

Palliative care in advanced HD

A scoping review

Dorine J. Boersema-Wijma, MD^{1,2} Erik van Duijn, MD, PhD^{2,3} Anne-Wil Heemskerk, MSc, PhD^{1,2} Jenny T. van der Steen, MSc, PhD, FGSA^{1,4} Wilco P. Achterberg, MD, PhD¹

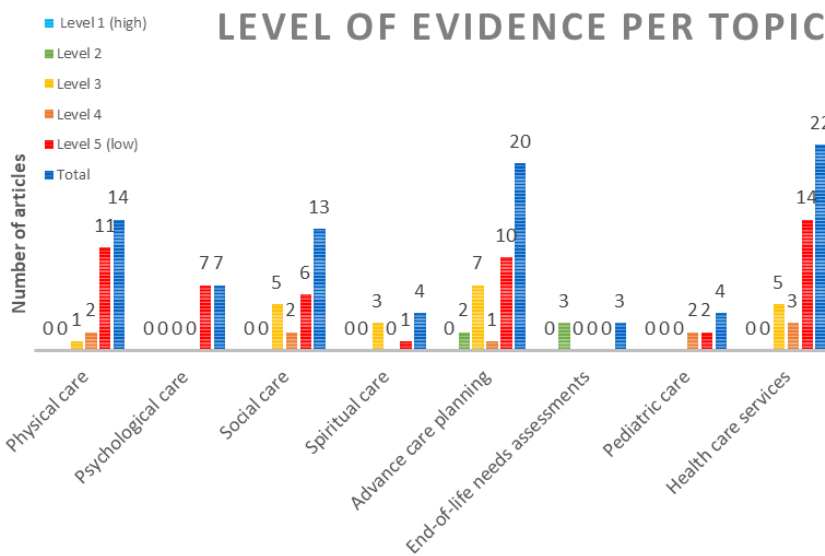
1. Department of Public Health and Primary care, Leiden University Medical Center, Hippocratespad 21, 2333 ZD Leiden, the Netherlands
2. Huntington Expertise Center, Topaz Overduin, Katwijk, Nachtegaallaan 5, 2225 SX Katwijk, the Netherlands
3. Department of Psychiatry, Leiden University Medical Center, Albinusdreef 2, 2333 ZA Leiden, the Netherlands
4. Department of Primary and Community Care, Radboud university medical center, Geert Grooteplein Noord 21, 6500 HB Nijmegen, the Netherlands

Background

As Huntington’s disease (HD) is a progressive disease for which there is no cure yet, patients in the advanced stage of HD may benefit from palliative care. However, there is limited knowledge of specific palliative care for patients with HD.

Aim and Methods

To understand what palliative care in advanced stage HD entails and the level of evidence, we conduct a scoping review of literature from 8 databases (Embase, Web of Science, Cochrane, Emtree, PsycINFO, Academic Search Premier, PMC PubMed Central and Pubmed) between 1993 and 2021. The literature was deductively classified based on topics that are part of the definition of palliative care, and inductively as care-related topics emerged from the literature.



Results

The search resulted in 333 articles, of which 38 were included. The literature covered the four main domains of palliative care: physical care, psychological care, spiritual care, and social care. Four additional topics were: advance care planning, end-of-life needs assessments, pediatric HD care, and need for health care services. However, most literature had a low level of evidence.

Interestingly, less is written about the patient himself in the advanced stage, much more about his general issues.

Conclusions

In palliative care for advanced HD patients, both medical and non-medical topics need to be addressed. As the level of evidence for palliative care in HD is low, further research is needed to characterize palliative care in HD, to demarcate the dying phase, and to determine which aspects are important for patients, caregivers and healthcare professionals.