AN INTERNATIONAL STUDY OF MENTAL HEALTH DIFFICULTIES AMONG FAMILIES AFFECTED BY HUNTINGTON'S DISEASE

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Objective:

To characterize mental health difficulties across families affected by Huntington's disease among an international cohort.

Background:

Mental health difficulties are a core feature of Huntington's disease, an incurable genetic neurodegenerative disorder. Despite the familial nature of this condition, very few studies have examined mental health difficulties in both Huntington's disease gene carriers and family members who do not have the gene.

Materials and methods:

Data were obtained from Enroll-HD a multinational, observational study of HD. Our data included mental health assessments using the Problem Behavior Assessment (short form) for Huntington's disease available from the project up to 2018. Our total sample included 5294 participants (Europe, n = 2643; US, n = 2339; Australasia, n = 275; Latin America, n = 37). Of this sample 2509 respondents were motor-symptomatic, 1226 respondents were pre-motor symptomatic, 808 participants were genotype negative and 751 participants were family controls. Descriptive statistics were used to examine prevalence across a range of mental health issues for the 4 groups.

Results:

Among those with a clinical diagnosis of Huntington's disease, apathy was the most prevalent mental health issue, affecting 47.7% of the sample. This was followed by anxiety (45.7%), depression (44.7%) and irritability (41.5%). Anxiety was the most common issue among gene carriers who had not yet developed motor signs (42.2%) and for family members without the gene.

Conclusions:

Apathy is a key feature of mental health difficulties among HD patients, but those pre-motor symptomatic and family controls more commonly experience anxiety and depression.

Table 1: illustrating prevalence of mental health issues across Huntington disease family members using the PBA-s for Huntington's disease (score ≥ 2)

	Motor-symptomatic (n=2509)	Pre-motor-symptomatic (n=1226)	Genotype negative (n=808)	Family Controls (n=751)
PBA-S items				
Depression	44.7%	37.8%	21.9%	30.8%
Suicide ideation	6.0%	4.8%	1.7%	1.3%
Anxiety	45.7%	42.2%	31.9%	36.9%
Irritability	41.5%	31.1%	17.6%	24.5%
Aggression	22.2%	12.6%	7.2%	8.8%
Apathy	47.7%	19.2%	9.2%	9.2%
Ob-Comp	32.9%	13.3%	6.8%	7.5%
Perseveration	19.2%	9.2%	6.7%	3.6%
Paranoid Thinking	4.4%	1.4%	1.0%	0.4%
Hallucinations	1.1%	0.6%	0.6%	0%
Disorientation	15.3%	2.0%	1.0%	0.4%

Bar chart demonstrating prevalence of mental health issues across Huntington disease family members using the PBA-s (score ≥ 2)

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