Epidemiology of Huntington's disease (HD) in the US Medicare population

Alex Exuzides,[1] Valerie Crowell,[2] Sheila Reiss Reddy,[3] Eunice Chang,[3] George Yohrling[4]

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4. Huntington's Disease Society of America (HDSA), New York, NY, USA.

Background | Objectives | Methods | Conclusions

Incidence and prevalence of HD in elderly Medicare beneficiaries in 2017 are higher than previously reported in a different US population

Incidence of **6.1** per **100,000** person-years

5.9 per 100,000 person-years in females

6.4 per 100,000 person-years in males

Click here for incidence data

Prevalence of **13.1** per **100,000** people

12.6 per 100,000 people in females

13.7 per 100,000 people in males

Click here for prevalence data

References and abbreviations > Acknowledgements >

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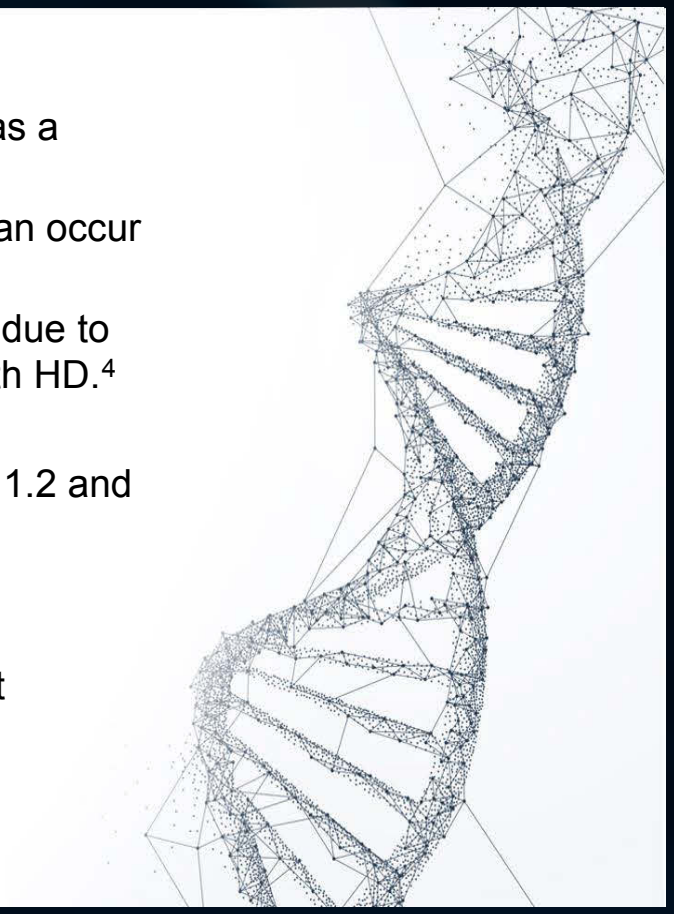
Background

- Huntington's disease (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] however, late-onset HD (LoHD) can occur amongst older patients.[3]
- Several studies have reported an increasing trend in overall HD prevalence over time, likely in part due to increased rates of diagnosis, particularly in older patients, and increased longevity in individuals with HD.[4]
- Few robust estimates of HD epidemiology in North America exist:
  - a recent study of commercially insured patients in the US calculated incidence and prevalence at 1.2 and 6.5 per 100,000, respectively[5]
  - 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.[6]
- Given this dearth of evidence, particularly for older patients, research is needed to generate current estimates in US populations.



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Objectives

To estimate the current incidence of HD (LoHD) and the prevalence of HD among US Medicare beneficiaries ≥65 years of age.

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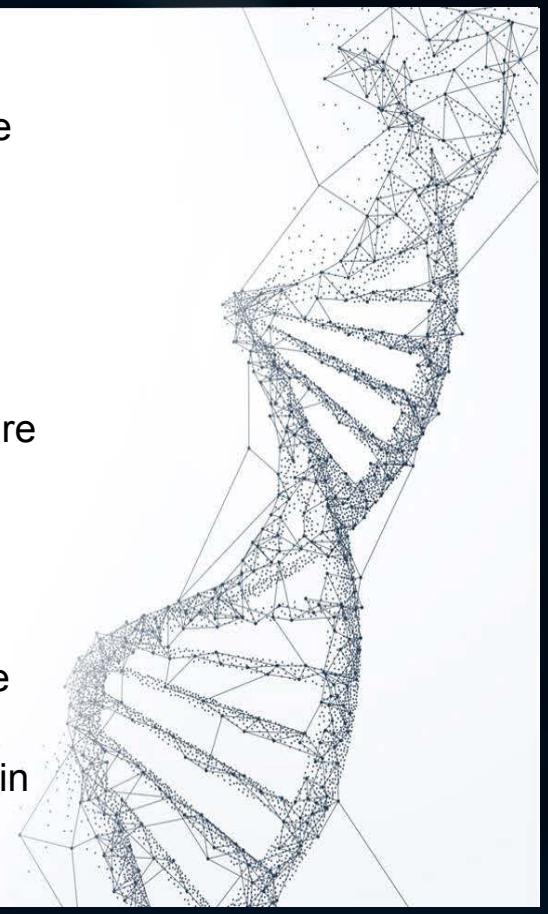
Methods

- Medicare Research Identifiable Files (100%) were used to identify beneficiaries ≥65 years of age who were diagnosed with HD based on the presence of ≥1 medical claim with a diagnosis for HD (International Classification of Diseases, Tenth Revision, Clinical Modification: G10) in 2017.
  - Beneficiaries <65 years of age were not included in the analysis due to limited population count.
- Prevalence was calculated as the number of HD cases in 2017 divided by all beneficiaries (reported per 100,000 persons).
  - All patients involved in the prevalence calculation were required to be enrolled in Fee-for-Service Medicare and Part D in 2017.
- Incidence was calculated as the number of new HD cases in 2017 (i.e. no claim for HD in 2016) divided by total at-risk patient-years from January 1st to diagnosis (cases) or enrolment end (non-cases) in 2017 (reported per 100,000 person-years).
  - All patients involved in the incidence calculation were required to be enrolled in Fee-for-Service Medicare and Part D in 2016 and 2017.
- Prevalence and incidence estimates were stratified by age category, sex, and disease stage as measured in 2017.



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Conclusions

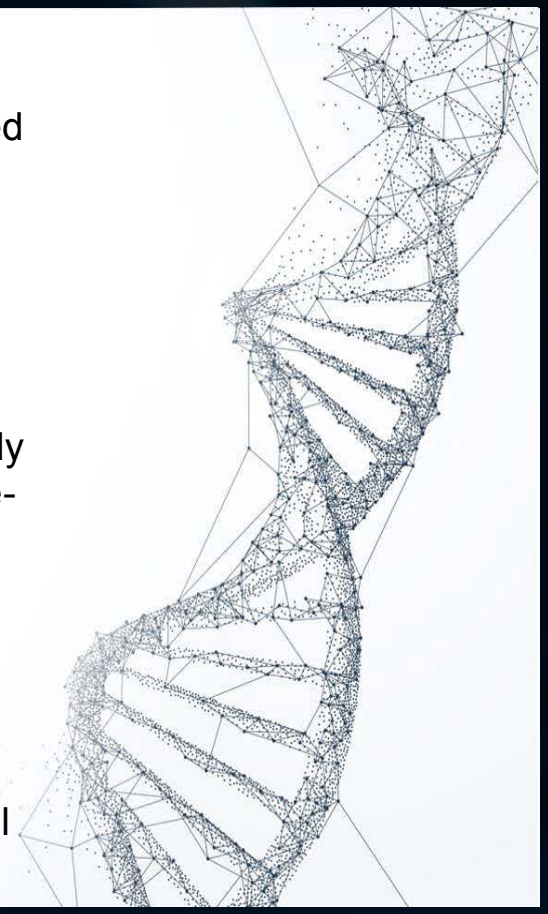
- Estimates of incidence and prevalence in beneficiaries ≥65 years of age are higher than previously reported for the commercially insured US population, highlighting the potentially significant disease burden for the elderly.
- Differences in estimates of HD incidence and prevalence may be due to to diagnostic changes over time, differences in studied populations, and variable methods for case ascertainment.

Limitations of claims-based epidemiology analyses

- Cases may be missed or misclassified. In this study, prevalence may be over-estimated, as valid cases only require one claim. On the other hand, the requirement that prevalent cases visit a physician during the one-year period of analysis (2017), could have led to an underestimate of disease prevalence.
- Due to challenges in identifying incident cases in administrative databases, disease incidence estimates generated using these sources are often over-estimated and should be interpreted with caution.

What does this study mean for the HD community?

The estimates of this study suggest that the incidence and prevalence of HD in the older US population are significant and higher than in a commercially insured population. Assessments of the epidemiology of HD will support further understanding of the burden of disease in different populations.



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Incident cases – beneficiaries ≥65 years of age

		CY 2017			
			Disease stage		
		All	Early	Middle	Late
N		819	174	244	401
%		100.0	21.2	29.8	49.0
Age, year	Mean	77.1	74.7	75.4	79.2
	(SD)	(7.4)	(6.3)	(6.5)	(7.7)
65-74	no.	352	104	126	122
	(%)	(43.0)	(59.8)	(51.6)	(30.4)
75-84	no.	320	57	90	173
	(%)	(39.1)	(32.8)	(36.9)	(43.1)
85+	no.	147	13	28	106
	(%)	(17.9)	(7.5)	(11.5)	(26.4)
Female	no.	466	93	141	232
	(%)	(56.9)	(53.4)	(57.8)	(57.9)
Race					
White	no.	705	147	210	348
	(%)	(86.1)	(84.5)	(86.1)	(86.8)
Black	no.	78	20	21	37
	(%)	(9.5)	(11.5)	(8.6)	(9.2)
Other/Unknown	no.	36	--[a]	13	16
	(%)	(4.4)	--[a]	(5.3)	(4.0)
Region					
Midwest	no.	297	53	70	174
	(%)	(36.3)	(30.5)	(28.7)	(43.4)
Northeast	no.	154	41	48	65
	(%)	(18.8)	(23.6)	(19.7)	(16.2)
South	no.	296	60	99	137
	(%)	(36.1)	(34.5)	(40.6)	(34.2)
West	no.	72	20	27	25
	(%)	(8.8)	(11.5)	(11.1)	(6.2)

[a] Reported per Centers for Medicare & Medicaid Services cell size suppression policy (<11).

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Prevalent cases – beneficiaries ≥65 years of age

		CY 2017			
			Disease stage		
		All	Early	Middle	Late
N		1,941	455	582	904
%		100.0	23.4	30.0	46.6
Age, year	Mean	74.5	73.0	74.0	75.5
	(SD)	(6.8)	(5.9)	(6.4)	(7.2)
65-74	no.	1104	304	341	459
	(%)	(56.9)	(66.8)	(58.6)	(50.8)
75-84	no.	652	129	195	328
	(%)	(33.6)	(28.4)	(33.5)	(36.3)
85+	no.	185	22	46	117
	(%)	(9.5)	(4.8)	(7.9)	(12.9)
Female	no.	1096	247	341	508
	(%)	(56.5)	(54.3)	(58.6)	(56.2)
Race					
White	no.	1742	417	526	799
	(%)	(89.7)	(91.6)	(90.4)	(88.4)
Black	no.	113	24	31	58
	(%)	(5.8)	(5.3)	(5.3)	(6.4)
Other/Unknown	no.	86	14	25	47
	(%)	(4.4)	(3.1)	(4.3)	(5.2)
Region					
Midwest	no.	679	143	182	354
	(%)	(35.0)	(31.4)	(31.3)	(39.2)
Northeast	no.	387	99	117	171
	(%)	(19.9)	(21.8)	(20.1)	(18.9)
South	no.	621	149	195	277
	(%)	(32.0)	(32.7)	(33.5)	(30.6)
West	no.	254	64	88	102
	(%)	(13.1)	(14.1)	(15.1)	(11.3)

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Abbreviations

CY, calendar year; HD, Huntington's disease; LoHD, late-onset HD.

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