

Results: Respondents described similar contexts for discussions about euthanasia: the topic arose at several key moments, usually with informal caregivers, and was motivated by patients considering the impact of disease progression both for themselves, thereby mainly wanting to avoid decline and maintain dignity, and their loved ones. Family caregivers paid considerable attention to the legality of euthanasia in dementia, specifically with regard to cognitive capacity, and elaborated on the difficulties and emotional impact of discussing euthanasia.

Conclusions: Considerations of people with young-onset dementia towards euthanasia appeared rooted in personal unbearable suffering and in expected interpersonal and societal consequences of their condition. Negative social framing of young-onset dementia might contribute to the livelihood of euthanasia in respondents' thoughts. The incorporation of euthanasia as a legal end-of-life option was mirrored in its incorporation in patients' and family caregivers' thought framework.

Perspectives of people with young-onset dementia on future quality of life: a qualitative interview study with implications for advance care planning

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Introduction: Advance care planning (ACP), one of the key domains of palliative care, enables individuals to define and discuss goals and preferences for future treatment and care with family and healthcare professionals. By exploring the views of people with dementia on quality of life now and in the future, including the end of life, care provisions can be tailored to their values. The perspectives of people with young-onset dementia (YOD), with a symptom onset before the age of 65, may differ from those of older people with dementia given the different life phase and family context. Qualitative research methods can be used to elicit the attitudes and beliefs to generate insight into their perspectives.

Methods: Qualitative study, as part of the Care4Youngdem-study, using semi-structured interviews with a criterion-based purposive sample of community-dwelling people with YOD (n=10) and their (family) caregivers in the Netherlands. We adapted the interview guide based on discussion of the transcripts. Double coding of three interviews resulted in a codebook. The codes were subsequently analysed through thematic analysis.

Results: Interviews took place between December 2019 and February 2022. The most prevalent dementia subtype was Alzheimer's (n=7). Four overarching themes, based on 21 categories, were derived from the interviews: (1) connectedness with others, (2) sense of dignity, (3) acceptance versus no acceptance of the impact of dementia, (4) concerning oneself with the future versus not wishing to concern oneself with the future. Connectedness with others and a sense of dignity were deemed prerequisites for (future) quality of life but were affected by YOD. These themes overlapped in terms of axial codes. Ambiguities were seen in the attitude towards the impact of YOD and the preparation for the future. The degree of acceptance of YOD affected the orientation towards the future.

Discussion: Family and professional caregivers should discuss with people with YOD how to maintain connectedness with others and a sense of dignity. Opposite ways of coping with the present and future were found. Professional caregivers should take personal coping styles into account when starting ACP conversations.