

End-of-Life conversations with patients with Huntington's Disease; a qualitative study

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Background

Patients with Huntington's Disease (HD) usually live their last years in skilled nursing facilities, where nurses or Primary Caregivers (PC) are responsible for the coordination of care. As the disease progresses, communication with HD patients becomes more difficult. Conducting early end-of-life conversations ensures connection, prevention of crisis situations, less fear, reduction of unfinished business, realization of wishes, helps making choices, peace of mind and saying goodbye. In short, a timely discussion is crucial to offer appropriate care in the last phase of life. It is not clear how PC conduct end-of-life conversations as part of palliative care and what the view of patients and family caregivers is regarding these conversations.

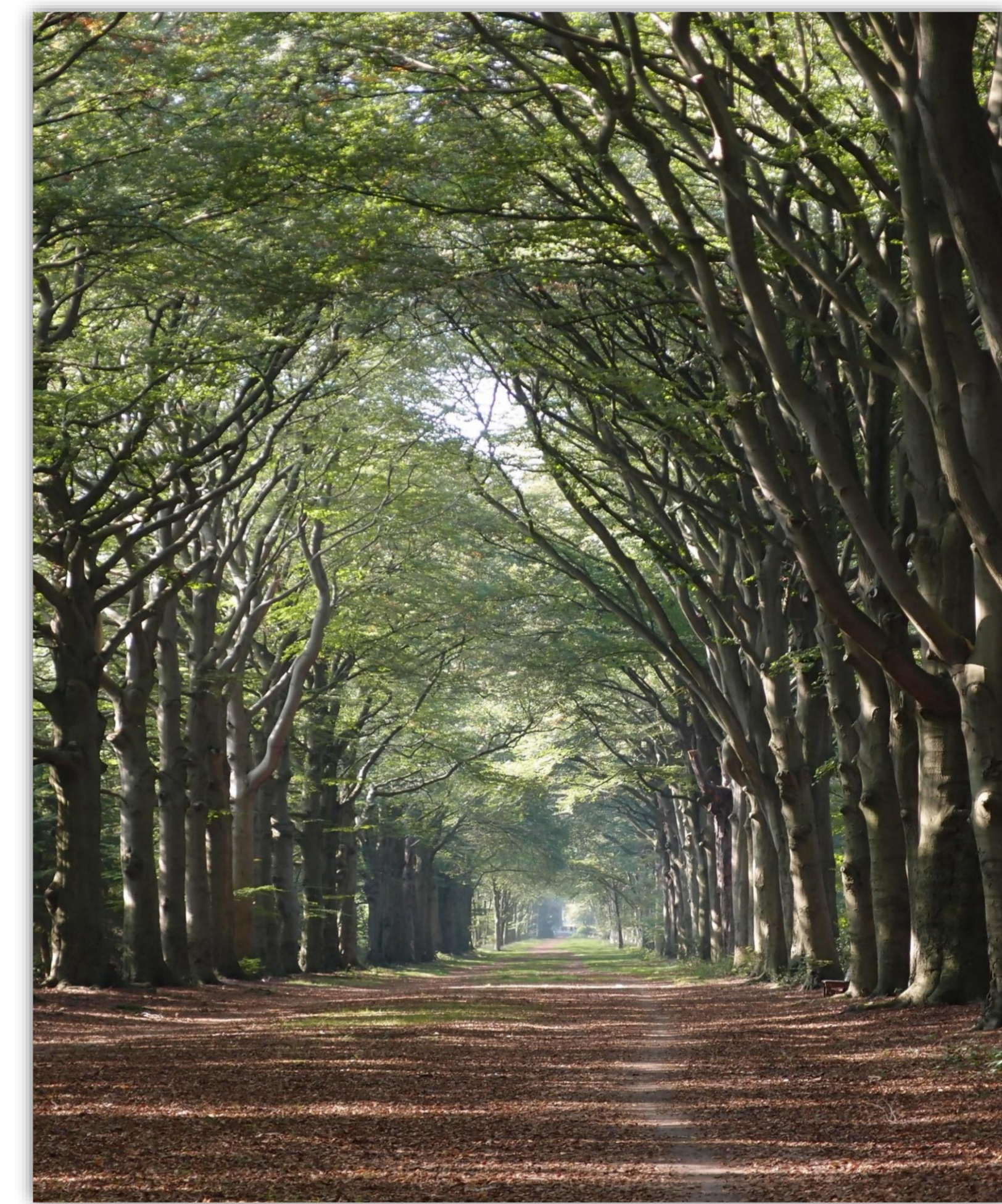
Aim

Enhancing the knowledge and insight in experiences and views of the PC regarding end-of-life conversations with HD patients and the needs and wishes of HD patients and family caregivers on end-of-life conversations.

Method

A qualitative study using semi structured interviews with PC, HD patients and family caregivers with end-of-life conversations.

Interviews are analyzed according to a thematic analysis.



Results

Primary Caregivers (n=9)

"I think I have that in my head, into my memory." (PC)

- PC conduct end-of-life conversations on intuition
- Different views exist on end-of-life conversations like 'not wanting to live anymore' or 'euthanasia'
- Knowing the patients while they still can communicate is important
- PC need training about palliative care and end-of-life conversations
- Wishes and needs of patients are not recorded in patient files

Patients and family care givers (n=7)

- Patients prefer having this conversation in the presence of a family member
- Both patients and family caregivers think that PC should take the initiative to start these conversations
- Family caregivers need medical and emotional support during the palliative trajectory

"I can't do it alone, and actually I don't want to do it alone." (family care giver)

Conclusions

PC conduct end-of-life conversations on intuition. They find it important to get to know the patient as well as possible, because communication is becoming increasingly difficult. PC are in need of training about palliative care and end-of-life conversations. Family care givers need support during the palliative trajectory, and both patients and family caregivers like the PC to take initiative.

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