Care for People with Young Onset Dementia towards the End of Life

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Understand perceptions of people with young-onset dementia and their family caregivers about quality of life, advance care planning and care including end-of-life care, and understand what professional caregivers can learn from understanding and...

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Structural brain disorders
Study type	Observational non invasive

Summary

ID

NL-OMON48701

Source
ToetsingOnline

Brief title
Care4Youngdem

Condition

- Structural brain disorders

Synonym
Young-onset dementia; early-onset dementia

Research involving
Human

Sponsors and support

Primary sponsor: Radboud Universitair Medisch Centrum
Source(s) of monetary or material Support: ZonMw;HGOG programma

Intervention

Keyword: Advance care planning, Palliative care, Qualitative research, Young-onset dementia

Outcome measures

Primary outcome

not applicable

Secondary outcome

not applicable

Study description

Background summary

The importance of palliative care in dementia is increasingly being recognized and the number of studies in this area is growing gradually. According to the World Health Organization, palliative care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. At the request of the European Association for Palliative Care (EAPC), a white paper was published containing 57 recommendations for optimal palliative care in dementia. However, these recommendations are only based on literature and consensus in late-onset dementia.
Almost no research is available regarding palliative care in people with a symptom-onset of dementia before the age of 65, also known as young-onset dementia. People with young-onset dementia are in a different phase of life and they have different needs. Therefore, we expect that the wishes regarding palliative care will be different for this specific group compared to people with late-onset dementia. We have asked healthcare professionals who have experience with young-onset dementia to assess which of the 57 recommendations of the white paper are of special interest to this group. According to them, these were in particular the recommendations regarding shared decision-making and the discussion of the progressive course of dementia.
The objective of Care4Youngdem study is to map current practice and wishes regarding palliative care in people with young-onset dementia and provide young-onset dementia specific recommendations for optimal palliative care. The research project started in October 2016 on specialized care units for people

with young-onset dementia. Questionnaires about palliative care are completed by family caregivers, doctors and carers. The research question regarding advance care planning will be further explored with qualitative interviews with persons with dementia, family caregivers and healthcare professionals. Persons with dementia and their family caregivers will be interviewed individually, whereas the healthcare professionals will be interviewed in a group setting, during focus group discussions.
Recently, a similar qualitative research project has been carried out with family caregivers of people with young-onset dementia. A couple of other studies have also been conducted in which persons with late-onset dementia have been interviewed about topics related to palliative care. These studies indicated that providing comfort is important and advance care planning can ensure that patients worry less about the future.

Study objective

Understand perceptions of people with young-onset dementia and their family caregivers about quality of life, advance care planning and care including end-of-life care, and understand what professional caregivers can learn from understanding and discussing these perceptions.

Study design

Qualitative research: individual interviews with persons with dementia and their family caregivers, followed by group interviews with professional caregivers.

Study burden and risks

There is a risk on emotional stress. However, the risk is limited to a minimum by providing clear explanations about the content of the interview beforehand. In addition, the interview can be stopped immediately at the respondent's request or in case of distress, and there are options for follow-up care if needed.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

(Individual interviews)
Person with dementia (about 10)
- Both the person with dementia and the family caregiver consent to participate in the interview
- Young-onset dementia (symptoms before age 65)
- Community dwelling
- Mild or moderate dementia according to the professional caregiver who asks the patient and the family caregiver to participate in the research, guided by the Dementia Severity Rating Scale
-Capable and prepared to reflect on their personal situation, illness, care, preferences and possible future developments. For this, awareness of the disease is needed, at least to some extent.;Family caregivers (generally healthy participants, also about 10)
-Being the person's main family caregiver, either living with the person with dementia or living apart;Group interviews
Professional caregivers (a total of about 16 in two or more group interviews): see Interview protocol.

Exclusion criteria

-Alcohol-related dementia, Korsakov dementia, dementia with Down syndrom, Huntington and acquired brain injury in the person with dementia

- Severe aphasia or communication disorder on part of the person with dementia or the family caregiver
-Objections to talk about the past (to reflect on the period since diagnosis until the time of the interview) on part of the person with dementia or their family caregiver.
Physically incapable of signing (in case the study is regarded to fall within the scope of the WMO regulation)

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Health services research

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	09-12-2019
Enrollment:	36
Type:	Actual

Ethics review

Approved WMO

Date:	14-08-2019
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
Other	NL 5834 (NTR, nieuw nummer)
CCMO	NL66510.091.19