Health-related quality of life among patients with Huntington's disease and their care partners in the US

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What does this study mean for the HD community?

Huntington's disease (HD) negatively impacts the quality of life of patients and their care partners. Appropriate mental health services are needed to support patients and care partners with the burden caused by HD on their quality of life.

Conclusions

- Individuals with HD experience more severe depression and lower HRQoL than the general population.
- HD care partners experience more depression compared with the general population.
- This study highlights the importance of ensuring appropriate mental health services are available to individuals with HD and their care partners.

BACKGROUND

- HD is a rare, genetic, neurodegenerative and ultimately fatal disease that has a devastating impact on families across generations.[1,2]
- HD is characterised by a triad of cognitive, behavioural and motor symptoms leading to functional decline and progressive loss of independence.[2,3]
- Individuals with HD will eventually require care as the disease progresses,[4] which is often provided by family members or professionals.

Objective: To describe the burden of HD on patients and care partners (CPs).

METHODS

- A cross-sectional web-based survey was conducted in the US, June–August 2019.
- Health-related quality of life (HRQoL) was measured in individuals with HD and their CPs.
  - Results were compared with individuals with Parkinson's disease (PD), PD CPs, and a sample of the general population.
- Bivariate analyses were used to compare individuals with HD and HD CPs with matched general population cohorts matched on age and gender from the 2018 US National Health and Wellness Survey (NHWS).
- Multivariate analyses were performed between individuals with HD and individuals with PD, as well as HD CPs versus PD CPs.
- HD-related QoL was measured in individuals with HD.

Measures of HRQoL

EuroQoL-5D (EQ-5D)
- Scoring health: 0=worst, 1=best health.

Patient Health Questionnaire-9 (PHQ-9)
- Depression severity scoring: none (0–4), mild (5–9), moderate (10–14), moderately-severe (15–19), severe (20–27).

Measure of HD-related QoL

HD-PRO-TRIAD[5]
- Patient-reported outcome (PRO) instrument of the HD symptom triad.
- Scoring: 1–15 indicating burden.

RESULTS

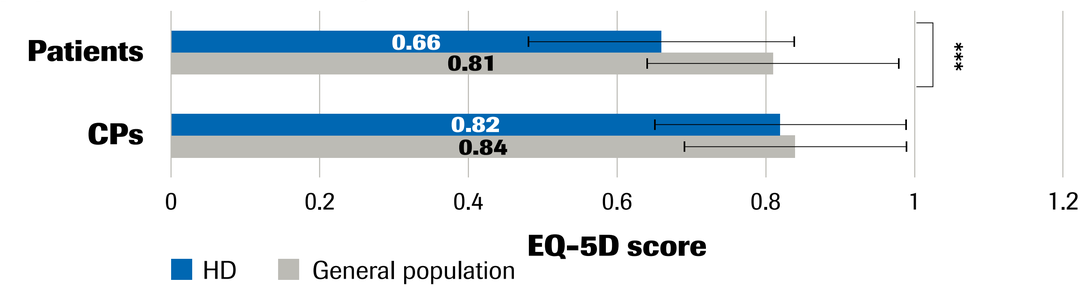
Burden of HD on patients and CPs

- Forty-one individuals self-reporting a HD diagnosis and 80 HD CPs were identified.

Measures of Health-Related Quality of Life

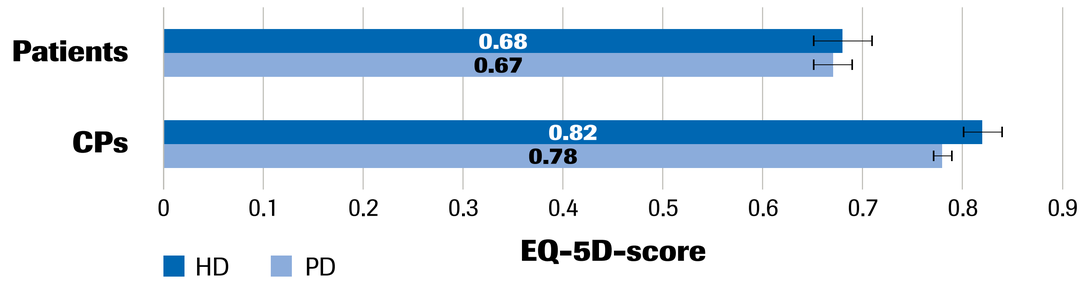
- EQ-5D score for individuals with HD was significantly lower than for the general population ($p<0.001$) (**Figure 1**) but not different from the score in individuals with PD (**Figure 2**).
- HD CPs' EQ-5D score was not different from the general population CPs (**Figure 1**) or PD CPs (**Figure 2**).

Figure 1. Mean EQ-5D score of individuals with HD, HD CPs and the general population (bivariate analysis)



***p<0.001 Error bars indicate standard deviation.

Figure 2. Mean EQ-5D score of individuals with HD, individuals with PD and their CPs (multivariable analysis)



Error bars indicate standard error of the mean.

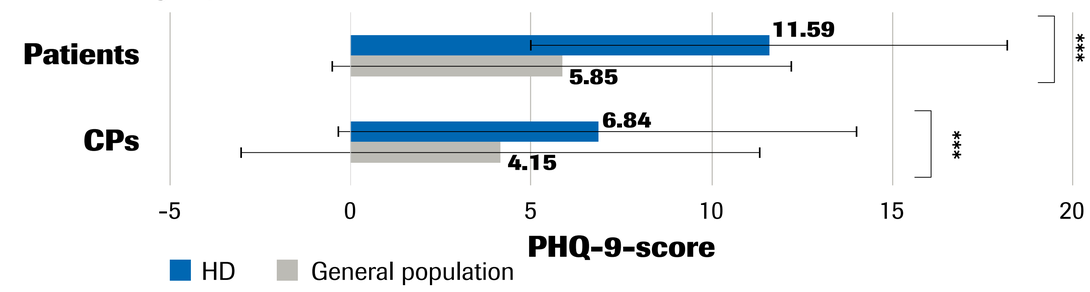
HD-Related Quality of Life

- Individuals with HD had a HD-PRO-TRIAD score of 9.25±2.24.

Measures of Depression

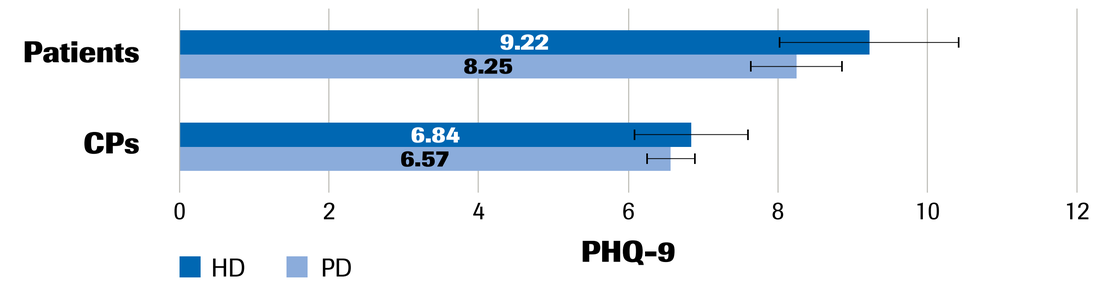
- The PHQ-9 score for individuals with HD was significantly higher than for the general population ($p<0.001$) (**Figure 3**) but not different from the score in individuals with PD (**Figure 4**).
- HD CPs' PHQ-9 score was significantly higher than the general population CPs ($p<0.001$) (**Figure 2**) but not different from the score PD CPs (**Figure 4**).

Figure 3. Mean PHQ-9 score of individuals with HD, HD CPs and the general population (bivariate analysis)



***p<0.001 Error bars indicate standard deviation.

Figure 4. Mean PHQ-9 score of individuals with HD, individuals with PD and their CPs (multivariable analysis)



Error bars indicate standard error of the mean.

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Abbreviations

CP, care partner; EQ-5D, EuroQoL-5D; general population CP, care partner for the general population; HD, Huntington's disease; HD CP, care partner for patients with HD; HRQoL, health-related quality of life; NHWS, US National Health and Wellness Survey; PD, Parkinson's disease; PD CP, care partner for patients with PD; PHQ-9, Patient Health Questionnaire-9; PRO, patient-reported outcome; QoL, quality of life.

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