

End of life with Huntington's Disease:

Most reported symptoms and interventions in addition to medical and nursing care

Background

It is unknown how the stage before death of patients with Huntington's disease (HD) is characterized and what kind of palliative care is provided¹.

Aims

We aim to describe the reported clinical symptoms and the non-pharmacological interventions given in addition to medical and nursing care, during the last month of living with HD.

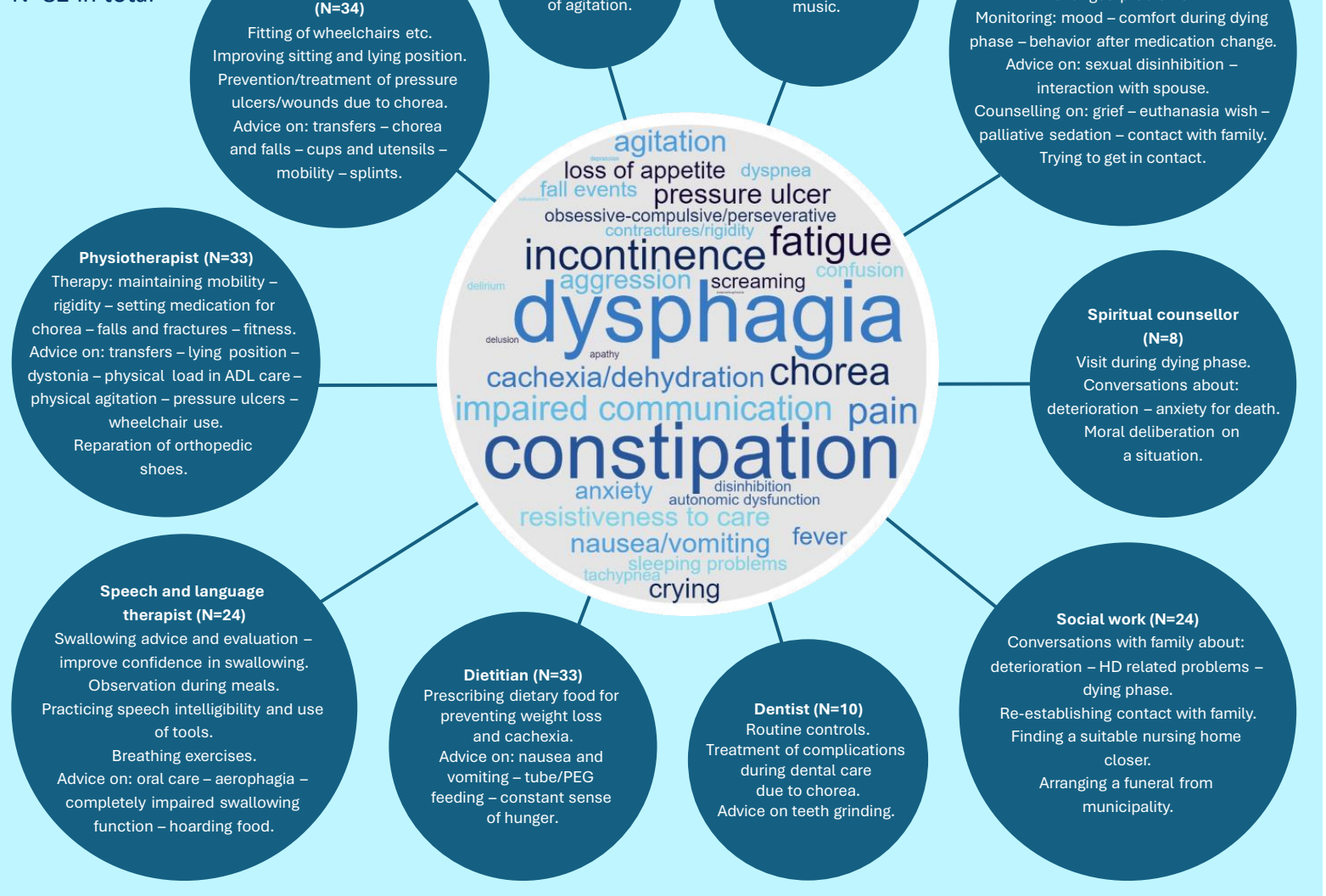
Methods²

A review of all charts of patients (n=82) who died between 2017 and 2021 in a Dutch specialized nursing home for HD. Data about characteristics and symptoms, and non-pharmacological treatments during the last month of life were abstracted and analyzed. The charts were reviewed by two researchers, who compared their data entry to achieve uniformity.

Results

The median length of stay in the nursing home was 4.1 years (IQR 1.7-7.2) and the mean age at death was 60.9 years (SD 11.2), and 45% was male. The median CAG repeat length was 44 (IQR 42-46). Almost all patients (97%) had a TFC score of 0-2. We found that the end stage of HD has a broad palette of physical and psychiatric manifestations (Figure 1). The most reported symptoms were dysphagia (89%), incontinence (89%), fatigue (84%), and chorea (82%). We also found that various disciplines were still involved in the end stage of HD, most prominently the occupational therapist, dietitian and physiotherapist. Other disciplines are involved by default and include nursing staff and hostesses who are responsible for the daily care in the wards; and the elderly care physician as the person with final responsibility for care.

Figure 1 – reported symptoms and interventions provided
N=82 in total



Highlights

- We described the symptoms and interventions during the last month of life with HD in a specialized HD nursing home in a relatively large population. The large majority of patients (93%) had died in the nursing home. We found a higher prevalence of pain (78 vs. 34%), anxiety (50 vs. 30%), nausea (57 vs. 18%), and dyspnea (38 vs. 10%) during the dying phase than has been found previously³.
- The high involvement of therapists underscores the importance of non-pharmacological interventions⁴. These therapists participated in multidisciplinary meetings.
- Interestingly, therapists' involvement may be of an active character, such as fitting wheelchairs, while it is expected to be more advising in the last month, such as swallowing advice. This may illustrate the difficulty of anticipating the dying phase³.
- Despite the wide range and high frequency of physical symptoms, not all symptoms may have been reported because they are difficult to assess or underreported, e.g., chorea when

these were seen as 'normal' for the patient and not leading to problems. Furthermore, not all patient contacts may have been reported.

- Additionally, the interventions by the nursing staff and the elderly care physician were not scored, because they are supposed to be involved during the daily care of patients.
- To provide good and proactive palliative care, we need to know how the end stage is characterized, prospective research is needed to examine changes over time up until the end of life. Further, knowing the wishes and needs from the perspective of patients and family caregivers will contribute to good quality of life during the last month⁵.

Conclusions

The end of life of HD is characterized by a variety of physical and psychiatric symptoms. Since the end of life is difficult to predict in HD, the non-pharmacological interventions are both active and advising. Involvement of the multidisciplinary team should be tailored day by day for each patient.

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To see more of the study:



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