Wishes and expectations concerning the end of life: the perspectives of frail elderly.

Published: 27-06-2019
Last updated: 10-04-2024

Gaining insight into the expectations of frail elderly people regarding the definition of treatment wishes and agreements about the end of life.

Ethical review	Approved WMO
Status	Recruiting
Health condition type	Age related factors
Study type	Observational non invasive

Summary

ID

NL-OMON48443

Source
ToetsingOnline

Brief title
Frail elderly and the end of life

Condition

- Age related factors

Synonym
end-of-life, Frailty

Research involving
Human

Sponsors and support

Primary sponsor: Radboud Universitair Medisch Centrum
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: advance care planning, end of life, Frail elderly, treatment wishes

Outcome measures

Primary outcome

What are the expectations of frail elderly about the discussion, recording and transfer of

treatment wishes andere agreements about the end of life?

Secondary outcome

What do frail elderly think is important when it comes to treatment wishes and agreements concerning it

end of life?

With whom do frail elderly people want to discuss treatment wishes and

end-of-life agreements?

In what way do frail elderly want to discuss treatment wishes and agreements

regarding the end of their life?

When do frail elderly want to discuss treatment wishes and agreements

concerning the end of their life or when do they want to rediscuss it?

What do frail elderly need to make informed choices about treatment wishes and

agreements concerning the end of their life?

What do vulnerable elderly people want to record where it concerns treatment

wishes and agreements concerning the

end of life?

Study description

Background summary

Treatment needs and end-of-life agreements have been discussed for years and is still one current issue. It comes in the news, in the debate, and is increasingly discussed in the general practice. Frailty in the elderly is an important factor to take into account in these considerations. In the Netherlands we define the elderly as - mostly very old - often with several disorders that are usually associated with physical, psychological, communicative and / or social limitations. Frail elderly are entitled to appropriate care. Recording treatment requirements and making agreements around the end of life ensures that the elder himself is in control of his appropriate care. Since 2014, "the care program for the frail elderly" has been implanted in general practice in the Netherlands. To determine the treatment wishes and agreements regarding the end of life is an important topic in this.
When admitted to hospital, these considerations still have to be made too often, in an often acute and stressful situations. Even in quiet situations, doctors do not find it easy to have this conversation. Also is it is not always clear when this conversation must take place.
GPs have already given their opinion about elderly care in their practice. It is still unclear what the opinion is of the elderly people themselves, what their wishes and expectations are. In this study we want to gain insight into the experiences of frail elderly people with this difficult conversation. With whom, how and at what time they prefer to do this conversation. What their expectations are about recording and sharing this information and what these findings mean for the frail elderly care program.

Study objective

Gaining insight into the expectations of frail elderly people regarding the definition of treatment wishes and agreements about the end of life.

Study design

Given the exploratory nature of the research goal, we will use a qualitative methodology with in-depth, face-to-face interviews. Purposive sampling will be used to ensure diversity in the study population.
We developed an interview guide on the basis of the research question and a literature review. The interviews will take place at the participants* homes and last 30-60min. The interviews are audio-taped and transcribed verbatim. Demographics are collected before the interviews. There will be eightteen to twenty interviews.

We will use the constant comparative method for analysing the data. This method

is part of the grounded theory approach in which data is analysed to develop a theory. We will use ATLAS.ti version 8.4.15 software to process the data. Analysis starts as soon as the first data was collected and will continue with each additional interview. The first step in analysis is data reduction. To minimize subjectivity, two researchers will code the transcripts independently. We will use open coding. This is the interpretive process by which data is broken down, examined, compared, conceptualized and categorized into codes. The goal is to obtain new insights by breaking through standard ways of thinking about phenomena reflected in the data. After two interviews we compare the codes and three researchers will discuss them until they reach consensus. Subsequently a new coding scheme is developed for further use. New codes could be added. We will group codes referring to the same phenomenon in categories, allowing the categories and names for categories to flow from the data. Finally, as part of the prospective grounded theory, we will try to relate the categories to each other. To ensure credibility by investigation triangulation, seven specialists on the topic are asked to give their opinion about the codes and categories in a peer-group discussion. This group will include one general practitioner, a PhD palliative care, a specialist elderly care, a professor of spiritual healthcare, a district nurse palliative care, an elderly and member of target group network 100 and the student researcher.

Study burden and risks

No risks associated with participation

Contacts

Public
Radboud Universitair Medisch Centrum

Geert grooteplein 21
Nijmegen 6525 EZ
NL
Scientific
Radboud Universitair Medisch Centrum

Geert grooteplein 21
Nijmegen 6525 EZ
NL

Trial sites

Listed location countries

Netherlands

Eligibility criteria

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

Inclusion criteria

Homedwelling frail elderly who participate in an Elderlycare Careprogramme in the Gelderland Region.

Exclusion criteria

Cognitive impairment, speech problem

Study design

Design

Study type: Observational non invasive

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

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	09-07-2019
Enrollment:	20
Type:	Actual

Ethics review

Approved WMO Date:	27-06-2019
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)
Approved WMO Date:	19-11-2019
Application type:	Amendment
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
CCMO	NL69758.091.19