ParkinsonSupport; Palliative care for people with Parkinson's Disease and their caregivers

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Ethical review	Approved WMO
Status	Will not start
Health condition type	Movement disorders (incl parkinsonism)
Study type	Observational non invasive

Summary

ID

NL-OMON45585

Source
ToetsingOnline

Brief title
ParkinsonSupport

Condition

- Movement disorders (incl parkinsonism)

Synonym
Parkinson Disease

Research involving
Human

Sponsors and support

Primary sponsor: Anesthesiologie
Source(s) of monetary or material Support: van ZonMw

Intervention

Keyword: Care, Caregivers, Palliative care, Parkinson Disease

Outcome measures

Primary outcome

Primary study parameters

- experiences with palliative care;

- Quality of life;

- Quality of care.

Secondary outcome

Secondary study parameters

- use of care;

- caregiver burden;

- disease severity;

- socio-demografic data.

Study description

Background summary

Parkinson*s disease (PD) is one of the most common neurodegenerative disorders. PD affects approximately 1% of the population over the age of 65 in Western countries. PD is an incurable disease and treatment exists of restraining symptoms. As PD progresses, patients can suffer from a wide range of symptoms like immobility, pain, fatigue, sleeping problems, cognitive deficits and dementia. A nursing home admission is inevitable in 20-40% of the PD patients. Disease management in advanced PD becomes more difficult, whereas the emphasize on quality of life becomes more important. Patients with PD experience considerable discomfort at the end of life and symptom burden is comparable to advanced cancer patients.

Many PD patients could benefit from palliative care. Palliative care is *an

approach that improves the quality-of-life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*. A palliative care approach can be beneficial. However, there is scarce knowledge about components for palliative care in PD. Hasson et al reviewed current evidence and reported few problems. Problematic is the identification of PD patients with palliative care. The absence of a concrete starting point makes it difficult to identify palliative needs during the disease course. A few specific disease symptoms have been recognized as indicators. Special attention for palliative care needs might be at the first episode of aspiration and the occurrence of key clinical features as visual hallucinations, regular falls, dementia and admission to residential care. However, the appearance of these specific disease symptoms do not sufficiently lead to recognizing palliative care needs or referral to palliative care services (PSC). PD patients and caregivers described a lack of knowledge of PSC. If PD patients and caregivers received care from a PCS, they reported poor coordination of care. Studies concludes that caregivers often feel alone in the care for the patient with advanced PD and preparedness for death. Only a few PD patients and caregivers receive palliative care in contrast to patients with malignant diseases.
Four studies reported professionals experiences with (the concept of) palliative care. Waldron et al showed that professionals have misconceptions on their value of rehabilitation in the palliative stage. Professionals felt unsure about the care they delivered in the palliative phase. Several studies reported that professionals experienced a lack of education and competence in this field. Furthermore, the collaboration between PSC and more general professionals missed. Perceived barriers in the collaboration were inadequate referral and lack of communication.

Most studies on patient needs evaluated patients with PD in early stages and pay less attention to patients with advanced PD. However, a few studies found unmet needs in advanced PD. Patients with advanced PD are cared for by family members, usually older spouses.20 Schrag et al reported that caregiver burden is greater with increasing disability, and with the symptoms of PD such as hallucinations, depression and falls. Caregivers of patients with advanced PD reported considerable changes in their life. Especially, spouses felt that their primary role in the relationship changes, due to cognitive deficits and speech problems of the patients. Caregivers struggle with caring for their loved ones as long as possible and specifically with the point of admission to a nursing home. Studies also reported that caregivers have fewer social contacts and opportunities to socialize, reduced financial income and tend to experience poor health, and this is particularly related to features of late stage PD. Carter et al explored pre-death grief in caregivers of advanced PD patients. Findings suggests that pre-death grief was a significant finding in caregivers and more associated with the presence of patient*s cognitive decline.

In order to address the knowledge gap, the ParkinsonSupport study aims to identify the experiences in the last phase of life of people with Parkinson*s disease, their family caregivers and professionals. Part of this project is qualitative research, which exists of a qualitative after death study and a multiple case study.

Study objective

The research question addressed in this study is:

How do patients with advanced PD, their family caregivers and professionals their problems, needs and received care?

This question will be explored by an examination of what patients, (former) family caregivers and professionals experience and how they think palliative care can be optimized. Important aspects of this exploration also includes identifying terminal care strategies that already have been used in practice and the identification of *red flags* in order to get more insight information for timing palliative care interventions. Subsidiary questions emerging from the research question are:

1. What opinions do patients, (former) family caregivers and professionals have on the quality of care provided?
2. What are specific disease symptoms for timing palliative care needs in advanced PD patients?
3. How do disease severity progress over 12 months in PD patients and what care needs do patients and caregivers experience?
4. Which are the major decisions and symptoms in dying with Parkinson disease?

Study design

This study is divided in two parts. We will start with an explorative qualitative after-death study. In-depth individual and focus group interviews with former family caregivers and professionals will be held. The second part exists of a qualitative prospective multiple case study design.24 This design enables us to understand the circumstances and experiences of patients with advanced PD, their family caregivers and professionals.

Explorative after death study
A topic list will be developed based on literature study. A pre-test will be held in a test panel to ensure comprehensibility and completeness of the topic guide. Subsequently, 10 professionals and 10 former family caregivers will be interviewed. We don*t expect to cover the whole spectrum of experiences by 20 in depth interviews. Therefore, focus group interviews will be held with professionals and caregivers until saturation is reached. This design allows us to get in depth information about the needs of caregivers of patients with

advanced PD and professionals.

Multiple-case study
Patients and their family caregivers will be the subject of our multiple-case study. We will follow 5 - 15 PD patients (and if present one family caregiver per patient) to address disease severity progress over 12 months and the experienced quality of life and quality of care. PD patients will be included based on the surprise question: *would I be surprised if this patient died in the next 12 months. Patients will be visited at home at baseline, six and 12 months after baseline to assess experiences, disease symptoms, quality of life and quality of care. Data will be collected by in depth interviews with the PD patient as well as his family caregiver. Next to interviews, questionnaires and document analysis (for example care records) will be used to broaden our understanding.

Study burden and risks

Interviews will be held at the patients home or another environment of their choice. For each interview the patient will be asked if he/she wants to be accompanied by a family carer. Preliminary on the interview, the communication ability of the patient will be checked. The protocol will be adjusted on the communication ability of the patient. The interview will take place when the patient is in an *on-state*. If the patient is in an *off-phase*, the interviewer will be organized another time.

Research activities can give potential emotional stress for the patient and his/her carer. To reduce the risks of emotional stress, the interview will not take longer than 40 minutes. Furthermore each questionnaire is short. If the patient or her/his carer experience emotional stress, the researcher will refer to the attending physician. If necessary, the researcher will contact the physician in consultation with the patient.

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

1. 18 years or above
2. Diagnosis of *idiopathic PD* according to UK Parkinson*s Disease Society Brain Bank clinical diagnostic criteria
3. Patients who are suffering from late-stage Parkinsonism classified according to Hoehn and Yahr stage (HY) IV or V in the *On*-state; OR who have developed significant disability (Schwab and England stage 50% or less) in the *On*-state
4. Cognitively able to complete questionnaires and to participate in interviews.
5. The patient*s attending doctor answers *No* to the surprise question: *Would you be surprised if the patient died within 1 year?*

Exclusion criteria

Patients who do not met the inclusion criteria. There are no further exclusion criteria.

Study design

Design

Study type: Observational non invasive
Masking: Open (masking not used)

Control:	Uncontrolled
Primary purpose:	Health services research

Recruitment

NL

Recruitment status:	Will not start
Enrollment:	20
Type:	Anticipated

Ethics review

Approved WMO

Date:	16-02-2017
Application type:	First submission
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	NL59266.091.16