Patient participation in end-of-life-decision-making

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Overall aim of the study is to investigate which decision-making models for patient participation are used in practice in end-of-life decision-making and how appropriate are these models for different patient groups.Secondary Objective(s): 1. In...

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Miscellaneous and site unspecified neoplasms malignant and unspecified
Study type	Observational non invasive

Summary

ID

NL-OMON38049

Source
ToetsingOnline

Brief title
Patient participation in end-of-life-decision-making

Condition

- Miscellaneous and site unspecified neoplasms malignant and unspecified
- Nephropathies

Synonym
dialyseren, Nephrologie

Research involving
Human

Sponsors and support

Primary sponsor: Vrije Universiteit Medisch Centrum
Source(s) of monetary or material Support: NWO

Intervention

Keyword: decision making, end of life, patient participation

Outcome measures

Primary outcome

Insight and knowledge about decision-making models or components of models in non-treatment decisions and how appropriate these models are for different patients groups.

Secondary outcome

not applicable

Study description

Background summary

The discussion model or shared decision-making model are often considered ideal. However, results of several empirical studies have given rise to the question whether these models are always the most suitable in all situations or in all patient groups. Important in the decision-making are the deliberation on the quality and quantity of life and the proportionality of the treatment. In this, the perspective of the patient is very important. It is known that when a patient is competent, end-of-life decisions are almost always discussed with patients in the Netherlands (92%).
The above illustrates the importance of patient-participation in end-of-life decision-making and the role decision-making models can play in researching this theme. While in this time and age the trend is to advocate shared decision-making models, existing studies already indicate that different groups of patients may have a different most preferred decision-making model. Many existing studies are retrospective or based on hypothetical cases (introducing e.g. recall bias and socially desirable answers) and focus either exclusively on the patient or the physician perspective on participation.
We will conduct prospective research, including the qualitative methods of observation and in-depth interviews, that is aimed at getting more insight in (combinations) of decision-making models used in practice in non-treatment decision-making in end-of-life care and how this is experienced by (different groups of) patients as the preferred way of participation in decision-making. The physician-perspective will be included since both the patient and physician

perspective are needed to truly understand patient-physician communication.

Study objective

Overall aim of the study is to investigate which decision-making models for patient participation are used in practice in end-of-life decision-making and how appropriate are these models for different patient groups.
Secondary Objective(s):
1. In which way and to what extent do patients (and their family) participate in decision-making processes on whether or not to start life-sustaining treatment in the last phase of life? (i.e. which (combinations of) decision-making models are used)
2. To what extent are patient (and their family) and physician satisfied with their participation in the decision-making?
3. What preferences do patients (and their family) have concerning participation in non-treatment decisions? Do these change in the course of an illness trajectory?
4. Which models or components of models are appropriate for non-treatment decisions in different patient groups in the last phase of life?
In answering these questions a point of focus are possible differences related to age, sex, religion, ethnicity, education level, and level of competence and possible other relevant factors that come up in the course of the study

Study design

We will perform a qualitative prospective study.
In order to study patient-physician communication and patient participation in decisions whether or not to forgo life-sustaining treatment, in this study the methods of participant observation and in-depth interviews will be used.

Study burden and risks

Patients can experience emotional distress caused by the interview. In-depth interviews may be emotional because patients are confronted with their illness and end-of-life phase. For the physicians who are interviewed the main burden will be an investment of time. Future patients and their partners/proxies may benefit from this study, the same holds true for the physicians.
In our view, the burden associated with participation is proportionate to the potential value of the research for future patients, their partners/proxies and the physicians.

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

Main inclusion criteria:
*Adults (>18 years)
*Patient must be competent when they are asked to participate in the study. ;Specific inclusion criteria neuro-oncology:
*Type of brain tumour: Glioblastoma multiforme (WHO grade IV glioma);Specific inclusion criteria general oncology:
* Patients must be diagnosed with metastatic colorectal cancer (stage IV)
* Patients will nog be eligible for operation on metastasis of their colorectal cancer;Specific inclusion criteria Nephrology
* Patient will not be eligible for kidney transplant
* Patient with older age and/or
* Comorbidity

Exclusion criteria

Patients cannot speak and understand the dutch language

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):	03-05-2010
Enrollment:	45
Type:	Actual

Ethics review

Approved WMO Date:	01-03-2010
Application type:	First submission
Review commission:	METC Amsterdam UMC
Approved WMO Date:	12-08-2011
Application type:	Amendment
Review commission:	METC Amsterdam UMC
Approved WMO Date:	31-01-2012
Application type:	Amendment
Review commission:	METC Amsterdam UMC

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	NL30236.029.09