REVIEW

Health Services in Huntington Disease

A Systematic Literature Review

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Abstract

Purpose of Review

Clinical trials for Huntington disease (HD) have primarily focused on managing chorea and, more recently, the development of disease-modifying therapies (DMTs). Nonetheless, understanding health services among patients with HD is essential for assessing new therapeutics, development of quality metrics, and overall quality of life of patients and families with HD. Health services assess health care utilization patterns, outcomes, and health care–associated costs, which can help shape the development of therapeutics and aid in policies that affect patients with a specific condition. In this systematic literature review, we analyze data of published studies looking at causes of hospitalization, outcomes, and health care costs in HD.

Recent Findings

The search yielded 8 articles published in the English language and comprising data from the United States, Australia, New Zealand, and Israel. The most common cause of hospitalization among patients with HD was dysphagia or dysphagia-related complications (e.g., aspiration pneumonia or malnutrition), followed by psychiatric or behavioral symptoms. Patients with HD had more prolonged hospitalizations than non-HD patients, and it was most prominent among those with advanced disease. Patients with HD were more likely to be discharged to a facility. A small percentage received inpatient palliative care consultation, and behavioral symptoms were a primary cause of discharge to another facility. Interventions such as gastrostomy tube placement had associated morbidity, and it was common among patients with HD with a diagnosis of dementia. Palliative care consultation and specialized nursing care were associated with more routine discharges and fewer hospitalizations. In terms of cost, patients with HD with private and public insurances had the highest expenditure with more advanced disease, and expenses were associated with hospitalization and medication costs.

Summary

In addition to DMTs, HD clinical trial development should also consider the leading causes of hospitalization, morbidity, and mortality in patients with HD, including dysphagia and psychiatric disease. No research study, to our knowledge, has systematically reviewed health services research studies in HD. Evidence from health services research is needed to evaluate the efficacy of pharmacologic and supportive therapies. This type of research is also critical in understanding health care costs associated with the disease and to better advocate and shape policies that can benefit this patient population.

Huntington disease (HD) is an autosomal dominant neurogenetic condition that presents with a triad of behavioral dysfunction, involuntary movements, and cognitive impairment. Symptoms usually present between the ages of 30 and 40 years, and life expectancy is between 10 and 20 years after diagnosis. Three disease stages exist based on the level of functional impairment of the individual, with people in early stages presenting with psychiatric and behavioral symptoms and

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those in late stages exhibiting significant physical disabilities, swallowing dysfunction, and dementia. Current HD epidemiology data report a prevalence of 4–7 per 100,000 persons among most European countries, although in certain regions such as British Columbia, Canada, it may be as high as 13.7 per 100,000.[1,2] In the United States, it is estimated that the incidence rate of HD over 14 years is about 1.22 per 100,000 persons.[3]

Given a young age at onset during critical years of peak income potential, patients with HD are at risk of losing employment at an early age because of physical, mental, and cognitive disabilities before retirement. These features also lead to high health care expenditure for patients and families, leading to a generational downward socioeconomic drift in families with HD. Furthermore, individuals with a family history or a confirmed HD diagnosis are often denied long-term care disability insurance.[4]

HD research has focused on improving the biological understanding of the disease and the development of symptomatic treatments and disease-modifying therapies (DMTs) to halt the progression of the disease. Many DMTs involve genetic manipulations with complex modes of delivery through lumbar punctures or direct brain injections. These modes of delivery raise concerns about the cost and accessibility of these therapies.[5-7]

Given the potentially high costs of DMTs, understanding health care utilization patterns, outcomes, and costs will become increasingly important, as new HD therapeutics enter the market. This information will be important in the development of HD quality metrics. This review summarizes existing health services research in HD, including health care utilization patterns, outcomes, and associated costs. Based on the current literature, we discuss gaps in HD health services research and HD-specific policy suggestions.

Methods

We performed a systematic literature review using MEDLINE, reviewing primary literature published between 2000 and 2021. The search took place between November 2021 and April 2022. One author (A.M.) conducted a literature extraction and examination in November 2021, and the second author (J.D.) examined the extracted literature in March 2022. A review by the second author led to the same findings as the first author. The inclusion criteria included studies on hospitalization patterns in adults with HD and health care costs associated with the disease. We were interested in articles discussing the causes of hospitalization for patients with HD, causes for morbidity/mortality, in-hospital procedures, posthospital discharge and placement, and causes of readmission. The primary MeSH term used was "Huntington's Disease," in addition to health services research terms including "Healthcare Utilization," "Hospitalizations," "Emergency Room," "Emergency Services," and "Healthcare Costs." Literature reviews, case reports, and case studies were excluded from the search. COVID-19–related studies were also excluded because this represents an extraordinary epidemiologic presentation and not usual HD care.

Results

The search yielded 25 articles. Ten abstracts met inclusion criteria. One paper was excluded because it discussed patients' perceived needs and outcomes[8] (Figure). Five studies used the US claims datasets, with the Nationwide Inpatient Sample or National Inpatient Sample being the most used datasets. One study presented claims data from 1 of 4 publicly funded insurance companies in Israel, and the retrospective chart reviews presented data from hospitals in Australia and New Zealand. A total of 8 articles met the inclusion criteria for assessment. One report was not available online nor through an interlibrary loan request. Abstract data from this article are included in the review. Table 1 summarizes the key findings of the articles selected for review.

Patterns of Health Care Utilization

Hospitalized patients with HD tend to be in the late stages of the disease.[9] Late-stage HD and long disease duration were associated with more emergency department services and overnight hospitalizations.[9,10] However, Medicare patients with HD in any stage of the disease were more likely to use emergency department services, be hospitalized, and less likely to use office visits.[9] Based on data using the National Inpatient Sample between 2003 and 2010, there has been a linear increase in the number of HD admissions in the United States.

Of the US studies that presented data on all insurance types, patients with HD were mainly covered by Medicaid or Medicare.[11-13] There was a noteworthy representation of

Figure Literature Review Selection Process

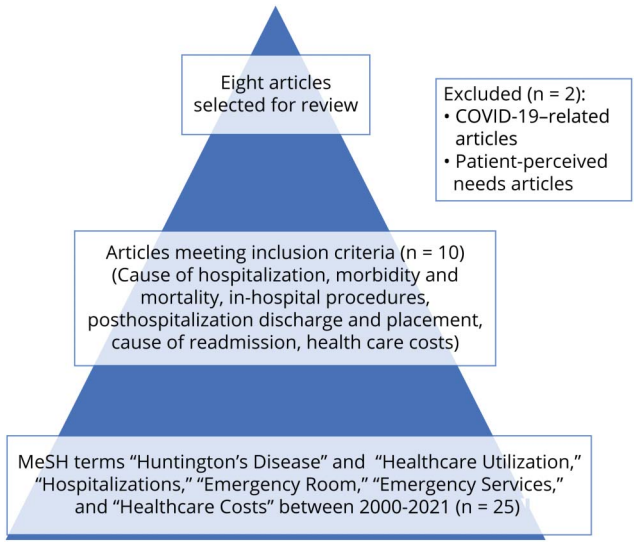

Table 1 Key Findings of Articles Selected for Review

Topic	Article	
Patterns of health care utilization	Dubinsky RM. No going home for hospitalized Huntington's disease patients. *Movement Disorders*. 2005;20(10):1316–1322. https://doi:10.1002/mds.20589	Methods of study Using the Nationwide Inpatient Sample database, patients with Huntington disease were identified. Admission cohorts were determined based on principal diagnosis and procedures. An analysis was made to determine the most common reasons patients with Huntington disease are admitted, understanding the expected payer of HD admissions, and outcomes after being discharged. Key findings Patients with HD were most commonly admitted to the hospital for nonelective care. Medicare and Medicaid most commonly were the funding sources for health care–associated costs. Among those admitted with HD, patients with European ancestry represented a majority of those admitted.
	Exuzides A, Reddy SR, Chang E, et al. Healthcare utilization and cost burden of Huntington's Disease among Medicare beneficiaries in the United States. *Journal of Medical Economics*. Published online November 3, 2021:1-26. https://doi:10.1080/13696998.2021.2002579	Methods of study Retrospective matched cohort study reviewing Medicare fee-for-service (FFS) claims data using Research Identifiable Files (2013–2017) Key findings Most hospitalized patients with HD tend to be in the late stages of the disease (52.1%), 24.8% were in the middle stage, and 23.1% were in the early stage. Significantly, patients in the later stages of HD use hospital care the most.
	Sokol LL, Bega D, Yeh C, Kluger BM, Lum HD. Disparities in palliative care utilization among hospitalized people with Huntington disease: a national cross-sectional study. *The American Journal of Hospice & Palliative Care*. Published online 2021. https://doi:10.1177/10499091211034419	Methods of study Cross-sectional study using the National Inpatient Sample hospital claims dataset, evaluating factors associated with inpatient palliative care consultation for patients with HD Key findings Among all the individuals with HD, only 3.8% of all patients admitted received consultations for palliative care. Significant correlations associated with the likelihood of seeking palliative care existed among the primary payer (private vs Medicare, OR 1.86, 95% CI 1.06–3.27) and median household income (top quartile vs bottom quartile [OR 1.77, 95% CI 1.06–2.95])
	Gavrielov-Yusim N, Barer Y, Martinec M, et al. Huntington's Disease in Israel: A population-based study using 20 years of routinely-collected healthcare data. *Journal of Huntington's Disease*. 2021;10(4):469–477. https://doi:10.3233/JHD-210500	Methods of study Retrospective population-based cohort investigation, studying an extensive dataset, collected over 20 years, from one of the most popular Israeli insurance providers (Maccabi Healthcare services). Key findings As HD progresses, patterns of health care utilization reflected an increase in visits to the emergency department and home health visits. The most common HD-related reasons for health care utilization included anxiety (40%), behavioral problems (34%), sleep disorders (21%), and falls (13%). Forms of treatment included prescriptions for antidepressants (69%), antipsychotics, and tetrabenazine (63%).
Causes of hospitalization	Fisher F, Andrews S, Churchyard A, Mathers S. Home or Residential Care? The Role of Behavioral and Psychosocial Factors in Determining Discharge Outcomes for Inpatients with Huntington's Disease. *Journal of Huntington's Disease*. 2012;1(2):187–193. https://doi:10.3233/JHD-120022	Methods of study Retrospective study of 59 HD hospitalized patient files from Calvary Health Care Bethlehem in Victoria, Australia. An evaluation of causes of hospitalization and health care outcomes in this patient group was conducted. Key findings Advanced cognitive dysfunction (37%), psychosocial difficulties (30%), behavioral complications (42%), psychiatric complications (35%), and physical complications (84%) were the most common complications causing hospitalization of patients with HD.
	Hamedani AG, Pauly M, Thibault DP, Gonzalez-Alegre P, Willis AW. Inpatient gastrostomy in Huntington's disease: Nationwide analysis of utilization and outcomes compared to amyotrophic lateral sclerosis. *Clinical Parkinsonism & Related Disorders*. 2020;3:100041. https://doi:10.1016/J.PRDOA.2020.100041	Methods of study Retrospective cross-sectional study using the National Inpatient Sample hospital claims dataset Key findings Main reasons for feeding tube placement included aspiration pneumonia (34.1%), dementia (31.3%), malnutrition (30.3%), and dysphagia (29.5%)
	Dubinsky RM. No going home for hospitalized Huntington's disease patients. *Movement Disorders*. 2005;20(10):1316–1322. https://doi:10.1002/mds.20589	Key findings Pneumonia (22%) was among the highest cause of hospitalization, followed by psychiatric complications (21.5%), debilitation (15.5%), nonpulmonary infections (11%), and trauma (5.7%).
	Gavrielov-Yusim N, Barer Y, Martinec M, et al. Huntington's Disease in Israel: A Population-based study using 20 years of routinely-collected healthcare data. *Journal of Huntington's Disease*. 2021;10(4):469–477. https://doi:10.3233/JHD-210500	Key findings Late-stage HD and long disease duration were associated with more emergency department services and overnight hospitalizations. Most patients with HD experience complications related to sleep, falls, anxiety, movement control, and cognitive impairment.

Continued

Table 1 Key Findings of Articles Selected for Review *(continued)*

Topic	Article	
Health care outcomes	Dubinsky RM. No going home for hospitalized Huntington's disease patients. *Movement Disorders*. 2005;20(10):1316–1322. http://doi:10.1002/mds.20589	Key findings Most patients were discharged to long-term care facilities (54.4%). Highest mortality was associated with pneumonia (7.68%) and sepsis (7.39%). Of the total, 3.7% faced mortality during admissions.
	Fisher F, Andrews S, Churchyard A, Mathers S. Home or Residential Care? The Role of Behavioral and Psychosocial Factors in Determining Discharge Outcomes for Inpatients with Huntington's Disease. *Journal of Huntington's Disease*. 2012;1(2):187–193. https://doi:10.3233/JHD-120022	Key findings The most common causes for discharge to another facility included financial issues (28.6%), breakdown of formal or informal supports (include 17.9% and 32.1%), lack of stable housing (71.4%), and behavioral difficulties (64.3%). Male patients with HD were more likely to have longer hospital duration in the neurologic inpatient unit discharged and admitted to long-term residential care (p = 0.045).
	Bourke D, Finucane G, Dysart J, Roxburgh R. The Appointment of a Huntington's Disease Nurse Specialist has Reduced Admission Rate and Improved Admission Quality. *Journal of Huntington's Disease*. 2012;1(1):27–30. https://doi:10.3233/JHD-2012-120003	Methods of study Retrospective cohort study using inpatient hospital admission data (Auckland Hospital, New Zealand) and evaluating hospitalization outcomes before and after including an HD nurse in an HD clinic Key findings After appointment of the Huntington disease nurse specialist, a 51% reduction in average monthly HD admission rates was observed, and admissions related to HD was decreased by 54%. Ultimately, the addition of an HD-specialized nurse led to a better quality of admissions and less discharges to a rehabilitation facility.
	Hamedani AG, Pauly M, Thibault DP, Gonzalez-Alegre P, Willis AW. Inpatient gastrostomy in Huntington's disease: Nationwide analysis of utilization and outcomes compared to amyotrophic lateral sclerosis. *Clinical Parkinsonism & Related Disorders*. 2020;3:100041. https://doi:10.1016/J.PRDOA.2020.100041	Key findings Feeding tube placement in patients with the following complications: aspiration pneumonia (OR 1.39, 95% CI 1.2–1.62), mechanical ventilation (OR 2.17, 95% CI 1.72–2.73), and sepsis (OR 1.76, 95% CI 1.81–2.05) were associated with extended hospitalizations and increased in-hospital complications.
	Sokol LL, Bega D, Yeh C, Kluger BM, Lum HD. Disparities in Palliative Care Utilization Among Hospitalized People With Huntington Disease: A National Cross-Sectional Study. *The American Journal Of Hospice & Palliative Care*. Published online 2021. https://doi:10.1177/10499091211034419	Key findings The odds of being discharged to a facility for individuals with HD who obtained palliative care was 0.43 (95% CI 0.32–0.58) times the odds of being discharged to a facility for individuals who did not obtain any palliative care treatment. The odds of in-hospital mortality for patients with HD who received PC was 7.56 (95% CI 5.25–10.88).
Health care costs	Divino V, DeKoven M, Warner JH, et al. The direct medical costs of Huntington's disease by stage. A retrospective commercial and Medicaid claims data analysis. *Journal of Medical Economics*. 2013; 16(8):1043–1050. https://doi:10.3111/13696998.2013.818545	Methods of study Retrospective study using the Medicaid database and Thomson Reuters MarketScan database, evaluating health care costs associated with HD at different disease stages Key findings Average annual cost for individuals with private insurance and in the early stages of HD is $4,947, compared with $22,582 for individuals in late stages with private insurance. Annual costs for individuals with Medicaid coverage in early stages of HD is $3,257, compared with $37,495 for individuals with Medicare and in late stages of HD. Overall, in comparison with commercially insured patients, more Medicaid patients were associated with receiving nursing home care (73.8%), contributing to 54.6% of the total costs in care for patients with late-stage HD. The average annual pharmacy costs per patient increased as HD progressed from the early to late stage. Annual pharmacy costs ranged from $1925 to $3999 for patients with private commercial insurance and $860 to $3094 for Medicaid beneficiaries.
	Exuzides A, Reddy SR, Chang E, et al. Healthcare utilization and cost burden of Huntington's Disease among Medicare beneficiaries in the United States. *Journal of Medical Economics*. Published online November 3, 2021:1-26. https://doi:10.1080/13696998.2021.2002579	Key findings Medicare patients with HD are more likely to endure a higher health care cost burden in comparison with patients without HD and Medicare insured ($41,631 [57,393] vs $17,222 [31,218]). Elevated health care costs were primarily driven by pharmacy costs ($19,182 [45,469] vs $4,318 [11,553]). Among Medicare beneficiaries with HD, total health care costs were highest among individuals with late-stage HD (mean [SD] cost: $20,475 [$41,122] for early stage vs $29,733 [$44,977] for middle stage vs $56,657 [$64,185] for late stage).

Medicare beneficiaries in the US claims data literature.[9,11-13] This finding is notable considering that the average onset of HD is 30–40 years of age, and life expectancy ranges between 10 and 20 years, which suggests that patients with HD with Medicare are eligible because of their level of disability and not necessarily based on age. The over-representation of Medicare benefitiares also indicates that hospitalization data in HD may be biased towards patients with more disability.

Causes of Hospitalization

Most patients with HD were hospitalized because of swallowing dysfunction and its associated complications, psychiatric conditions, cognitive impairment, and physical disabilities.[9-16] Common complications of swallowing dysfunction included aspiration pneumonia, malnutrition, and dehydration.[12] The most common psychiatric conditions associated with admission were depression and anxiety,[9,10,14,15] and regardless of the stage of the disease, most patients with HD were prescribed an antidepressant or anxiolytics.[9,16] Patients with HD with depression were also less likely to receive palliative care consultation services.[13] Although the authors did not explain the reason for this finding, it is possible that those admitted due to depression tended to be younger patients with HD with less advanced disease requiring palliative consultation. Nonetheless, psychiatric illness was a common comorbidity and cause of admission in patients with HD, although it is unclear whether it is associated with a specific disease stage.

Advanced cognitive impairment or dementia is a hallmark of late stages of HD. Cognitive dysfunction, senility, and dementia are common causes of admission in patients with HD.[12,14,16] In a study reviewing feeding tube placements in HD, the authors noted that dementia was commonly associated with this procedure.[11] Feeding tube placement is not recommended for patients with Alzheimer dementia. Physicians recommend against this procedure in this patient group because of high rates of medical complications with little survival benefit or improvement in the quality of life.[17] It is not clear whether there is a survival benefit for patients with HD because quality metrics for HD do not exist currently. Additional studies are necessary to evaluate the cost effectiveness of this procedure in HD.

Health Care Outcomes

Hospitalized patients with HD are likely to be discharged to a long-term care facility.[12,16] In a small study of patients with HD seen in a neurologic unit in Australia, the authors found that psychosocial difficulties, such as financial issues, breakdown of formal or informal supports, and unstable housing, were some of the factors associated with discharge to a long-term facility.[16] The same study found that irritability, aggression, and apathy were associated with a discharge to another facility. On average, these patients also had more prolonged hospitalizations. At the end of life, patients with HD also have high utilization of health care services, including inpatient hospitalizations and emergency department visits.[9] A small percentage, however, of all patients with HD received inpatient palliative care consultation, and privately insured and high-income patients were more likely to receive these services.[13] Feeding tube placement was also associated with more prolonged hospitalizations and in-hospital complications, including death.[11] This same study found that patients with HD with feeding tube placement were more likely to be discharged to a long-term facility, primarily if they had a diagnosis of dementia or delirium during the admission.

Only 2 studies discussed interventions lowering health care utilization. One retrospective study from New Zealand found that HD-specialized nursing services were associated with fewer hospitalizations, a better quality of admissions, and more discharges to patients' original residence.[14] Palliative consultation was also associated with a greater likelihood of discharge to home with services.[13]

Health Care Costs

Admissions for respiratory dysfunction, debilitation, trauma, and sepsis were associated with the highest inpatient hospital charges.[12] For all patients with HD, regardless of the insurance payor type, health care costs increased as the disease progresses.[9,15]

Among commercially insured patients with HD, the average annual cost during the early stages of the disease is $4,947 and in late stages is $22,582.[15] For Medicaid patients, the yearly cost in the early stages is $3,257 and $37,495 in the late stages.[15] Among Medicare beneficiaries, the mean annual cost in early HD was $13,264 compared with $40,761 in late HD.[9]

The main drivers of health care costs varied based on insurance coverage. In commercially insured patients with early-stage HD, most of the expenses were ancillary services, followed by pharmacy costs.[15] With disease progression, there were more costs associated with inpatient hospitalizations. Medicaid beneficiaries also saw a similar trend. With disease progression, the costs shifted from outpatient costs (including ancillary services) and pharmacy costs to inpatient hospitalization costs.[15] Patients with Medicaid were also more likely to use inpatient services in earlier stages of the disease, and pharmacy costs were lower than those commercially insured.

Compared with Medicaid, patients with HD with Medicare incur higher health care costs. In this group, most of the costs are driven by pharmacy costs. On average, patients with HD with Medicare pay $19,182 a year in prescription drugs.[9] Inpatient hospitalizations are the second source of expenses ($13,325), followed by outpatient costs ($10,213). Similarly, with disease progression, there is an increase in health care costs.

Discussion

Patients with HD in late stages are likely to be hospitalized and incur high health care costs, particularly during the end of life.[9,12,15] The most common causes of hospitalizations in patients with HD are those associated with late-stage HD, including swallowing dysfunction and related complications such as aspiration pneumonia, malnutrition, and sepsis.[12] These conditions are also associated with the highest morbidity, mortality, and long inpatient hospitalizations.[12] Psychiatric disorders, behavioral disturbances, and cognitive impairment are other common causes of hospitalization.[10,12,15,16] Patients with HD are also more likely to be discharged to long-term facilities, and dementia, behavioral disturbances, and psychosocial difficulties are associated with a greater likelihood of long-term placement.[11,12,16] Multidisciplinary approaches such

Table 2 Suggestions for Future Health Services Research in HD

- Cost effectiveness of multidisciplinary interventions (i.e., speech and swallow, mental health services, and social work support)
- Studies on HD-specific comorbidities and costs to the health care systems (including mental health services, dysphagia, and falls)
- Cost effectiveness of ancillary testing and procedures
- Long-term care services, outcomes, and costs in HD

as HD-specialized nursing care and palliative care consultation are associated with a lower length of hospitalization and a lower likelihood of discharge to a long-term facility.[13,14] Other interventions such as feeding tube placement may be related to high inpatient comorbidities, and more studies are needed to evaluate its utility in patients with HD.[11]

This literature review highlights critical areas of intervention for developing HD quality metrics and future research areas that can identify cost-effective interventions for the care of patients with HD (Table 2). Swallowing difficulties and their complications were the leading cause of hospitalization for patients with HD. Speech and swallow therapy is crucial in preserving swallowing function and early recognition of interventions necessary to improve swallowing or avoid complications. These therapies may reduce morbidity and mortality associated with malnutrition or aspiration pneumonia. It has been recognized that psychological and psychiatric care is vital in the management of HD. This review found that psychiatric conditions and behavioral disturbances were a common cause of hospitalization. In the United States, however, many challenges continue to exist in accessing mental health services. Considering that mental health illnesses such as substance abuse are also associated with earlier onset of motor symptoms, HD[18,19] psychiatric care should be consistently incorporated in the care of all patients with HD, and policy interventions advocating for better access and reimbursement of mental health services are critical for the adequate care of patients with HD. Other interventions that can reduce health care utilization and costs include palliative and hospice care services and HD-specialized nursing care. Avoiding high health care use at the end of life is important to contain overall health care costs for the health care system but even more so for families with HD who may be at risk of developing the disease themselves, along with its related financial difficulties. More studies evaluating the cost effectiveness of multidisciplinary interventions in HD care are needed.

For patients at all stages of HD, there are high health care costs associated with ancillary services. Future research needs to identify which patients with HD are using ancillary services and whether these services are warranted.[15] Given the health care costs associated with HD, policy interventions should be considered (Table 3). First of all, access to general health care services is key for the prompt diagnosis and early management of HD. In the United States, patients with disabilities are eligible for Medicare coverage, and many patients with HD qualify because of physical and cognitive disabilities associated with the disease. However, patients with a disability, including patients with HD, must wait 2 years before they are eligible for Medicare, which could lead to lapses in health care coverage during those 2 years and financially catastrophic out-of-pocket expenses for patients and their families. Among hospitalized patients with HD, most of them are discharged to long-term care facilities. In the United States, these services are not covered by Medicare, and most families pay out-of-pocket costs for these services. Policies expanding long-term care coverage for Medicare beneficiaries will benefit patients with HD and their families. Controlling prescription drug pricing is another important policy that will reduce health care costs for patients with HD, particularly Medicare beneficiaries. HD is a progressively disabling disease, and at some point, most patients with HD will become Medicare eligible before reaching the age of 65 years. Controlling drug prescription costs is also essential for this patient population and even more so with the development of DMTs with complex and costly delivery modes. Pharmaceutical companies should also consider including health care utilization as an outcome of interest during the drug development stage. Furthermore, additional health economics studies should be conducted to compare the overall health care costs of HD with other neurodegenerative conditions and use this information to shape policy around neurologic conditions.

As with any literature review, the initial search might not have captured all articles on health care utilization in HD. Most of the studies used US-based claims datasets, and these datasets used 5%–20% of hospital samples in the United States. These samples may not be representative of all HD care in the United States. These datasets also do not include data from long-term care or psychiatric facilities. US health care system structure may also lead to many patients with HD not having access to health care and never coming in contact with the

Table 3 Proposed Policy Interventions

- Ensuring general health care access for early diagnosis and management of HD
- Include long-term care coverage as part of Medicare services
- Medicare prescription drug pricing negotiations
- Waive 2-year disability Medicare eligibility criteria for patients with HD
- Expand Medicaid and Medicare coverage of supportive therapies, including speech and swallow, palliative care, and home services

TAKE-HOME POINTS

- This literature review highlights patterns of health care utilization, causes of hospitalization, health care outcomes, and health care costs in HD, information that can be used to develop HD quality metrics and identify cost-effective interventions for the care of patients with HD and their families.
- The most common causes of hospitalizations in patients with HD are among those classified in late-stage HD and associated with complications of swallowing dysfunction, all of which are correlated with high morbidity and complications during hospitalization.
- Multidisciplinary approaches to treatment such as HD-specialized nursing care and palliative care may be associated with decreased duration of hospitalization, and policy interventions should consider greater support for nursing and palliative care in HD.
- Extreme costs associated with care and treatment for patients with HD reveal the importance of implementing innovative policies such as expanding long-term care coverage for Medicare beneficiaries and controlling prescription drug pricing.

health system. Claim datasets also use unique identifiers, which prevent the identification of multiple admissions for the same patient. These datasets do not identify conditions that require multiple hospitalizations each year. This limitation may underrepresent the severity of some comorbidities. We also presented data from 4 health care systems (Australia, Israel, New Zealand, and the United States). Given the differences in each system, there may be different incentives and resources available to patients, leading to differences in health care utilization and outcomes.

This study showed that health care utilization in HD is driven by patients with late-stage disease and its associated complications of swallowing dysfunction, psychiatric illness, and cognitive impairment. These comorbidities are associated with high health care utilization and high health care costs. More cost-effectiveness studies are needed to create quality metrics for HD care and reduce health care utilization and costs. Quality metrics, including health care utilization and outcomes, should guide the development of new therapeutic agents and improve health care outcomes in HD.

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Disclosure

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