

Impaired Awareness of Functional Deficits in People with Huntington's Disease Living in Specialized Long Term Care Facilities.

Esther de Groot, Ruth B. Veenhuizen, Marina R. Ekkel, Martin Smalbrugge, Cees, M. P. M. Hertogh & Anouk M. van Loon

Department of Medicine for Older People, Amsterdam Public Health Research Institute, Amsterdam University Medical Center, van der Boechorststraat 7, 1081 BT, Amsterdam, The Netherlands

Background

Impaired awareness has been observed in people with Huntington's disease (HD). How this relates to the quality of life (QoL) and neuropsychiatric symptoms (NPS) in people with HD living in long term care facilities (LTCFs) is currently unknown.

Aims

1. To investigate if impaired awareness of functional deficits is present in patients with HD living in LTCF.
2. To explore the association between impaired awareness and neuropsychiatric symptoms, quality of life, physical and social functioning in residents with HD living in LTCFs

Methods

- This cross-sectional study included people with HD living in LTCFs.
- The Patient Competency Rating Scale (PCRS) was used to assess the level of awareness of functional deficits. Both patient and formal caregiver gave their rating in order to calculate a discrepancy score.
- Scan the QR-code for additional information about methods and results.



Results

Table 1. Baseline characteristics and study outcomes, presented by level of awareness category

	Level of impaired awareness			Total N=84	P-value
	No/mild (score <28) n=52 (61.9%)	Moderate (score 28-51) n=22 (26.2%)	Severe (score >51) n=10 (11.9%)		
Age, years; mean (SD)	58.7 (14.5)	52.6 (16.7)	51.5 (11.1)	56.3 (14.9)	0.153
Male; n (%)	25 (48.1)	14 (68.2)	7 (70.0)	47 (56.0)	0.158
Length of stay, years; median (IQR)	2.1 (2.6)	2.5 (2.6)	2.0 (2.3)	2.2 (2.6)	0.737
Any psychotropic drug n (%)	39 (75.0)	18 (81.8)	6 (60.0)	63 (75.0)	0.418
DISCs; mean (SD)	1.0 (2.0)	1.0 (1.0)	0	1.0 (2.0)	0.437

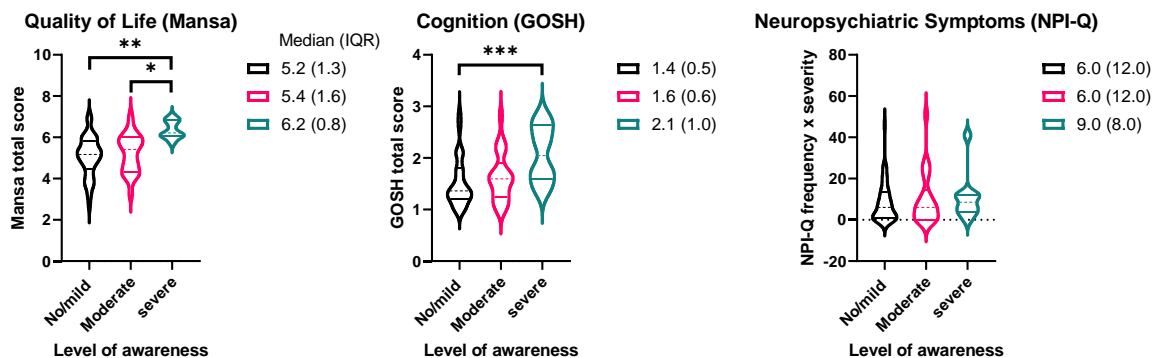


Figure 1. Study outcomes presented by level of awareness category. * p = 0.005, ** p = 0.000, *** p = 0.007.

Key conclusions

Impaired awareness of functional deficits occurs in 38% of people with HD living in LTCFs and is associated with cognitive impairment and QoL, but not with NPS. The results of this study could contribute to a deeper understanding of awareness in patients with HD and potentially help develop guidelines for clinical practice.

Impaired Awareness of Functional Deficits in People with Huntington's Disease Living in Specialized Long Term Care Facilities.

Esther de Groot, Ruth B. Veenhuizen, Marina R. Ekkel, Martin Smalbrugge, Cees, M. P. M. Hertogh & Anouk M. van Loon

Department of Medicine for Older People, Amsterdam Public Health Research Institute, Amsterdam University Medical Center, van der Boechorststraat 7, 1081 BT, Amsterdam, The Netherlands

Background

Impaired awareness has been observed in people with Huntington's disease (HD). How this relates to the quality of life (QoL) and neuropsychiatric symptoms (NPS) in people with HD living in long term care facilities (LTCFs) is currently unknown.

Aims

1. To investigate if impaired awareness of functional deficits is present in patients with HD living in LTCF.
2. To explore the association between impaired awareness and neuropsychiatric symptoms, quality of life, physical and social functioning in residents with HD living in LTCFs

Methods

- This cross-sectional study included people with HD living in LTCFs.
- The Patient Competency Rating Scale (PCRS) was used to assess the level of awareness of functional deficits. Both patient and formal caregiver gave their rating in order to calculate a discrepancy score.
- Scan the QR-code for additional information about methods and results.



Results

Table 1. Baseline characteristics and study outcomes, presented by level of awareness category

	Level of impaired awareness			Total N=84	P-value
	No/mild (score <28) n=52 (61.9%)	Moderate (score 28-51) n=22 (26.2%)	Severe (score >51) n=10 (11.9%)		
Age, years; mean (SD)	58.7 (14.5)	52.6 (16.7)	51.5 (11.1)	56.3 (14.9)	0.153
Male; n (%)	25 (48.1)	14 (68.2)	7 (70.0)	47 (56.0)	0.158
Length of stay, years; median (IQR)	2.1 (2.6)	2.5 (2.6)	2.0 (2.3)	2.2 (2.6)	0.737
Any psychotropic drug n (%)	39 (75.0)	18 (81.8)	6 (60.0)	63 (75.0)	0.418
DISCs; mean (SD)	1.0 (2.0)	1.0 (1.0)	0	1.0 (2.0)	0.437

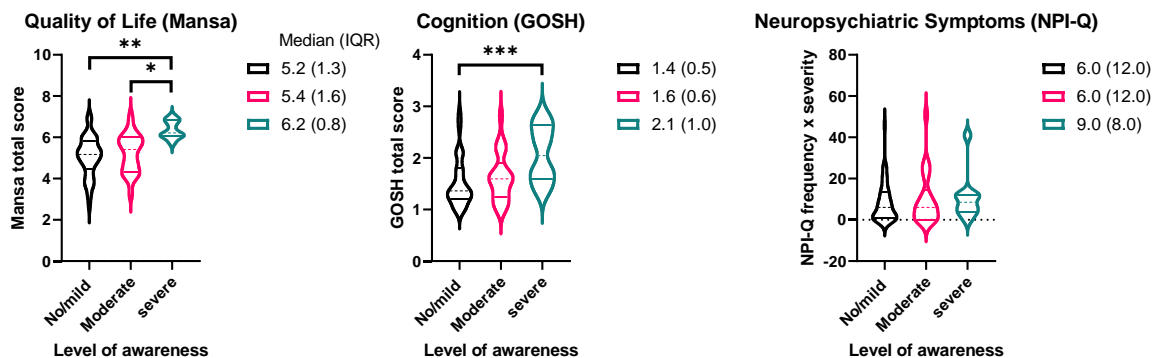
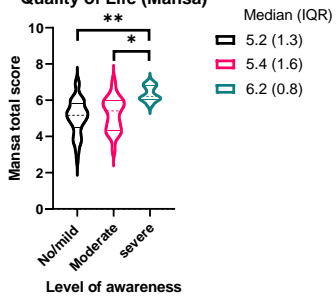


Figure 1. Study outcomes presented by level of awareness category. * $p = 0.005$, ** $p = 0.000$, *** $p = 0.007$.

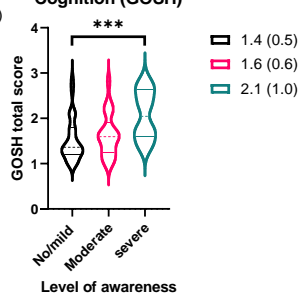
Key conclusions

Impaired awareness of functional deficits occurs in 38% of people with HD living in LTCFs and is associated with cognitive impairment and QoL, but not with NPS. The results of this study could contribute to a deeper understanding of awareness in patients with HD and potentially help develop guidelines for clinical practice.

Quality of Life (Mansa)



Cognition (GOSH)



Neuropsychiatric Symptoms (NPI-Q)

