Nursing support of family caregivers in end of life care at home

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Aim:To evaluate the effects of a structured nursing supportive intervention on family caregivers in palliative home care. Question:What are the effects of a new nurse-led supportive intervention on family caregivers* preparedness and burden?

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Other condition
Study type	Interventional

Summary

ID

NL-OMON48129

Source
ToetsingOnline

Brief title
InCaSu@home

Condition

- Other condition

Synonym
burden, overburden

Health condition

overbelasting mantelzorger

Research involving
Human

Sponsors and support

Primary sponsor: Erasmus MC, Universitair Medisch Centrum Rotterdam
Source(s) of monetary or material Support: ZonMw

Intervention

Keyword: end-of-life care, family caregivers, nursing, palliative care

Outcome measures

Primary outcome

Our primary outcome:

- Caregiver burden as measured by the Selfrated Burden Scale (SRB), 1 item.

(van Exel, et al., 2004)

Secondary outcome

The secondary outcomes:

1) Caregiver burden as measured by the Caregiver Reaction Assessment (CRA), 24 items

(Given et al., 1992, Nijboer et al., 1999)

2) Caregivers* preparedness as measured by the Preparedness for Caregiving Scale (PCS), 8 items.

(Archbold et al., 1990, Hudson & Hayman-White, 2006)

3) The incidence of acute hospital admissions of the patient.

Study description

Background summary

Patients in the end of life phase mostly want to be cared and die at home. Without the help of family caregivers it would be impossible to remain at home. Family caregivers are often intensively involved with personal and emotional care and household tasks and they provide this an average of 26 hours per week. Many family caregivers of terminal ill patients experience a heavy to severe burden, especially in the last week of life. Burden may be a risk factor for burnout and fatigue. Some family caregivers feel insufficiently supported by professional caregivers. Healthcare professionals like nurses usually focus on the patient and his needs for care and treatment. They usually involve family caregivers only when needed in patient care. The position of the caregiver should not only be seen as 'co-caregiver' but also as 'co-client'. The important role and needs of the family caregivers should be addressed in palliative care. District nurses have a unique position in primary health care to assess family caregivers' needs and to provide supportive interventions aimed at reducing caregivers* burden. However, little is known about how nurses can support family caregivers in palliative home care and which interventions are effective. More research about nursing interventions to reduce burden is warranted.

Study objective

Aim:
To evaluate the effects of a structured nursing supportive intervention on family caregivers in palliative home care.

Question:
What are the effects of a new nurse-led supportive intervention on family caregivers* preparedness and burden?

Study design

We will conduct a cluster randomized trial to evaluate the effect of a new supportive intervention on the well-being of family caregivers. Twelve home care services in the southwest of the Netherlands will participate in the trial. Nurses of six services will be trained in the new intervention and the others not. After training, participants in the intervention group (with family caregivers) will receive the new intervention and the control group the usual care.

Intervention

Intervention:
The nurses (of the intervention group) will use the Caregiver Support Needs Assessment (CSNAT)-tool. It is a valid tool for the direct measurement of family caregivers' support needs in palliative home care. The CSNAT comprises 14 domains in which carers commonly say they require support in relation to enabling them to care for the patient at home, as well as support for their own health and well-being.
Completion of the CSNAT tool is the start of a process, existing of 5 stages:
Stage 1: Introducing the CSNAT to the family caregiver.
Stage 2: Carer consideration of needs. Family caregivers will use the CSNAT to identify domains where they need more support..
Stage 3: Assessment conversation. A conversation between the family caregiver and the nurse will take place to determine needs and priorities will be discussed.
Stage 4: Shared action plan. A shared action plan will be create .
Stage 5: Shared review: Review of the family caregivers' needs will be ongoing.
(Aoun et al., 2015; http://csnat.org)

Training:
Therefore nurses will be trained in the use of the CSNAT. The training program will consist of an e-learning program, two group sessions, and three intervision sessions (totally 20 hours).

The nurses of the control group will provide care as usual and will not be trained.

Study burden and risks

Burden:
Family caregivers (both intervention- and control group) will be ask to complete the questionnaires (SRB, CRA, PCS) at 2-4 time points:
- at baseline (T0)
- one months after baseline (T1)
- two months after baseline (T2) and
- 4-6 weeks following the patients* death or hospital/hospice admission (T3).
The questionnaires should take around 15-20 minutes to complete.

Risks:
The family caregivers of the intervention group will receive the new intervention. This means that family caregivers should think about their support needs and we realize that this can cause emotional reactions.

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

Family caregivers:
- family caregivers of terminally ill patients (with 3-6 months life expentancy).
- written informed consent to participate

Exclusion criteria

Family caregivers:
- family caregivers of patients with less than 2 weeks anticipated life expectancy.
- family caregivers of patients with severe dementia.
- enable to complete the Dutch questionnaire

Study design

Design

Study type:	Interventional
Intervention model:	Other
Allocation:	Randomized controlled trial
Masking:	Open (masking not used)
Control:	Active
Primary purpose:	Health services research

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	14-06-2019
Enrollment:	92
Type:	Actual

Ethics review

Approved WMO

Date:	19-04-2019
Application type:	First submission
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

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

ID: 29019
Source: Nationaal Trial Register
Title:

In other registers

Register	ID
CCMO	NL68453.078.18