The DiaMove Study: Effects of neurologists* communication about a diagnosis of Parkinson*s disease on patients* well-being. A prospective mixed-methods study.

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Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Movement disorders (incl parkinsonism)
Study type	Observational non invasive

Summary

ID

NL-OMON54577

Source
ToetsingOnline

Brief title
DiaMove

Condition

- Movement disorders (incl parkinsonism)

Synonym
Parkinson's disease

Research involving
Human

Sponsors and support

Primary sponsor: Academisch Medisch Centrum
Source(s) of monetary or material Support: NWO (VENI)

Intervention

Keyword: Diagnosis, Parkinson's disease, Physician-patient communication, Uncertainty

Outcome measures

Primary outcome

Aim 1: Duration and content of information provided during diagnostic and

post-diagnostic consultations by the neurologist; Number and type of

uncertainty statements by the neurologist;

Aim 2: Experienced levels of stress by the neurologist;

Aim 3: Patients* and their significant others* levels of satisfaction and

trust, feelings of uncertainty and anxiety, recall of information, and in-depth

reports about the communication with the neurologist.

Secondary outcome

n/a

Study description

Background summary

How physicians communicate about PD during diagnostic and any post-diagnostic consultations may have important consequences for patients* well-being. Communication in the (post)diagnostic phase currently may be suboptimal, as patients have reported to feel insufficiently educated about the course and prognosis of their disease.

Several issues may hamper the communication when neurologists communicate the diagnosis of PD, including the complexity of information, persisting uncertainty about diagnosis and disease progression, and unpredictable

treatment effects. Moreover, among patients potential cognitive impairments as well as strong emotional reactions to the bad news may negatively impact information processing.

It is largely unclear how neurologists should optimally inform their patients about PD. Support in conducting diagnostic and post-diagnostic conversations tailored to patient preferences, for example through communication skills training, might help them further improve their communication skills. First, we need insight in how these consultations are presently conducted, how they are experienced by patients, their significant others and neurologists, and their psychological impact on everyone involved.

Study objective

The aims of this study are to investigate:
1. How and when neurologists communicate the diagnosis of PD in diagnostic and post-diagnostic consultations, particularly focusing on timing, content, communication style and the impact of neurologist characteristics.
2. How patients and their significant others experience these consultations, particularly focusing on their information recall, evaluation (satisfaction/trust) and emotional experience of the consultations and impact on their psychological well-being; and
3. How these consultations are experienced by the neurologists conducting them, focusing on their experienced emotional burden and the impact of their tolerance for uncertainty.

Study design

A prospective mixed-methods observational longitudinal design to capture both factual observations and subjective experiences. Qualitative interview data are combined with quantitative data gathered through questionnaires and video-recorded consultations with a total follow up duration of 2 months.

Study burden and risks

Burden for patients and significant others
• Three questionnaires need to be completed by each participant: preceding the diagnostic consultation (T0), shortly after it (T1), and two months later (T2). At T1, the researcher additionally assesses patients' cognitive functioning using a screening instrument (15 minutes). If a second diagnostic consultation is planned directly after the first diagnostic consultation, participants are asked to complete an additional questionnaire directly after the second consultation (Pat-T1b, Car-T1b). Questionnaire completion takes 50-90 minutes in total, divided over three or four time points.
• A video recording is made of the diagnostic consultation(s), which may be experienced as disruptive by patients

• A subset of 25 patients is purposively selected and invited to participate in an in-depth qualitative interview - six weeks after the first diagnostic consultation - at the location of their preference, which will take 30-60 minutes of their time.

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

Participants are:
1. patients referred to a Neurology out-patient clinic by the GP for a first diagnostic consultation for suspected Parkinson disease;
2. the significant others of the patients in 1.

Inclusion criteria:

For patients:
• 18 years of age or older
• Referral to Neurology outpatient clinic for suspected Parkinson*s disease
• Participation in the study (evidenced by the Informed Consent) by the neurologist to whom the patient has initially been referred
For patients* significant others:
• 18 years of age or older
• Accompanying patient to the Neurology outpatient appointment(s).

Exclusion criteria

A potential subject who meets any of the following criteria will be excluded from participation in this study:

For patients:
- Insufficient Dutch language proficiency
- Pre-existing, known severe cognitive condition that would hinder questionnaire completion and/or interview participation
- Previous analysis for suspected PD by a neurologist
- Other severe medical condition which may lead to reduced life expectancy or severe impairments to daily life
- No informed consent

For patients* significant others:
- Insufficient Dutch language proficiency
- Severe cognitive impairment that would hinder questionnaire completion and/or interview participation
- No informed consent

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):	30-06-2020
Enrollment:	73
Type:	Actual

Ethics review

Approved WMO Date:	03-03-2020
Application type:	First submission
Review commission:	METC Amsterdam UMC
Approved WMO Date:	23-04-2020
Application type:	Amendment
Review commission:	METC Amsterdam UMC
Approved WMO Date:	02-09-2020
Application type:	Amendment
Review commission:	METC Amsterdam UMC
Approved WMO Date:	04-05-2021
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	NL71998.018.19