

Mobility in the last month of life

Physical functioning and symptoms in end-stage Huntington's Disease

Stella van der Niet, MSc¹, Dorine J. Boersema-Wijma, MD^{1,2}, Jenny T. van der Steen, MSc, PhD, FGSA^{1,3}, Erik van Duijn, MD, PhD^{1,2}

1. Huntington Centre of Expertise Topaz Overduin, Katwijk, The Netherlands

2. Dept of Public Health and Primary Care, Leiden University Medical Center, Leiden, The Netherlands

3. Radboudumc Alzheimer Center and Department of Primary and Community Care, Nijmegen, The Netherlands

Background

The mobility of people with Huntington's disease (HD) gradually deteriorates as the disease progresses. However, there is little understanding of this progression in the last stage of the disease. Based on expert views and clinical experience, physical symptoms such as chorea, pain, rigidity and cachexia negatively impact mobility.

Aim

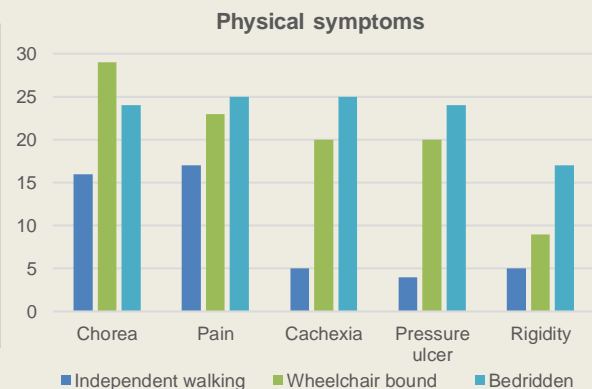
To investigate the physical functioning in the final month of life of individuals with HD and identify physical symptoms most closely associated with physical functioning in end-stage HD. Secondly, we aimed to gain insight into the application of physiotherapy in this stage.

Methods

Charts of 82 patients who died between 2017 and 2021 in a Dutch specialized nursing home for HD were reviewed. Two researchers abstracted data and compared their data entries to ensure uniformity. Data on mobility and physical symptoms were analysed with Spearman's Rho.

	Total N=82	Independent walking N=20	Wheelchair bound N=31	Bedridden N=31
Gender (m/f)	37/45	12/8	15/16	10/21
CAG repeat length	44 (42-46)			
Age at clinical diagnose, years	49.7 ± 1.3	51.2 ± 3.0	49.5 ± 1.7	48.9 ± 2.4
Age at death, years	60.9 ± 11.2	58.7 ± 12.2	59.8 ± 9.4	63.5 ± 12.1
Length of admission, years	4.1 (1.7-7.2) ***	1.9 (1.0-3.9)	2.3 (1.7-5.3)	8.1 (4.8-10.8)***
TFC score				
0	63	12	20	31
1	13	5	8	0
2-4	6	3	3	0

M: male, f: female, n: patient, TFC: total functioning capacity scale in HD. Data are mean (±standard deviation) for age at clinical diagnose and age at death; median (IQR) for CAG repeat length and length of admission, and number for TFC score. *p<0.05, *** p<0.001.



Results

We identified three groups with differential mobility: independent walking (n=20), wheelchair-bound (n=31), and bedridden (n=31). The most common physical symptoms across all three groups were chorea and pain. Cachexia, pressure ulcers and rigidity were found to have a moderate correlation with physical functioning, suggesting that these symptoms are more common when mobility tended to decline. Physiotherapy treatment ranged from active intervention to advice only, and in some cases no physiotherapy was provided anymore in the final month.

Conclusions

This study provides insight into the physical functioning and symptomatology in the final month of life for people with HD. The findings highlight that declining mobility is associated with symptoms such as cachexia, pressure ulcers and rigidity. Similar to earlier stages, the end-stage of HD is characterized by a variety of symptoms. Mobility in the last month is also highly diverse. Physiotherapy treatment, when provided up until the end of life, is tailored to symptoms and mobility, and varies from active treatment to consultation only.

Corresponding author: Stella van der Niet
Email: s.vanderniet@topaz.nl

