Burden of illness among US Medicare beneficiaries with late-onset Huntington's disease

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What does this study mean for the Huntington's disease (HD) community?

People with late-onset HD (LoHD) can require extensive care, yet there is little information about the burden of illness in LoHD. We address this knowledge gap by describing the extent of healthcare resource utilization and costs among US Medicare beneficiaries with LoHD. Our results highlight a significant unmet medical need within this HD population.

Conclusions

- Medicare beneficiaries with late-onset Huntington's disease (HD) had greater healthcare resource utilization and higher costs compared with beneficiaries without HD over 3 years post-index.
- These results highlight a significant unmet medical need within this HD population.

BACKGROUND

- Huntington's disease (HD) is a rare, genetic neurodegenerative disease that is ultimately fatal and has a devastating impact on families across generations.[1,2]
- HD is typically diagnosed between the ages of 30 and 50 years, but 4.4–11.5% of affected individuals are aged >60 years at disease onset (late-onset HD [LoHD]).[2,3]
- Although people with LoHD can require extensive care, limited evidence exists for the burden of illness in LoHD.
- This study describes healthcare resource utilization (HRU) and costs among US Medicare beneficiaries with LoHD.

Objective

To examine HRU and costs among US Medicare beneficiaries with LoHD.

METHODS

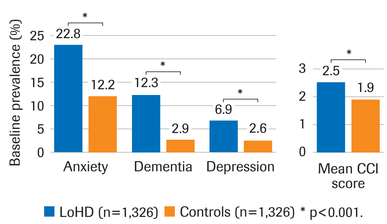
- This was a retrospective, longitudinal cohort study using 2008–2017 Medicare Research Identifiable Files (100%).
- We identified Medicare beneficiaries with newly diagnosed LoHD, defined as:
  - having ≥1 medical claims with an HD diagnosis between 2009 and 2014
  - being ≥60 years old at first HD diagnosis (index date) and having no HD claims for 1 year prior to the index date.
- We identified beneficiaries without HD (controls) using a 5% random sample of Medicare beneficiaries, who were matched to beneficiaries with LoHD 1:1 on age, sex, geographic region, and index year.
- All beneficiaries were continuously enrolled in Medicare fee-for-service (FFS) Part A/B and Part D for 1 year before and 3 years after the index date.
- Baseline demographic and clinical characteristics were measured during the 1-year pre-index period.
- We measured all-cause HRU and costs (in 2017 US dollars [USD]) over 3 years post-index and compared groups using chi-square tests (categorical variables) and t-tests (continuous variables).
- Among beneficiaries with LoHD, all-cause and HD-related HRU and costs were further stratified by disease stage (early/middle/late) as determined by the presence of disease markers (i.e. diagnoses and services) in claims (**see Table S1 in Supplementary materials**).[4]

RESULTS

Baseline demographics and comorbidities

- A total of 2,652 Medicare beneficiaries were included in the analysis (1,326 with LoHD and 1,326 controls).
- Beneficiaries were mostly female (64.4%) and had a mean (standard deviation [SD]) age of 74.7 (7.4) years.
- Beneficiaries with LoHD had a higher mean Charlson Comorbidity Index (CCI) and prevalence of anxiety, dementia, and depression than controls **(Figure 1)**.

Figure 1. Baseline comorbidities



Beneficiaries with LoHD had higher prescription drug use compared with matched controls

- The use of antidepressants, anxiolytics, anti-epileptics, and antispasticity drugs was higher in beneficiaries with LoHD compared with controls in Years 1–3 post-index **(Figure 2)**.

Figure 2. Prescription drug use

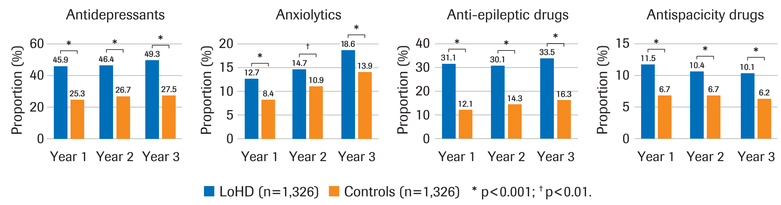
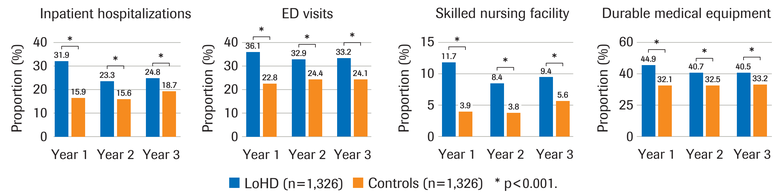


Figure 3. All-cause HRU

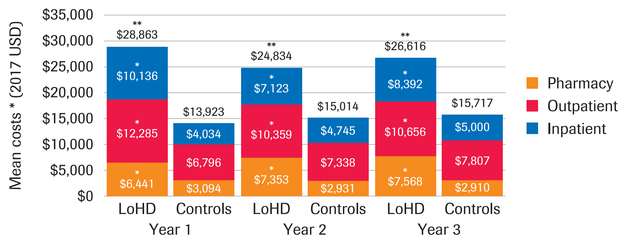


At Years 1–3 post-index, all-cause HRU and healthcare costs remained significantly higher among beneficiaries with LoHD compared with matched controls (Figure 3 and 4)

A higher proportion of LoHD beneficiaries had hospitalizations, emergency department (ED) visits, skilled nursing facility (SNF) stays, and durable medical equipment (DME) utilization than matched controls **(Figure 3)**.

- Mean (SD) office visits were higher in LoHD beneficiaries compared with controls (Year 1: 18.0 [15.4] vs. 13.4 [11.6]; Year 2: 16.0 [14.8] vs. 13.8 [12.6]; Year 3: 15.5 [15.2] vs. 13.9 [12.7]; all p<0.01).
- Higher mean annual total costs for LoHD beneficiaries were driven by higher outpatient medical costs **(Figure 4)**.

Figure 4. Mean all-cause healthcare costs



* Rounded to nearest USD. ** p<0.001. Inpatient costs: acute hospitalization, SNF, and hospice services; Outpatient costs: outpatient hospital, ED, office, lab, or other outpatient services. Pharmacy costs represented outpatient pharmacy costs.

Limitations

- Our study was limited to the Medicare FFS population; therefore, these results may not be generalizable to individuals enrolled in Medicare-managed care plans or other types of insurance (e.g. Commercial, Medicaid).
- Our analysis of Medicare claims data did not consider indirect costs and may not fully capture disease burden among Medicare beneficiaries with LoHD.

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Abbreviations

CCI, Charlson Comorbidity Index; DME, durable medical equipment; ED, emergency department; FFS, fee-for-service; HD, Huntington's disease; HRU, healthcare resource utilization; LoHD, late-onset HD; SD, standard deviation; SNF, skilled nursing facility; USD, US dollars.

References

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4. Divino V, et al. *JME*. 2013; 16:1043–1050.

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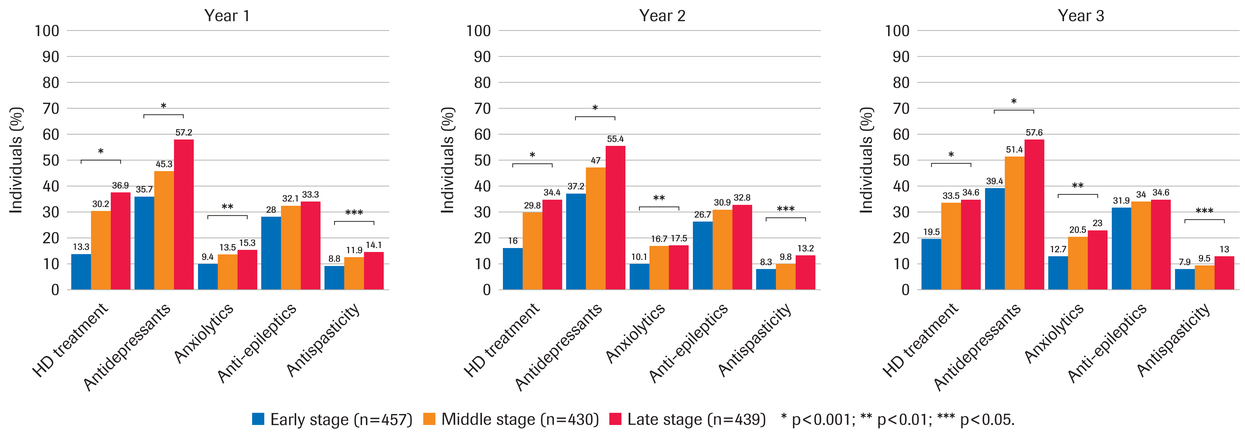
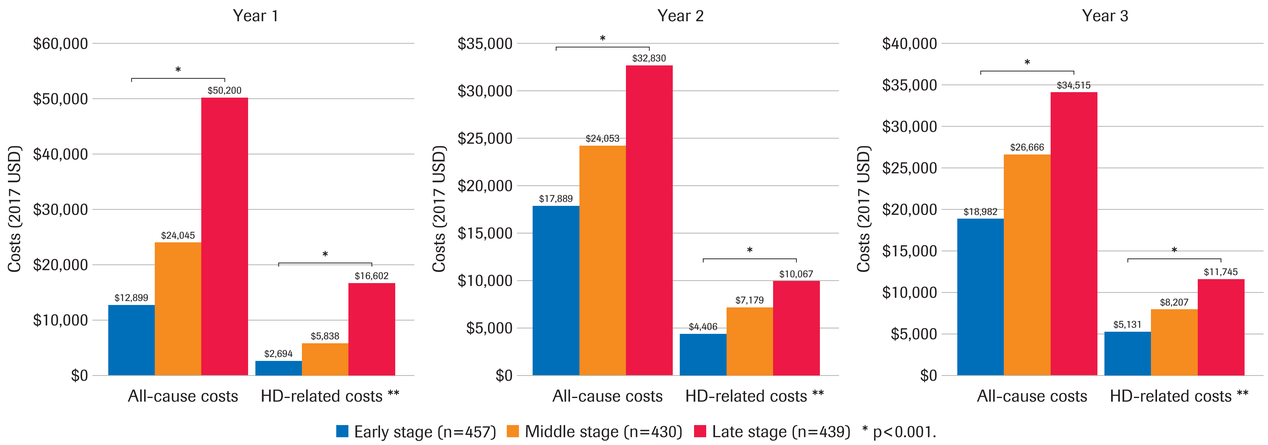
Supplementary materials

Figure S1. Prescription drug use stratified by Huntington's disease (HD) stage



HD treatment includes the following: tetrabenazine, deutetrabenazine, glutamatergic-modifying drugs, donepezil, minocycline, nabilone, coenzyme Q10, neuroleptics, energy metabolites.

Figure S2. Mean all-cause and HD-related total healthcare costs stratified by HD stage



Costs include inpatient, outpatient and pharmacy costs. ** Claims with any diagnosis of HD, HD symptoms or HD treatment.

Table S1. All-cause and HD-related healthcare resource utilization stratified by HD stage

		Early stage (n=457)	Middle stage (n=430)	Late stage (n=439)	p-value
Year 1	All-cause hospitalizations, n (%)	56 (12.3)	116 (27.0)	251 (57.2)	<0.001
	All-cause ED visits, n (%)	96 (21.0)	175 (40.7)	208 (47.4)	<0.001
	All-cause office visits, mean (SD)	14.8 (11.4)	20.3 (16.2)	19.1 (17.5)	<0.001
	HD-related* hospitalizations, n (%)	27 (5.9)	71 (16.5)	160 (36.4)	<0.001
	HD-related* ED visits, n (%)	21 (4.6)	39 (9.1)	73 (16.6)	<0.001
	HD-related* office visits, mean (SD)	1.9 (4.6)	2.2 (3.5)	2.6 (5.2)	0.076
Year 2	All-cause hospitalizations, n (%)	84 (18.4)	93 (21.6)	132 (30.1)	<0.001
	All-cause ED visits, n (%)	126 (27.6)	142 (33.0)	168 (38.3)	0.003
	All-cause office visits, mean (SD)	14.8 (12.1)	17.3 (15.5)	16.0 (16.4)	0.035
	HD-related* hospitalizations, n (%)	32 (7.0)	46 (10.7)	75 (17.1)	<0.001
	HD-related* ED visits, n (%)	31 (6.8)	29 (6.7)	48 (10.9)	0.033
	HD-related* office visits, mean (SD)	1.2 (3.1)	1.6 (3.9)	1.7 (3.8)	0.147
Year 3	All-cause hospitalizations, n (%)	80 (17.5)	101 (23.5)	148 (33.7)	<0.001
	All-cause ED visits, n (%)	118 (25.8)	156 (36.3)	166 (37.8)	<0.001
	All-cause office visits, mean (SD)	15.2 (12.3)	17.1 (17.3)	14.4 (15.6)	0.027
	HD-related* hospitalizations, n (%)	34.0 (7.4)	54 (12.6)	94 (21.4)	<0.001
	HD-related* ED visits, n (%)	27 (5.9)	39 (9.1)	53 (12.1)	0.005
	HD-related* office visits, mean (SD)	1.3 (3.4)	1.7 (4.8)	1.6 (3.7)	0.325

* Claims with any diagnosis of HD, HD symptoms or HD treatment.

Acknowledgments

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Abbreviations

ED, emergency department; HD, Huntington's disease; SD, standard deviation; USD, US dollars.

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