Palliative care for people with addiction and multiple problems: an explorative study of problems, needs, improvements and good examples experienced by healthcare professionals, patients and proxies.

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

Summary

ID

NL-OMON44194

Source
ToetsingOnline

Brief title
PAL V

Condition

- Other condition
- Psychiatric disorders NEC
- Lifestyle issues

Synonym
addiction, palliative phase

Health condition

elke palliatieve somatische aandoening of palliatieve fysieke gesteldheid

Research involving
Human

Sponsors and support

Primary sponsor: Radboud Universitair Medisch Centrum
Source(s) of monetary or material Support: Fondsenwerving Leger des Heils

Intervention

Keyword: palliative care, qualitative research, substance abuse, vulnerability

Outcome measures

Primary outcome

N.A.

Secondary outcome

N.A.

Study description

Background summary

Practice and the (scarce) literature show that healthcare professionals often lack knowledge about the specific needs of people with addiction and multiple problems in a palliative care phase and their proxies. Additionally, the way such care is organized, is often unclear to them. Perspectives of patients and proxies are hardly known.

Study objective

The main question of this study is: "how is palliative care for people with addiction and multiple problems organized in the Netherlands, and which problems, needs, improvements and good examples are experienced by healthcare professionals, patients and proxies?*. The objective of this study is to contribute to more cohesive and univocal care practice and policies for people with addiction and their proxies. Furthermore, this project forms the base of a

future educational course for healthcare professionals. Additionally, a study protocol and two empirical publications will contribute to the scientific knowledge gap.

Study design

The study has a qualitative design and will take approximately one year. Patients and proxies will be interviewed with a semi-structured interview guide. These interviews will be predominantly analyzed in an inductive and a thematic way. These results will be presented to and more or less validated by patients with addiction in comparable situations. All (group)interviews will be held with a semi-structured interview guide too and will be thematically and inductively analyzed. A SWOT analysis (Strengths, Weaknesses, Opportunities and Threats) will also be done on the data of the group interviews to concretize and summarize the findings. We expect data collection to take six months.

Study burden and risks

To limit the (physical and psychological) risks, several experts, an expert by experience and a patient, studied the protocol, interview guides and the information brochures thoroughly. The patient and proxy interviews will be limited to respectively one and one-and-a-half hour. The patients that are asked to give their opinion to the results, are in better condition than the included patients. Additionally, the researchers will join a board that is held monthly for residents of a care home. These residents join voluntarily. By joining the board instead of organizing a separate gathering, patients will not be burdened additionally. Finally, the researchers are trained in having contact with vulnerable patients. Research however, shows that patients do barely or not experience stress from participating in qualitative interviews. They instead, experience it is a meaningful. Each participant can stop at any time (s)he wants.

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

Within this research project, inclusion is possible if the patient:
1) is dependent on substances like, alcohol, cannabis, cocaine, opioids (including heroin), sedatives (often benzodiazepines) and/or GHB;
2) is diagnosed with the DSM-V classification severe *substance use disorder* or otherwise assessed as such by a competent professional caregiver;
3) is suffering from multiple problems (not obligatory, but often true for this patient group) like a) co-morbid psychiatric problems; b) being homeless or having a history of homelessness or; c) vulnerable or little social relations;
4) is 18 years or older;
5) has mastered Dutch in such way that it allows him/her to participate in an interview;
6) is cognitively capable enough to answer interview question (due to their addiction, many patients are cognitively damaged);
7) understands what the study comprehends for him/her.;Furthermore, the central professional caregiver:
8) has to answer *no* to the following question with *no*: *would it surprise you if this patient would die within five years?*. The original surprise question is extended to increase inclusion;
9) has explicitly communicated with the patient about the fact that (s)he is not going to be cured and now reached a palliative phase: this is either caused by somatic disease or as a consequence of severe, increasing physical deterioration as a result of addictive behavior.

Exclusion criteria

People with only non-physical addiction are excluded: addiction that is only mental or is behavioral only, such as, gambling, porn/sex or gaming. These addictions do not directly

result in physical problems. Furthermore, people that do suffer from addiction in tobacco/nicotine only, are excluded because this addiction does not necessarily impact life domains outside the physical. Finally, people that are severely cognitively impaired will be excluded.

Study design

Design

Study type: Observational non invasive

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

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	29-09-2017
Enrollment:	15
Type:	Actual

Ethics review

Approved WMO Date:	30-08-2017
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)

Approved WMO Date:	14-02-2018
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	NL61944.091.17