Healthcare utilization and cost burden at the end of life among Medicare beneficiaries with Huntington's disease

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

Currently, little is known about the economic costs and healthcare use for end-of-life care in HD. This study demonstrates that hospice care and HD treatments are the most common healthcare resources used by Medicare beneficiaries with HD during the months preceding death, while the highest costs are due to inpatient care. These results may guide future insurance plans for individuals with HD, though the results of this study may not be generalized to other patient populations not included in the study.

Objective

To examine healthcare utilization (HCU) and costs occurring at the end of life among deceased Medicare beneficiaries who were diagnosed with Huntington's disease (HD).

Conclusions

- Huntington's disease (HD) is associated with substantial healthcare utilization (HCU) and costs at the end-of-life, with the greatest resource utilization occurring in the final few months of life, often when individuals are in late-stage HD.
- Hospice care and HD drug treatments were most commonly used preceding death.
- Highest healthcare costs at the end of life resulted from inpatient and outpatient healthcare, both of which are higher in HD Medicare beneficiaries than in the general Medicare population.[1]

BACKGROUND

- HD is characterized by a triad of cognitive, behavioral and motor symptoms leading to functional decline.[2,3]
- HD can be described as a continuum and onset of symptoms may occur earlier (juvenile-onset HD; ≤20 years) or later (elderly-onset HD; ≥60 years) in life.[4,5]
- HD results in increasing disability, loss of independence and death, with a median survival of 15 years after the onset of unequivocal motor symptoms.[6]
- This retrospective study investigated end-of-life HCU and costs among Medicare beneficiaries using 2013–2017 Medicare Research Identifiable Files (100%).

METHODS

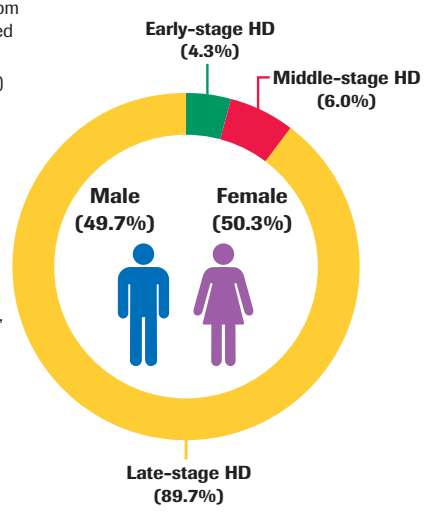
- Beneficiaries were identified if they had a diagnosis of HD, defined by the presence of ≥1 medical claim with a diagnosis code for HD (International Classification of Diseases [ICD]-9-CM: 333.4; ICD-10-CM: G10) during 2013–2017 and died between 2014 and 2017.
- The date of death was defined as the index date.
- All beneficiaries were required to have continuous enrollment in Medicare fee-for-service Parts A/B and Part D in the 1 year preceding the index date (baseline period).
- Beneficiaries were categorized into early-, middle- and late-stage HD using an algorithm with a hierarchical assessment of markers of disease severity.[7,8]
- Comorbidities and disease severity were assessed during the baseline period.
- HCU and costs were measured in the quarter immediately preceding death (Q1) and the quarter before this (Q2).
  - All costs were adjusted for inflation to 2018 USD values (based on Consumer Price Index medical care component).

RESULTS

Demographics

- We identified 6,289 beneficiaries diagnosed with HD who died between 2014 and 2017, of whom 1,687 were continuously enrolled during the baseline period.
- Mean (standard deviation [SD]) age at death was 73.2 (12.9) years, and beneficiaries were mostly white (91.6%) and in late-stage HD (89.7%) (**Figure 1**).
- Beneficiaries had a mean (SD) Charlson Comorbidity Index of 4.4 (4.0) and, on average, reported 7.5 (3.0) chronic conditions (including dementia, depression and anxiety).

Figure 1. Proportion of individuals by disease stage



In the two quarters preceding death (Q1, Q2), HCU was common

- Hospice care (56.7%, 20.7%) and hospitalization (48.7%, 20.0%) were common among beneficiaries (**Figure 2**).
- Use of HD treatment (45.9%, 48.9%), antidepressants (46.7%, 48.7%), anti-epileptic drugs (34.4%, 34.6%), and anxiolytics (23.3%, 21.2%) were common among beneficiaries (**Figure 3**).
- Mean (SD) number of office visits was 1.6 (2.9) in Q1 and 2.1 (3.7) in Q2.

Figure 2. Quarterly HCU among deceased individuals with HD

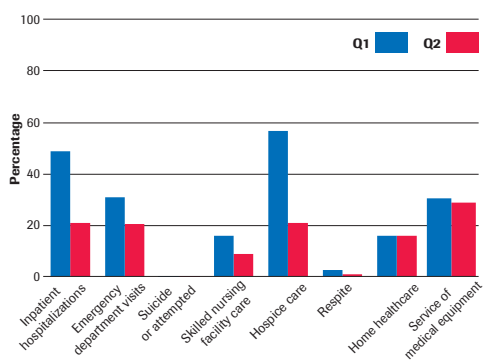
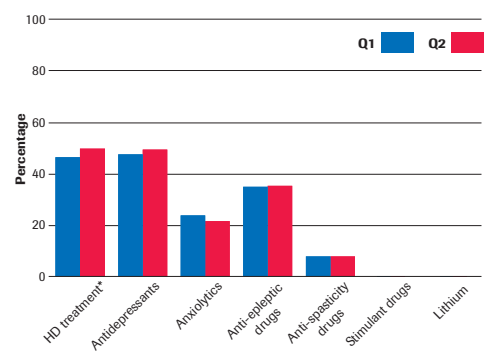


Figure 3. Quarterly prescription drug use among deceased individuals with HD



* HD treatments include: tetrabenazine, deuterabenzene, glutamatergic-modifying drugs, neuroleptics (antipsychotics), energy metabolites.

Healthcare costs were greater in the quarter preceding death

- Mean (SD) total costs per beneficiary were $28,145 ($31,932.8) in Q1 and $17,348 ($24,759.1) in Q2 (**Table 1**).

Table 1. Quarterly healthcare costs among deceased individuals with HD

All-cause healthcare costs	Q1 Mean (SD)	Q2 Mean (SD)
Inpatient costs*	**$18,302 (25,695.8)**	**$8,955 (19,630.9)**
Outpatient costs†	$5,798 (7,945.1)	$4,375 (7,617.2)
Outpatient pharmacy costs	$4,045 (10,651.4)	$4,018 (9,703.5)
Total costs	$28,145 (31,931.8)	$17,348 (24,759.1)

* Inpatient costs include: acute hospitalization, skilled nursing facility and hospice services.
† Outpatient costs include: outpatient hospital, emergency department, office, lab or other outpatient services.

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Abbreviations

HCU, healthcare utilization; HD, Huntington's disease; ICD, International Classification of Disease; SD, standard deviation.

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