The influence of caregivers on patients' treatment decisions

Published: 27-11-2007
Last updated: 09-05-2024

This study will address the question: what is the role of caregivers of lung cancer patients in collecting information and communicating ? What influence do they have on choices and decisions these lung cancer patients make ?

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

Summary

ID

NL-OMON31405

Source
ToetsingOnline

Brief title
caregiverstudy

Condition

- Other condition

Synonym
lung cancer

Health condition

het onderzoek richt zich niet op de aandoening (longkanker) maar om de communicatie daar omheen.

Research involving
Human

Sponsors and support

Primary sponsor: Longkanker Informatiecentrum
Source(s) of monetary or material Support: Zonmw

Intervention

Keyword: caregivers, decision, lung cancer, patient

Outcome measures

Primary outcome

not applicable

Secondary outcome

not applicable

Study description

Background summary

This project is relevant because caregivers play an important role in the choices patients make. We are inclined to focus solely on the patient himself in our communication. Thereby we imply that the patient is completely independent, rational and self-reliant. In reality it seems, however, that every patient has his own context. His choices are influenced by the people arounds him. It also appears that patients frequently prefer to leave someone else to decide: doctor, partner, children.

Not everyone is able to make choices independently,due to lack of knowledge or skills, to emotional involvement, or underlying personality structure. In short, 'making your own decisions' seems ideal, but is that what the patient wants and is capable to do.

There is no large body of evidence on the role of caregivers in decisionmaking. This study will provide insight to professionals in health care, but also to patients and caregivers themselves. It will provide practical guidelines for patients, caregivers, health professionals and also policy makers on how to cope with the triangle relation patiënt-caregiver-health professional. As far as we know, similar research has not been conducted yet, in any case in the Netherlands. This research will give more clarity concerning the role of caregivers, and will give input to policymakers in this regard.

Study objective

This study will address the question: what is the role of caregivers of lung cancer patients in collecting information and communicating ? What influence do they have on choices and decisions these lung cancer patients make ?

Study design

This is an explorative study on perception. A longitudinal, qualitative study: repeated interview

The study will be conducted in three hospitals, one academic centre, and two peripheral hospitals. Within every hospital we will collaborate with one or two pulmonologists. We will ask them to invite the first five lung cancer patients they diagnose to participate in the study, as of a certain starting date, in order to minimise the selection-bias.

These 15 lung cancer patients, one up to four of their caregivers and their physicians will be interviewed three times, in order to be able determine possible changes in the course of the time. Each participant will be interviewed shortly after the diagnosis, during first line treatment and afterwards.

For the interview a semi-structured questionnaire will be used.

The subjects covered in these interviews are:
- which decisions and choices have been made, and what is the role of patient, caregivers and doctor in that decision or choice
- how do patient and caregivers collect information, and how do share they this information with each other?
- what do patient and caregivers think of the communication process, and how do they deal with that?
- to what extent do patient and caregiver want the same, and if not, how do they cope with that?
- if caregivers play a large role in the provision of information and taking choices, how do patient, caregiver and physician interact?
- Do caregivers divide certain roles among themselves? Are there changes over time in roles?
- how does the doctor deal with the role of the caregiver?
- what is according to patient, doctor and caregiver the impact of the involvement of caregivers?

The interviews will be conducted, transcribed and analysed. The results are processed to a research report with concrete practical recommendations for doctor, patient and caregivers.

Additionally the results will be used to develop an accessible book for patients and caregivers with recognizable stories and tips for patients and caregivers on how to take decisions together effectively. This book will be supplemented by a workbook for health professionals to be used for intervision and trainings.

Moreover a number of training modules for care workers will be developed in communicating with patient and caregivers. These modules will be tested in a number of treatment teams, and will be made available once proven to be helpful for health professionals.

Study burden and risks

This research can be burdening in the sense that every participant (patient and caregivers) is interviewed three times. These interview could last up to an hour, which may be tiring for the patient. Also it is possible that as a result of the interview, participants may become more aware of dysfunctional family patterns. (which could also be a good thing, of course)

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

patient is newly diagnosed with lung cancer, 18 years or older and capable of making deicisions

Exclusion criteria

none

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Other

Recruitment

NL

Recruitment status:	Pending
Start date (anticipated):	01-09-2007
Enrollment:	60
Type:	Anticipated

Ethics review

Approved WMO

Application type:	First submission

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	NL17133.029.07