord Off J Mov Disord Soc. 20 (10) (2005) 1316–1322, https://doi.org/10.1002/ mds.20589.
- [17] C. St Germaine-Smith, A. Metcalfe, T. Pringsheim, et al., Recommendations for optimal ICD codes to study neurologic conditions: a systematic review, Neurology. 79 (10) (2012) 1049–1055, https://doi.org/10.1212/WNL.0b013e3182684707.