Epidemiology of Huntington's disease in the US Medicaid population

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

The estimates reported in this study suggest that prevalence of HD in the US population is significant and higher than previously reported. This finding could reflect how age of onset of HD and patient eligibility requirements for Medicaid capture a population with greater disability. Assessments of the epidemiology of HD will support further understanding of the burden of disease in the US.

CONCLUSIONS

- In this study, the estimates of Huntington's disease (HD) prevalence, including the overall prevalence of 15.2 per 100,000 people, are higher than those previously reported in other US patient populations.
- This may reflect both the age of onset of HD and the unique eligibility qualifications of Medicaid that give way to a population with greater disability.

Objective: To generate estimates of Huntington's disease (HD) prevalence among beneficiaries covered by Medicaid.

BACKGROUND

- HD is a rare, genetic, neurodegenerative and ultimately fatal disease that has a devastating impact on families across generations.[1,2]
- HD is typically diagnosed between the ages of 30 and 50 years[2] and median survival is 15 years after the onset of unequivocal motor symptoms.[3]
- Few robust estimates of HD epidemiology in North America exist.
  - A recent study of commercially insured individuals in the US calculated incidence and prevalence at 1.2 and 6.5 per 100,000 person-years and persons, respectively.[4]
  - A recent study evaluating clinical and genetic data of people with HD in British Columbia, Canada estimated the true prevalence of HD in the US overall population to be 12.7 per 100,000 people.[5]
- Given this dearth of evidence, research is needed to generate current estimates of HD prevalence in US populations.

METHODS

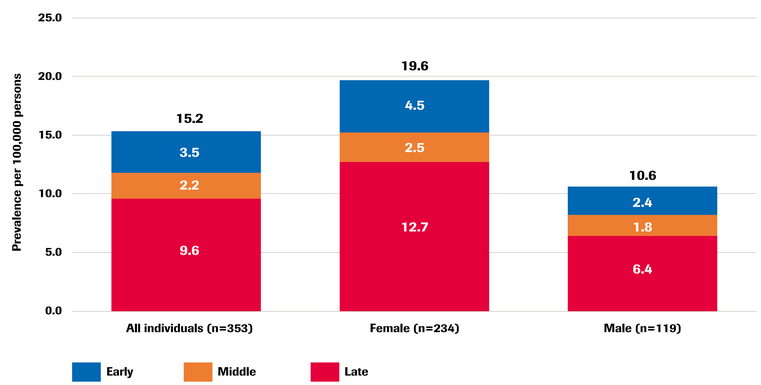
- Medicaid Analytic eXtract data from 17 states were used to identify beneficiaries ≤64 years of age who were diagnosed with HD based on the presence of ≥1 medical claim with a diagnosis for HD (ICD-9/10-CM: 333.4) in 2014.
- Prevalence proportion was calculated as the number of HD cases in 2014 divided by all beneficiaries enrolled in 2014 (reported per 100,000 people). To be included in the numerator or denominator, beneficiaries needed to be ≤64 years of age, non-dual eligible, and continuously enrolled in Fee-for-Service Medicaid during the entire year.
- Estimates were stratified by sex, age category (≤17, 18–34, 35–44, 45–54, 55–64 years of age) and disease stage (early, middle, late).[6]

RESULTS

Prevalence of HD in US Medicaid population in 2014 is estimated to be 15.2 per 100,000 people (Figure 1).

Figure 1. Prevalence of HD in Medicare beneficiaries in 2014

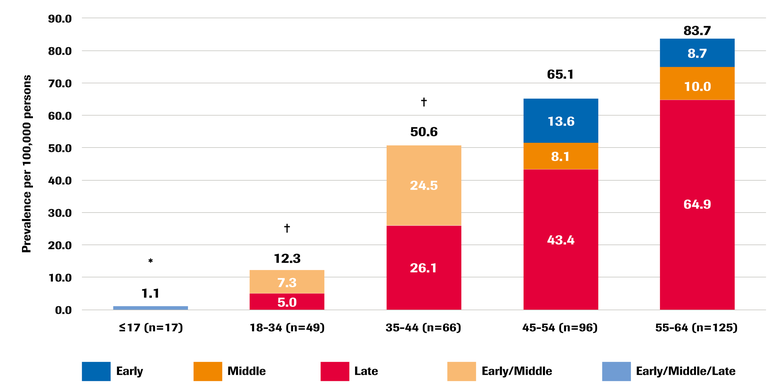
Individuals with late-stage disease had the highest prevalence in both male and female cohorts (Figure 2).



Prevalence estimates reported by stage may add up to more than the total due to rounding error.

Figure 2. Prevalence of HD among Medicaid beneficiaries in 2014, by sex

HD prevalence increased by age category (Figure 3).



* All three disease stages were combined to adhere to Centers for Medicare & Medicaid Services (CMS) cell size suppression policy.
† Early and middle disease stages were combined to adhere to CMS cell size suppression policy. Prevalence estimates reported by stage may add up to more than the total due to rounding error.

Figure 3. Prevalence of HD among Medicaid beneficiaries in 2014, by age

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Abbreviations

CMS, Centers for Medicare & Medicaid Services;
HD, Huntington's disease; ICD-9/10-CM: 333.4, International Classification of Diseases, Ninth Revision, Clinical Modification code: 333.4.

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