

What makes a 'good death' in Huntington's Disease? for patients, family caregivers and healthcare professionals

Introduction

For patients with Huntington's disease (HD), it is of great importance to not only improve the quality of life but also the quality of dying. It is unclear to what extent palliative care is provided in current practice and what an effective palliative intervention entails in end of life with HD¹, which makes it more difficult to provide tailored care. The purpose of this study is to understand key themes that make a 'good death' in HD according to three important groups, (1) patients, (2) family caregivers and (3) healthcare professionals.



Methods

We conducted a qualitative study with focus group interviews, with a total of 40 participants. The participants were recruited from three specialized HD centers in the Netherlands, ultimately resulting in the participation of six patients, two family caregivers and 32 healthcare professionals. In one session, both patients and family caregivers participated; other sessions involved the groups separately. The conversations were transcribed verbatim and analyzed through inductive thematic coding with two researchers with a medical background.

Quotes

"I'm just, darn it, I am my own boss after all!"

"Look, if I can't talk anymore, if I can't say my thoughts, it's the end of the story for me."

"She agreed with [palliative sedation] and we could see that peace came over her."

Results: six themes



Loss of autonomy and wanting to retain control

- Making your own decisions during the disease process
- Importance of advance care planning
- The possibility of physician-assisted dying



Being close to caring people

- Presence of loved ones
- Engagement of healthcare professionals



Blind faith in limited expertise

- Blind faith in healthcare professionals
- Desire for more knowledge



Comfort and preventing suffering at the time of death

- Avoiding pain and anxiety
- Supporting family



Acceptance: when is the right time to die

- autonomy brings peace with death
- being present brings peace with death



Finding meaning and purpose at the end of life

- Cultural backgrounds
- Dedication of the family caregiver

Discussion

Six important themes for a good death were identified in the focus groups.

During the focus groups it became clear that the topic of death was harder to discuss with patients with an advanced stage of HD, as cognitive disabilities and dysarthria complicated the conversation. Previous research is consistent with seeing difficult conversations and therefore difficult advance care planning in an advanced stage of HD^{1,2,3}, which stresses the importance of initiating the conversation of advance care planning early in time.

The three target groups emphasized the importance of the presence of caring people during the dying phase, not only for the patient but also for the family, since this aids in creating acceptance. This important theme is also supported by previous research in general palliative care.

Moreover, patients often set their minds on the possibility of physician-assisted dying to retain control. This stresses the importance of starting advance care planning early in time and clarifying subjects such as physician-assisted dying. A limitation of this study was a small number of participating family caregivers. This may lead to an incomplete saturation of the family caregivers' perspective. However, their raised themes were very similar to themes of the other participating groups.

Conclusion

The six themes reflect personal, existential and care-related aspects that are relevant for a good death in HD according to patients, family caregivers and healthcare professionals. They inspire the delivery of palliative care to help shape a good death and relieve the great burdens at the end of life with HD.

Quotes



"When she gets to that point [death], I'll just be here 24 hours a day. There's no one to send me away. No way."



"When [death] happens, I want to be there. That gives me a bit of peace. I also experienced that with my father. I was there, and that gives you a certain kind of peace. You can say goodbye, even if he doesn't respond."



"[The healthcare professionals] see exactly what's going on and what she wants and doesn't want, and what's best for her at that moment."

Quote



"People from different cultural backgrounds sometimes have a different idea of what a good dying process looks like. (...) There are cultures whose approach is to keep the person alive as long as possible, at any cost. That does bump up a bit against our expectation of when you still speak of comfort."

References

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To see more of the study:



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