Optimization of complex palliative care at home by making use of expert consultation via telemedicine - a socio-ethical study

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

Summary

ID

NL-OMON34456

Source
ToetsingOnline

Brief title
Optimization of complex palliative care at home via telemedicine

Condition

- Other condition

Synonym
n.v.t.

Health condition

de terminale levensfase als gevolg van a) kanker of b) COPD

Research involving

Human

Sponsors and support

Primary sponsor: Universitair Medisch Centrum Sint Radboud
Source(s) of monetary or material Support: NWO,ZZG zorggroep

Intervention

Keyword: Good death, Palliative care, Telemedicine, Videoconversation

Outcome measures

Primary outcome

• Participants* experiences of the use of telemedicine in the practice of home based palliative care.

• The (moral) acceptability of telemedicine in palliative care.

Secondary outcome

• The absorption of the telemedicine-application into existing palliative care giving and/or social routines, or the creation of new routines for the telemedicine-application.

• Communication patterns (in terms of transmission, registration, consultation, and conversation) facilitated by the telemedicine-application.

• The consequences of the mediation by the telemedicine-application for communication in existing or new supportive and/or care giving relationships (in terms of maintenance, elaboration, and modification).

• (Normative) evaluation of the *fit* of telemedicine in participants* and bioethicists* conceptions about a *good death* and *good palliative care*.

• (Normative) evaluation of the effects of telemedicine on the patient*s position in his/her own care process.

Study description

Background summary

Due to the extensive growth of non-acute ways of dying in Western countries and a growing demand by people to die at home, Western societies have a desire to locate high-quality palliative care at the patient's home. Good caring and supporting relationships between the patient, the family, and the caregivers in the practice of palliative medicine and care are at the basis of high quality end-of-life care. Communication is central in building these relationships.
It is believed that the desire to locate high-quality palliative care at the patient's home can be realized with telemedicine, while telemedicine facilitates communication: both the general practitioner and the patient can easily converse with the medical specialist. In addition to these conversations the patient and his/her proxies have easy access to the home care institution as well as other sources of information, and the patient has a multifunctional tool to build new and maintain existing social networks. A telemedicine-application, however, will not only facilitate communication within existing caring and supporting relationships but also change it and even create possibilities for new relationships.

Study objective

The primary objective of this qualitative, socio-ethical study is to investigate how patients, proxies, general practitioners, and medical specialists experience a multifunctional telemedicine-application at the patient*s home, introduced primarily for the purpose of a weekly palliative care teleconversation with the patient, and whether (and why) they find this telemedicine-application acceptable.
The secondary objectives read as follows: a) to investigate whether and how the TM-application mediates interpersonal communication between patients, proxies, caregivers, and medical specialists via the application as well as computer-mediated communication with the application (e.g. Twitter), b) to investigate whether and how the people involved in the process of care giving in the last phase of life adapt to the weekly palliative care teleconversation with an expert and create new every day routines in the care for the patient, c) to investigate whether, how and why the use of a telemedicine-application for the purpose of palliative home care can be reconciled with ideas about *a good death* and *good palliative care* of patients, proxies, caregivers, medical specialists, and bioethicists, and d) to investigate whether and how the telemedicine-application empowers the patient to stay in control of his/her own care.

Study design

The central focus in this study lies on the participants* experiences with as well as their acceptance of a telemedicine-application in the practice of home based palliative care. Inasmuch as experiences and acceptance are personal matters residing in the subjects' inner thoughts these can be revealed by asking them about their experiences with and the ways they (do not) accept the telemedicine-application - this is called interviewing. In addition we will monitor the patients' and others' conduct with the TM-application by doing observations. In this study multiple observations at different points in time will precede the follow up interviews.

Intervention

A telemedicine-application, installed at the patient*s home for the purpose of a weekly palliative care teleconversation between the patient and the medical specialist

Study burden and risks

For the observations, participants have to open up their homes to the researcher. For the interviews, participants have to reserve some time. For the patient and proxies the interviews can be tiring, both physically and mentally. For saving patients and proxies the burden of interviews taking too long, sequences of shorter interviews have been introduced.
We also foresee that patients and proxies can somehow be affected by the topics discussed during the interviews, although the (use of the) TM-technology will always be the point of departure. A problem-solving protocol is designed to manage potential problems (see section 7.2).
The benefit lies with the teleconversations with the medical specialist and the home care institution, which can empower the patient to stay in control of his/her own care process. Moreover, the telemedicine-application can help to build new and maintain existing social networks. The teleconversations between the medical specialist and the patient could also enrich the advisory relationship between the medical specialist and the general practitioner.

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

GP's:
• are willing to participate in the study, i.e. willing to make time for the implementation of TM in their daily practice, to make time for interviews with the researcher, and leave room for their patients to participate in this research.
• have to be willing to resolve patient*s issues, caused unintentionally by the interviews.
• have shown some affection with research in the past.;The sample of gp*s will vary on:
• willingness to adopt advanced communication technologies
• the experience with treating and caring for palliative patients. ;PATIENTS:
• Patients are included if they either a) suffer of cancer or b) suffer of COPD .
* The patient finds him-/herself in a progressive palliative phase (Karnofsky-score < 60).
* Estimated life expectancy < 3 months.
* Patients are included if they have received a ZZP10 home care-indication.
* In case of COPD patient trajectories are rather difficult to determine. We will include 6 patients with COPD who seem to be in the last phase of their disease and bear in mind that these patients might live beyond these 8 to 12 weeks.
• Patients are included if they fit one of the three age-subgroups
* age 18-45 (6 patients)
* age 45-65 (12 patients)
* age 65- ... (6 patients);Inclusion criteria designed to guarantee homogeneity within the studied patient-group.;• Patients are included when they are aware of their disease as well as the state of their disease.
• Patients are included if they are surrounded by proxies.
• Patients are included if both the patient and his/her proxies give their informed consent.
• Patients are included if the patient and his/her proxies agree to be assisted by the ZZG

home care organization during the palliative trajectory.

Exclusion criteria

• The patient is incompetent.
• The patient wishes to die in a hospice.
• The patient does not speak and/or understand Dutch.

Study design

Design

Study type: Interventional

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

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	22-11-2010
Enrollment:	30
Type:	Actual

Ethics review

Approved WMO Date:	22-09-2010
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)
Approved WMO Date:	02-02-2012
Application type:	Amendment
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)
Approved WMO	

Date:	06-02-2012
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	NL32164.091.10