

The needs of cancer patients and their carers for information regarding the end-of-life.

Published: 24-04-2007

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The objective of this study is to make a first step in clarifying the information needs regarding the end of life.

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Other condition
Study type	Observational non invasive

Summary

ID

NL-OMON30545

Source

ToetsingOnline

Brief title

Information needs of cancerpatients and their carers.

Condition

- Other condition

Synonym

cancer, oncology

Health condition

aandoening kanker

Research involving

Human

Sponsors and support

Primary sponsor: Universitair Medisch Centrum Utrecht

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: cancer, end of life, information needs, terminal

Outcome measures

Primary outcome

Needs for information.

Secondary outcome

none

Study description

Background summary

Discussing the end of life is difficult for people. It is often unclear what the information needs of people with regard to the end of life are. Yet being well informed about the last stage of life is important. Information about the end of life can diminish the fears of dying people and their caregivers. It gives them a mainstay and helps them to make well-informed decisions.

Study objective

The objective of this study is to make a first step in clarifying the information needs regarding the end of life.

Study design

The information needs of patients and their caregivers will be explored in a qualitative study.

The study takes place in Twente. Respondents will be selected by means of purposive sampling.

The data is collected by means of interviews. The goal is to conduct 15 interviews. The maximum duration of an interview is one hour. The guide-line

for the interviews is a topiclist which is based on a literature-review about the information needs regarding the end of life. Topics which are discussed in the interviews are the last stage of life, life expectancy, the last days before dying and the dying process.

Data analysis will be done following the method of the Grounded Theory. According to this research approach there is an alternation of data collection and -analysis during the study.

In order to guarantee the quality of the study, the following, for qualitative research usual, objectivity strategies are used: the researcher receives interview training, a log-book will be kept during the research, a digital record of the interviews will be made, investigator triangulation, peer reviews and (during the interviews) member-checking will take place.

The interviews will be conducted during the period February-April 2007. The analysis of data and writing of the report on the study will endure till June 2007. The report on the study will be finished in July 2007.

Study burden and risks

The duration of the interviews is maximum one hour. The interviews can be confronting for patients and their caregivers, because death and dying will be discussed. Emotional reactions may occur. When participants need someone to talk to, they can contact the researcher or the independent doctor.

Contacts

Public

Universitair Medisch Centrum Utrecht

postbus 85060

3508 ab

Nederland

Scientific

Universitair Medisch Centrum Utrecht

postbus 85060

3508 ab

Nederland

Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

Elderly (65 years and older)

Inclusion criteria

Patients:

- > 18 years
- Dutch speaking
- diagnosed with cancer
- worse prognosis
- life expectancy < 6 months; Carers
- > 18 years
- Dutch speaking
- Carer of a patient who is diagnosed with cancer
- Carer of a patient with a worse prognosis
- Carer of a patient with a life expectancy < 6 months

Exclusion criteria

- Patients with dementia or psychiatric diseases

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL
Recruitment status: Recruitment stopped
Start date (anticipated): 01-02-2007
Enrollment: 15
Type: Anticipated

Ethics review

Approved WMO
Date: 24-04-2007
Application type: First submission
Review commission: METC Universitair Medisch Centrum Utrecht (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	NL16127.041.07