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EHDN Clinical Research Congress Kraków 2026

Advance care planning towards end of life with Huntington's disease:

A chart review and implications for upcoming research, currently in preparation

Introduction

Advance care planning (ACP) is relevant for people with Huntington's disease (HD) as this is a progressive, neurodegenerative disease.[1] Neuropsychiatric symptoms and cognitive decline may affect mental capacity and decision-making, which complicate conversations about ACP.[2,3]

Aim

Reporting on care wishes and availability of advance directives (AD) of patients with HD who had resided in a long-term care facility and died. Therefore, we first report on treatment goals and treatment orders, and whether these changed over the last month of life. Second, we map the presence and content of ADs, including ADs regarding euthanasia.

Methods

A retrospective chart review[4] of 118 HD patients who had resided and died in a specialized long-term care facility in the Netherlands between 2017 and 2024. Data on treatment goals, advance treatment orders, the availability and content of ADs were collected over the last month before death.



Results – Treatment goals

Health records of 118 patients were included. Their mean age at death was 62.0 years (SD 12.1) and 56% was female. Most deaths resulted from severe swallowing disorders (36%), end-stage HD (27%), and non-natural deaths (11%) including physician-assisted dying (5%), euthanasia (5%), and suicide (1%).[2]
At the beginning of the last month before death, patients had had their most recent treatment orders and care goals in place for a median of 416 days (IQR 195-911; median length of stay was 4.2 years). The care goal changed in the last month in 30% of the patients, with an increase from 42 to 65% in maximization of comfort (Figure 1). Most treatment orders were based on forgoing treatments.

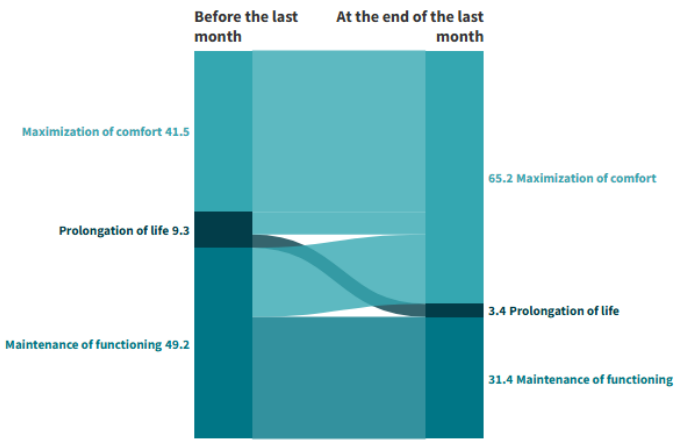


Figure 1. Changes (in percentages) in treatment goals during the last month in 35 patients (30%).

Results – Advance directives

ADs were present in 40 patients (34%) of whom 36 patients (31%) described the situation in which they would opt for euthanasia in their AD (Figure 2). Other treatments were addressed by 13 patients (11%), 9 patients addressed both. All ADs included refusal of life-prolonging treatments, some conditional on future decline in functioning and quality of life. These ADs were written a median of 5 years (IQR 2.5-8) after diagnosis, and 3 years (IQR 2-6) before death.

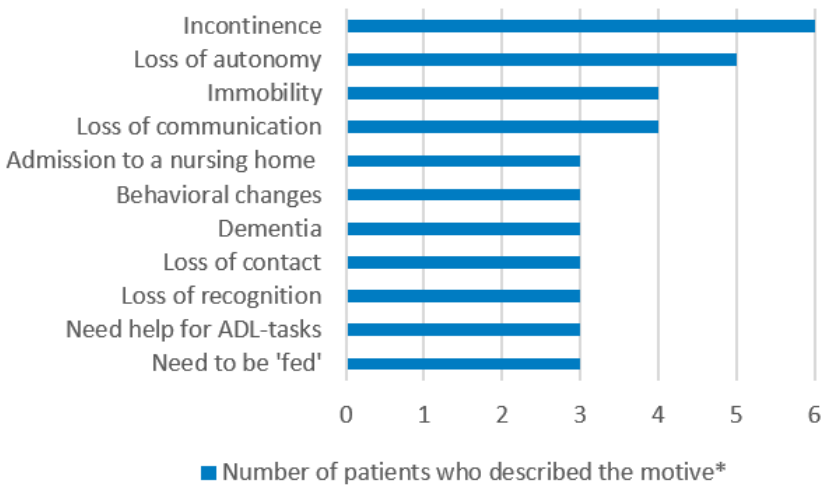


*Figure 2. Explicit motives (36 in total) for patients to opt for euthanasia as described in their advance directive regarding euthanasia (N=17). *Patients may have mentioned more than one motive.*

Conclusions

Despite the hereditary nature and progressive disease trajectory, a minority of the HD patients had an AD at any time during their stay in a specialized long-term care facility in the Netherlands.
However, ACP in HD is part of default care in these facilities and treatment orders were in place for almost all patients.
Nevertheless, detailing preferences in ADs, including regarding euthanasia (if legal), is helpful in honoring the patient's wishes and autonomy.
Future research is conducted to improve timely and person-centered ACP.

Personalized Advance Care Planning Tailored to persons with Huntington's disease (PATH)

PATH – Personalized Advance Care planning Tailored to persons with Huntington's disease

From current practice to tailored ACP[5]
Our previous study highlights the importance of timely and ongoing advance care planning (ACP) in Huntington's disease (HD). However, no evaluated, disease-specific approach is currently available to support ACP throughout the HD trajectory. PATH aims to improve timely and person-centered ACP by developing, implementing and evaluating an ACP working method tailored to the specific characteristics of HD and the needs of patients, their relatives, and healthcare professionals.

A four-phase mixed-methods study

1. **Exploring needs and readiness:** A survey among patients, relatives, and healthcare professionals will explore their needs and readiness for ACP, including preferences regarding timing, frequency and initiation of conversations.
2. **Understand current practice:** A multiple case study of ACP conversations will examine how current practice aligns with these needs. ACP conversations will be audio-recorded and complemented by interviews with patients, relatives, and healthcare professionals before and after the conversation.
3. **Co-create a tailored approach:** Focus groups and nominal group technique sessions will bring together patients, relatives and healthcare professionals to reach consensus on an HD-specific ACP working method.
4. **Implement and evaluate:** The working method will be implemented in routine HD care across the Netherlands and pilot-evaluated for feasibility, acceptability, and usability.

References

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Photo credit: Maarten Boersema

Acknowledgments

The funding for this research comes from the Durch 'Zorgondersteuningsfonds. Funding for the research currently being conducted comes from the Dutch Ministry of 'ZonMw.'

ZORG ONDER STEUNINGS FONDS

ZonMw

Huntington Expertisecentrum Topaz Overduin