Demand-oriented care for people with dementia. Testing a methodology.

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The objective of this research is reviewing the effectiveness of a methodology which aimes at giving content to demand-oriented care for people with dementia and caregivers and at being a useful tool for professional carers to provide demand-...

Ethical review Approved WMO **Status** Recruiting

Health condition type Dementia and amnestic conditions

Study type Interventional

Summary

ID

NL-OMON33559

Source

ToetsingOnline

Brief title

Demand-oriented care for people with dementia. Testing a methodology.

Condition

Dementia and amnestic conditions

Synonym

dementia - Alzheimer's disease

Research involving

Human

Sponsors and support

Primary sponsor: GGZ Den Bosch (Den Bosch)

Source(s) of monetary or material Support: Verschillende verpleeghuis-

;verzorgingshuis- en thuiszorginstellingen en GGZ uit de regio 's-Hertogenbosch (zij bijlage 5

in het onderzoeks protocol).

Intervention

Keyword: demand-oriented care, dementia, healthcare quality assessment, patient reports

Outcome measures

Primary outcome

Peopl	le	with	dem	entia:

- 1. experienced degree of demand-oriented care
- 2. experienced quality of life
- 3. experienced quality of care

Caregivers:

- 1. experienced degree of demand-oriented care
- 2. experienced quality of life
- 3. experienced quality of care
- 4. the quantity met needs
- 5. the quantity unmet needs
- 6. experienced burden
- 7. feeling of competence

Care providers:

1. experienced competenties to be able to offer demand-oriented care

Secondary outcome

People with dementia:

- 4. the quantity met needs
- 5. the quantity unmet needs
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Caregivers:

- 4. the quantity met needs
- 5. the quantity unmet needs
- 6. experienced burden
- 7. feeling of competence

Study description

Background summary

By the government policy, new legislation, and the rise of customer organisations within the health care in the Netherlands, the last years the emphasis has come to lie more and more on the active role of the customer in the care attribution. Instead of offering 'supply-oriented care', institutions try to offer 'demand-oriented' and sometimes 'demand-driven' health care. The client perspective becomes normative for the aid offer and the organisation of the health care. Among other things, care programmes are designed to realize the 'demand-oriented' health care (Van Baalen, 2002).

In the region s-Hertogenbosch several care providers (nursing homes, home care institution, general hospital and GGz) have taken the initiative to develop a regional care programme for people with dementia. In a regional care programme stands the whole care offer of the region for a specific target group in an univocal manner defined. The basis for a care programme form the wishes and needs of this specific target group. For this reason it is important to inventory what the wishes and expectations are with respect to (quality of) care of people with dementia and caregivers. This inventory forms the basis of a PhD project. In this protocol the second phase of this project is described. The first phase of the project has been performed in 2005-2006 and implementation of it was approved by the Medical Ethical Testcommission for institutions in the mental health care (METiGG, protocol 5,120) the results of the first phase of the research (in which the term ' quality of care' from the perspective of people with dementia at an early stage at issue was) has been described in a separate report (Van Baalen, 2007).

At this second stage of the project the central objectives beside 'quality of care' are 'needs' and 'quality of life'. In a concept model 'demand-oriented care' these objectives are connected with each other. The idea has arisen that a methodology which explores in a structured manner the needs of people with dementia at an early stage and caregivers and the important aspects around quality of care from the customer perspective can make a contribution to forming demand-oriented care. Using this methodology ('Client Centred

Care-Dementia'- work name 'CCC-DEM') the care provider can clarify the care needs of the customer and his caregiver in a systematic manner and it can be useful in providing the care that qualitatively connects with what the customer finds important.

Study objective

The objective of this research is reviewing the effectiveness of a methodology which aimes at giving content to demand-oriented care for people with dementia and caregivers and at being a useful tool for professional carers to provide demand-oriented care.

Study design

This research has a quasi-experimental design. It does not meet all the requirements of experimental research because complete blindness of the intervention (use methodology) is not possible. The intervention is single-blind applied (only the one who applies the intervention applies knows this, the test person not). There will be an experimental and a control group which will be composed by means of randomisation. One pretest and two posttest measures will be done.

The design shows schematically as follows:

Time t 0 t1 t 2

R Group I O X C M O experimental group R Group II O Xa M O control group

O *observation*: data are collected

X experimental intervention (use methodology)

Xa regular care

t 0,1,2 time 0 (pretest), time 1 (6 weeks after t0) and time 2 (3 months after t 0)

C measurement of compliance

M care that results from the outcome of the methodology or regular care R randomisation, by randomisation respondents are assigned to the experimental or control group

Intervention

In the experimental group case managers the use a methodology with which the needs of people with dementia and their caregivers can be clarified in a systematic manner and it can be useful in providing the care that qualitatively fits with what these people find important.

The control group receives regular care.

Study burden and risks

People with dementia at an early stage are asked to answer questions concerning their perspective on the experienced quality of life, on the degree of demand-oriented care, (un)met needs and the experienced quality of care. These questions are conducted at 3 different times with people what will confiscate in sum approximately 2.5 hour time (2x 1 hours and 1x 1/2 hours). The research doesn't withhold any risks.

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

People with dementia:

- diagnosis 'dementia' (GDS nivo 3-5; MMSE over 12 and under 24)
- client is capable to provide informed informed consent according to the casemanager involved
- client speaks Dutch language
- client is capable to concentrate in a conversation up to one hour
- client's ability to understand, hear and see is sufficient enough for the conversation according to the professional caregiver
- client has a central caregiver who wants to join the research project; Caregivers:
- caregiver provides care for a person with dementia who has agreed to take part in the research project
- caregiver is capable to provide informed consent
- caregiver speaks Dutch language
- caregiver is capable to fill in some questionnaires (duration about 1/2 uur)

Exclusion criteria

- diagnosis Mild Cognitive Impairment (MCI)
- suffering from severe behavioural problems

Study design

Design

Study type: Interventional

Intervention model: Parallel

Allocation: Randomized controlled trial

Masking: Single blinded (masking used)

Control: Active

Primary purpose: Health services research

Recruitment

NL

Recruitment status: Recruiting
Start date (anticipated): 01-10-2008

Enrollment: 256

Type: Actual

Ethics review

Approved WMO

Date: 29-09-2008

Application type: First submission

Review commission: METIGG: Medisch Ethische Toetsingscommissie Instellingen

Geestelijke Gezondheidszorg (Utrecht)

Approved WMO

Date: 05-11-2008

Application type: Amendment

Review commission: METIGG: Medisch Ethische Toetsingscommissie Instellingen

Geestelijke Gezondheidszorg (Utrecht)

Approved WMO

Date: 06-05-2009

Application type: Amendment

Review commission: METIGG: Medisch Ethische Toetsingscommissie Instellingen

Geestelijke Gezondheidszorg (Utrecht)

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 NL24662.097.08