Course in functioning and care needs in young onset dementia

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

Summary

ID

NL-OMON39455

Source
ToetsingOnline

Brief title
Study into young onset dementia

Condition

- Structural brain disorders

Synonym
dementia

Research involving
Human

Sponsors and support

Primary sponsor: Psychiatrie en Neuropsychologie
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: care needs, dementia, early onset, problem behaviour

Outcome measures

Primary outcome

The main outcome variables are care needs, assessed with the Camberwell Assessment of Needs (CANE, Reynolds et al. 2000); problem behaviour, measured with the NeuroPsychiatric Inventory (Cummings, 1994); and sense of competence (Vernooij-Dassen, 1999). These outcome variables will be assessed every 6 months during 4 years.

Secondary outcome

Secondary variables for the patient:

- Depressive symptoms (Cornell scale for depression)

- Dementia severity (Global Deterioration Scale)

- Cognitive functioning (MMSE; Frontal Assessment Battery)

- Awareness (GRAD)

- ADL functioning (IDDD)

Secondary variables for the caregiver:

- Depressive symptoms (HDRS)

- Psychological complaints (SCL-90)

- Personality (neuroticism; NEO-FFI)

- Copingstyle (UCL)

- Quality of life(RAND-36)

- Quality of the relationship

- Care strategy

- Problems (qualitative interview)

Study description

Background summary

Dementia characteristically affects older people but can also have an onset before the age of 65. Early-onset dementia has devastating consequences for the person with dementia and the family. They experience specific problems due to their relatively young age.
However, most care facilities are focussing on an elderly population and can't fulfill the needs of these young-onset-dementia patients.
Despite its importance, investigators have paid little attention to the specific problems and needs of young-onset-dementia patients and their families. More knowledge is needed to develop specific and appropriate care facilities for this group.

Study objective

The present study will examine how young-onset-dementia patients and their families can be supported in their home environment as long as possible and institutionalisation can be delayed. For this the functioning and care needs of young-onset-dementia patients and their families will be examined.

Study design

It is a 2 year longitudinal observational study of 2 cohorts (patients in early stage and patients in day care).

Study burden and risks

The burden concerns 5 visits in 2 years; the measurements at 6 and 18 months are short monitoring visits; visits at baseline, 1 and 2 years are more extensive. A structured interview will be performed (± 1 1/2 hour) with patient and caregiver; caregivers are asked for an additional interview (±50 min.) and questionnaires (±75 min.). A semi-structured interview will be performed with the caregiver and possibly other family members. In addition a postal survey will be adminstered two times every year after the two-year follow-up period. This means a total follow-up time of four years.Methods are in line with data collected for regular patient care. There are no risks involved. The examination only concerns a time investment. Since the purpose of this study is to examine needs in young-onset-dementia it is neccesary to include dementia

patients and family caregivers in this study.

Contacts

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Scientific
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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adolescents (12-15 years)
Adolescents (16-17 years)
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Dementia diagnosed according to the DSM-IV criteria for dementia
Early dementia onset (before age 65)
Part 1: community living patients without daycare
Part 2: community living patients with day care

Exclusion criteria

Dementia caused by HIV, Down syndrome, Brain injury, Huntington's disease
Lack of a reliable informant
Lack of informed consent

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Basic science

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	01-10-2007
Enrollment:	250
Type:	Actual

Ethics review

Approved WMO

Date:	25-07-2007
Application type:	First submission
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)

Approved WMO

Date:	15-11-2007
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)

Approved WMO

Date:	12-03-2008
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)
Approved WMO Date:	16-04-2008
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)
Approved WMO Date:	23-06-2008
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)
Approved WMO Date:	16-02-2011
Application type:	Amendment
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)
Approved WMO Date:	11-11-2013
Application type:	Amendment
Review commission:	MEC academisch ziekenhuis Maastricht/Universiteit Maastricht, MEC azM/UM (Maastricht)

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
CCMO	NL17289.068.07