

SPECIALISED MULTIDISCIPLINARY DAY CARE FOR PATIENTS WITH HUNTINGTON'S DISEASE, LIVING AT HOME

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Background

Independent living of patients with a chronic disease is preferred by most citizens. A chronic progressive disease, such as Huntington's disease (HD) may threaten this independent living.

Aim

To assess whether a specialised, multidisciplinary day care program for patients with HD, is effective in preserving or improving self-efficacy and self-management skills, in order to maintain independent living and postpone admission. Baseline data are presented in this paper.

Methods

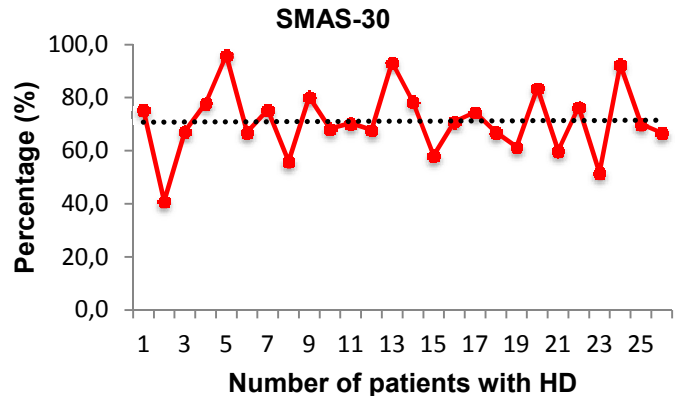
In a cohort study, patients with HD and their informal caregiver were interviewed.

Results

A total of 26 patients with HD (mean age: 51.7 years, range: 29-72, 9 males and 17 females), and 22 informal caregivers were interviewed.

Outcome measures

Primary	Self-management	SMAS-30
Secondary	Self-efficacy	SES-NL
	Quality of Life	EQ-5D
	Functioning	KATZ-ADL, Lawton-iADL, TUG, PPT
	Satisfactory	VAS-scale
Caregiver	Caregiver Burden	SRB-scale
	Care Needs	CANE



Patients tend to classify themselves as self-manageable (SMAS-30: mean 71.1, SD=12.6), self-efficacious (SES-NL: mean 31.5, SD=5.4), pertain a relatively high level of functioning (KATZ: mean 6.7, SD=1.2) and quality of life (EQ-5D VAS; mean 70.4, SD=18.2), whereas informal caregivers observe several existing care needs (CANE: mean 9.0, SD=2.4) and experience themselves a moderate to severe care burden (SRB: 76% between score 50-80). Both patients and informal caregivers are satisfied with the specialised care program (patients; mean 8.6, SD=1.2, and informal caregivers; mean 7.9, SD=0.9).

Conclusion

Patients, as well as informal caregivers, appreciate the specialised care program. Future research will determine if this program is effective in preserving self-management abilities to maintain independent living and to postpone admission.