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

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Presenter disclosures: Jamie Ta is an employee of Genentech Inc.

Objective: To examine healthcare resource utilization (HRU) and costs among US Medicare beneficiaries with late-onset Huntington's disease (LoHD).

What does this mean for the HD community?

People with late-onset Huntington's disease (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 (HRU) and costs among US Medicare beneficiaries with LoHD. Our results highlight a significant unmet medical need within this HD population.

Background

- Limited evidence exists for the burden of illness in LoHD.

Methods

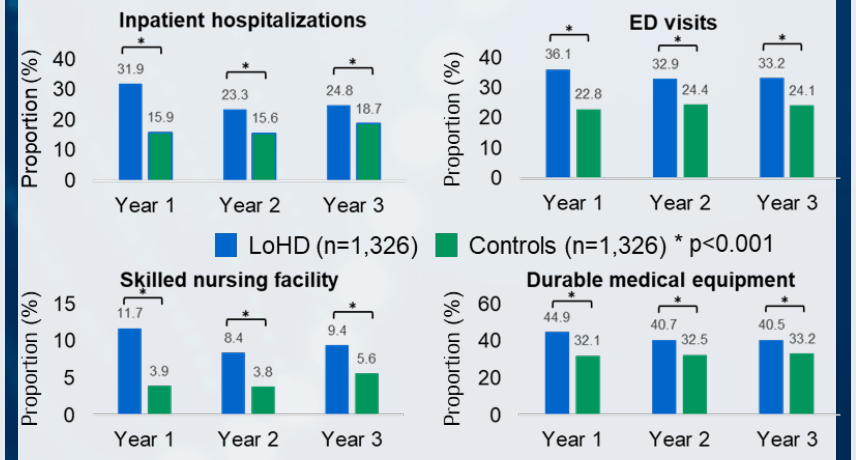
- This was a retrospective longitudinal cohort study using 2008–2017 Medicare Research Identifiable Files (100%).
- We identified Medicare beneficiaries (N=2,652): 1,326 with newly diagnosed LoHD and 1,326 beneficiaries without HD (controls), and matched them 1:1 on age, sex, geographic region, and index year.
- We measured all-cause HRU and costs over 3 years, and compared groups using chi-square tests (categorical variables) and t-tests (continuous variables).

Conclusions

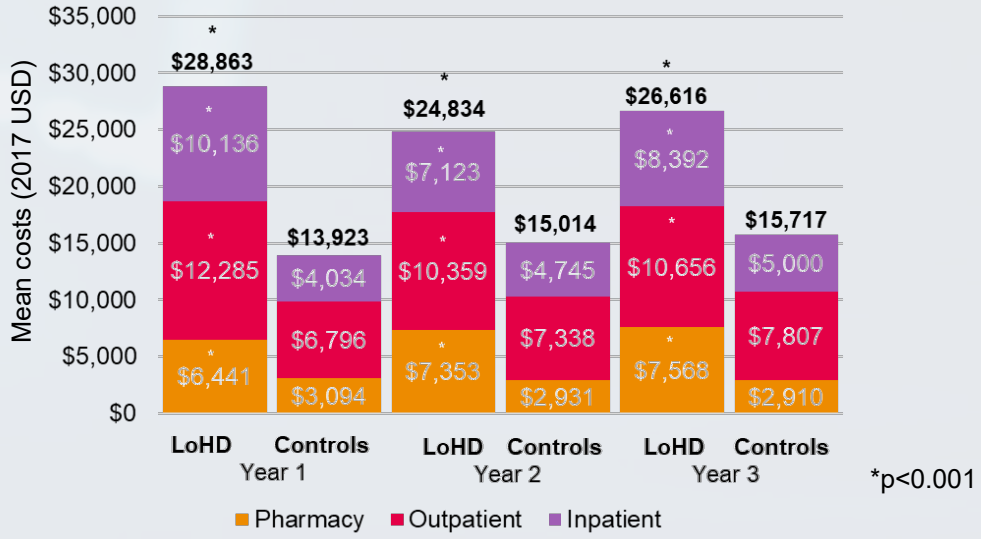
- Compared with controls, LoHD Medicare beneficiaries had greater HRU and higher healthcare costs.

LoHD beneficiaries had higher prevalence of anxiety, dementia, and depression than controls at baseline

All-cause HRU and prescription drug use were higher in LoHD beneficiaries compared with controls in Years 1–3 post-index



At Years 1–3 post-index, mean all-cause healthcare costs remained higher among LoHD beneficiaries compared with controls



All-cause and HD-related HRU, prescription drug use, and costs increased with HD disease stage (Supplementary materials)

References, abbreviations and acknowledgments ›

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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 over 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.

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 one or more medical claims with an HD diagnosis between 2009 and 2014
  - being at least 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) over 3 years post-index and compared groups using chi-square tests (categorical variables) and t-tests (continuous variables).
- Among LoHD beneficiaries, 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.[4]

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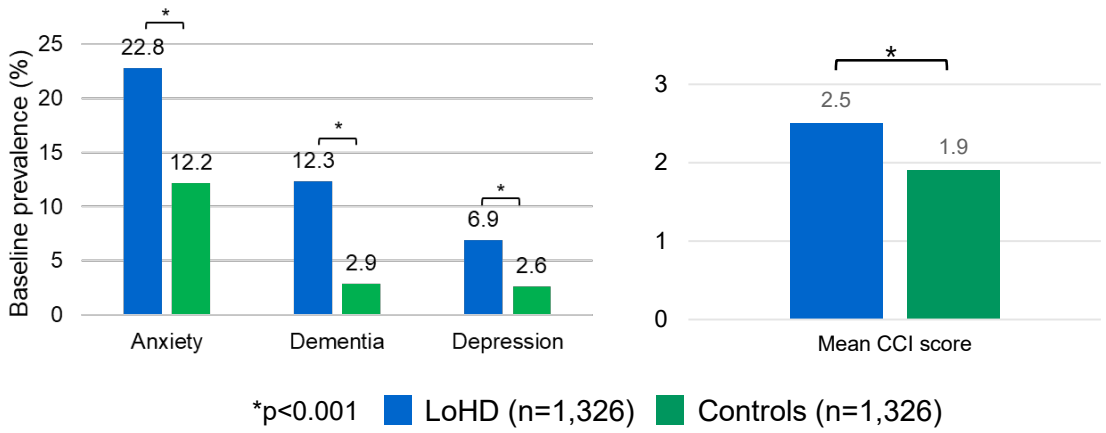
Baseline demographics and comorbidities

- 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.
- LoHD beneficiaries had a higher mean Charlson Comorbidity Index (CCI) and prevalence of anxiety, dementia, and depression than controls (**Figure 1**).

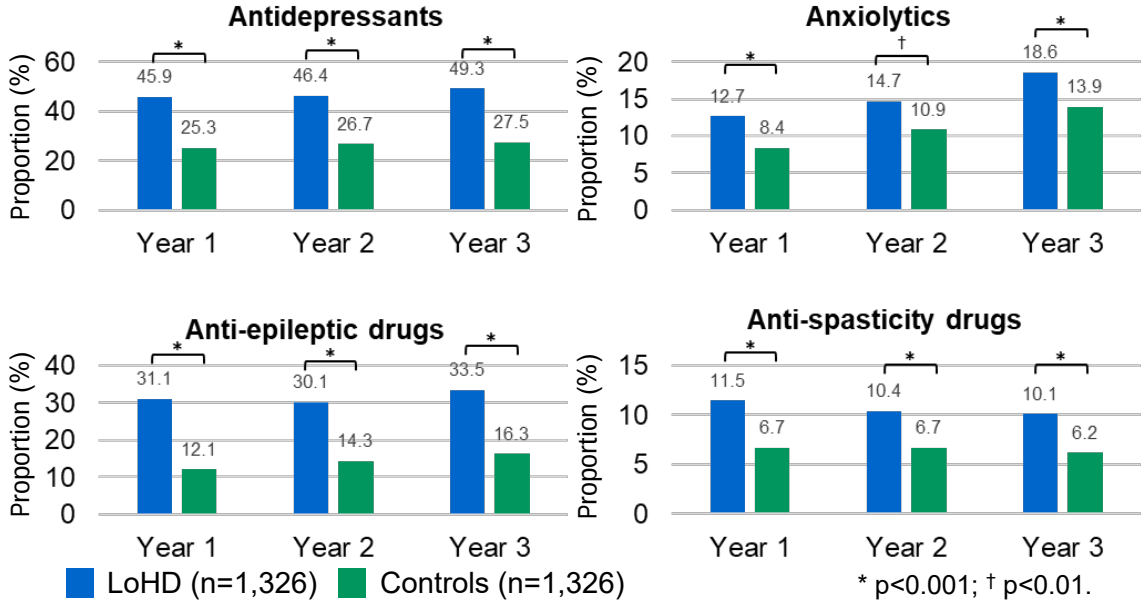
Figure 1. Baseline comorbidities



LoHD beneficiaries had higher prescription drug use compared with matched controls

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

Figure 2. Prescription drug use



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At Years 1–3 post-index, all-cause HRU and healthcare costs remained significantly higher among LoHD beneficiaries compared with matched controls (Figure 4 and 5)

- 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 was 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 3: All-cause HRU

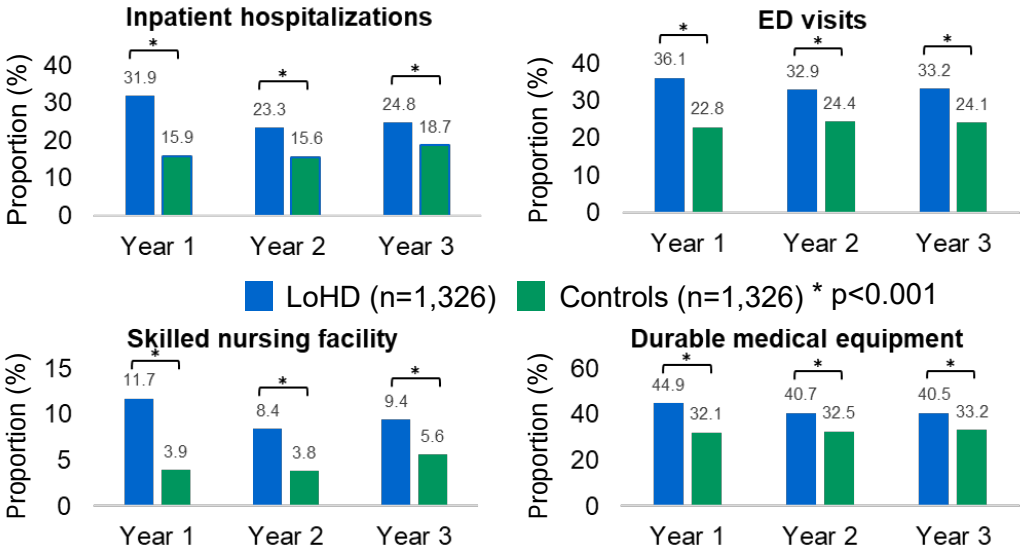
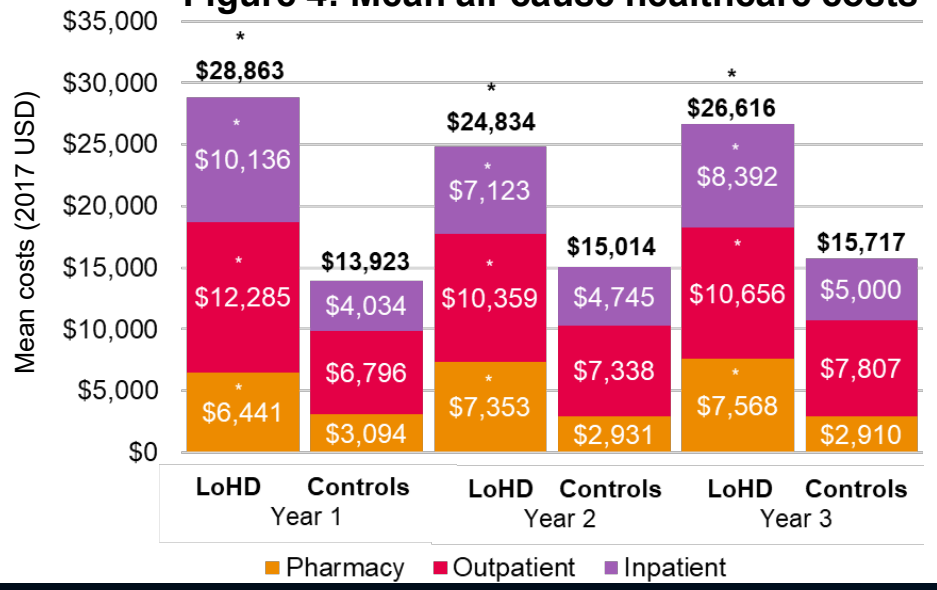


Figure 4: Mean all-cause healthcare costs



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.

* p<0.001

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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.

Conclusions

- LoHD Medicare beneficiaries had greater HRU 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.

References

1. Bates GP, et al. *Nat Rev Dis Primers*. 2015; 1:15005; 2. Roos RA. *Orphanet J Rare Dis*. 2010; 5:40;
3. Chaganti SS, et al. *J Huntingtons Dis*. 2017; 6:95–103; 4. Divino V, et al. *JME*. 2013; 16:1043–1050.

Abbreviations

CCI, Charlson Comorbidity Index; DME, durable medical equipment; ED, emergency department; FFS, fee for service; HD, Huntington's disease; HRU, healthcare resource utilization; ICD-9-CM, International Classification of Diseases Ninth Revision Clinical Modification; ICD-10-CM, International Classification of Diseases Tenth Revision Clinical Modification; LoHD, late-onset Huntington's disease; SD, standard deviation; SNF, skilled nursing facility; USD, United States dollars.

Acknowledgments

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