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Published in:
Journal of Parkinson's Disease

DOI:
[10.3233/JPD-171195](https://doi.org/10.3233/JPD-171195)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2017

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Lennaerts, H., Groot, M., Rood, B., Gilissen, K., Tulp, H., van Wensen, E., Munneke, M., van Laar, T., & Bloem, B. R. (2017). A Guideline for Parkinson's Disease Nurse Specialists, with Recommendations for Clinical Practice. *Journal of Parkinson's Disease*, 7(4), 749-754. <https://doi.org/10.3233/JPD-171195>

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Research Report

A Guideline for Parkinson's Disease Nurse Specialists, with Recommendations for Clinical Practice

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Accepted 22 July 2017

Abstract.

Background: Parkinson's Disease Nurse Specialists (PDNS) play an important role in the care for patients with Parkinson's disease (PD) and their caregivers. Until now, there were no nursing guidelines in PD, and interventions were based solely on daily clinical practice because there is no evidence to support the merits of nursing interventions. Consequently, there is little uniformity in current care delivery.

Objective: Developing a guideline for PDNS.

Methods: We developed a guideline based on a questionnaire among PDNS and a literature review, supplemented with expert opinion plus the input of patients and caregivers. The questionnaire was filled in by 97 PDNS and 51 generic nurses with knowledge of PD to identify barriers in PD nursing care. Subsequently, we did a systematic literature search and transformed these sources of information into practice recommendations, which were developed according to international standards for guideline development.

Results: Based on the results of the questionnaire we identified seven specific core areas: defining the role of PDNS in terms of caseload, education, competences and care coordination; medication adherence; provision of information and education; coping; caregiver support; urogenital function and orthostatic hypotension. The systematic literature search identified 186 studies, of which 33 studies were finally analyzed. Furthermore, we developed practice recommendations based on good clinical practice for the following areas: self-care, mental functioning, mobility, nutrition, sexuality, work, sleep, palliative care and complementary (integrative) care.

Conclusion: This guideline provide ground to harmonize care delivery by PDNS in clinical practice, and offer a foundation for future research.

Keywords: Evidence-based medicine, Parkinson's disease, Parkinson's Disease Nurse Specialist, guideline

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INTRODUCTION

Parkinson's disease (PD) is a common neurodegenerative disorder that affects approximately 1% of the population over the age of 65 in Western countries [1]. Patients with PD can manifest a wide range of symptoms that can have an immense impact on daily functioning and quality of life. Parkinson's Disease Nurse Specialists (PDNS) have a key role in assisting patients with PD and their caregivers in their need of support, knowledge, access to other services and coordination of care [2, 3]. The first PDNS started working in 1989 in the UK, and in 1997 in The Netherlands. Until now, there were no nursing guidelines in PD, and interventions were based solely on daily clinical practice. Indeed, there is to date no good evidence to support the merits of nursing interventions. However, stimulated by a widespread belief in their added value, many hospitals in various countries have introduced PDNS into the routine care delivery. A survey in 2010 among Dutch PDNS reported that 82% worked in an outpatient hospital clinic [4]. Other PDNS worked in home care, rehabilitation centres or a research centre. Only few PDNS working in an outpatient clinic have the opportunity to visit PD patients and their caregivers at home.

Because there are no guidelines to inform practice, there is currently little uniformity in care delivery, leading to wide discrepancies in the roles, interventions and caseloads between nurses. We therefore decided to develop a nursing guideline for PD, with specific attention to organizational issues and to specific nursing interventions. Our aim was to develop practice recommendations according to international standards for guideline development. With these recommendations, we intend to create greater uniformity and to facilitate the efficacy of nursing care in PD. Furthermore, practice recommendations provide physicians and other healthcare workers useful insights into the possibilities and limitations of nursing care in PD, thereby stimulating dedicated and timely referrals. Finally, these recommendations can provide a basis for future research in nursing care. The present article describes the guideline development and key recommendations about the role of PDNS.

METHODS

The initiative for this guideline was taken by the Dutch Society of PDNS and ParkinsonNet, a Dutch

nationwide healthcare network consisting of professionals specialized in treating PD patients [5]. ParkinsonNet also includes a group of specifically trained PDNS.

PDNS were surveyed to collect their opinions regarding barriers to nursing care for PD patients and their caregivers. Furthermore, survey questions were designed to collect data on basic demographic factors (education, age, duration in job, qualifications), nurses' workloads, nurses' evaluations of the quality of care, collaboration with other healthcare workers and care coordination. The questionnaire was administered in 2013 to all PDNS and generic nurses with knowledge of PD ($n = 148$) working at a hospital, in home care or in a rehabilitation centre. All nurse respondents are involved in direct care and a member of the Dutch Society for PD nurses and/or ParkinsonNet. Nurses received the questionnaire by e-mail. Non-respondents received a reminder at 6 weeks. A 68.2% response rate was achieved.

Subsequently, a systematic literature research was performed in the electronic databases of Pubmed, Cinahl and the Cochrane Library. We included guidelines, systematic reviews, trials, patient series and expert opinions published after 1995 until April 2014. In total, 186 titles and abstracts were examined and a preliminary list of 33 articles that appeared to describe specific nursing interventions and/or nursing role in PD were selected. Many of these studies were excluded because they were irrelevant to PD nursing. These 33 studies were assessed for quality of the study design. When evidence was not available in published studies, recommendations were formulated based on consensus among group members. The Guideline Development Group consisted of seven expert PDNS and one neurologist. Evidence was graded according to Evidence Based Guideline Development (EBRO) recommendations (Table 1). EBRO is an initiative of the Dutch Cochrane Center and the Dutch Institute for Healthcare Improvement (CBO, <http://www.cbo.nl>) [6]. Consensus was gained during informative meetings with the Guideline Development Group members. Furthermore, a group of two patients and three caregivers supported the Guideline Development Group to ascertain input from the perspective of patients and caregivers. Practice recommendations were graded based on their levels of evidence (Table 1). Afterwards, a group of secondary members (which included 22 different professionals and a patient panel; the total group consisted of 48 members) reviewed the practice recommendations until consensus was reached. Finally,

Table 1
EBRO classification of study results and recommendations [6]

<i>Classification of the study results according to the level of evidence</i>	
A1	Meta-analyses (systematic reviews), which include at least some, randomized clinical trials at quality level A2 that show consistent results between studies
A2	Randomized clinical trials of a good methodological quality (randomized double-blind controlled studies) with sufficient power and consistency
B	Randomized clinical trials of a moderate methodological quality or with insufficient power, or other nonrandomized, cohort or patient-control group study designs that involve intergroup comparisons
C	Patient series
D	Expert opinion
<i>Classification of the recommendations according to the level of evidence</i>	
1	Supported by one systematic review at quality level A1 or at least two independent trials at quality level A2
2	Supported by at least two independent trials at quality level B
3	Supported by one trial at quality level A2 or B, or research at quality level C
4	Based on the expert opinion (e.g., of working group members)

the Dutch Nurse Society (V&VN) approved the guideline in October 2015.

KEY RECOMMENDATIONS ON THE ROLE OF PDNS

Several studies reported that care delivered by PDNS was associated with positive effects [7–9]. In a small study by Jahanshahi and colleagues [7], 40 patients with PD received two home visits and five telephone contacts from a PDNS during a 6-month period. There was no statistically significant change in psychosocial functioning between the intervention group and a control group (who received standard care without input from a PDNS). However, the intervention group showed an improvement in anxiety and depression. In another study, Jarman et al. [8] reported significant benefits in patients' perceptions of their wellbeing when they were attended by PDNS, compared to standard care. Furthermore, quality of life improved and expenditure on health and social care was lower. Another study by Reynolds et al. [9] followed 108 patients with PD for 12 months. Care provided by a PDNS was compared with care delivered by a consultant neurologist. The results showed that physical functioning and general health improved in patients with PD who were looked after by a PDNS. Other publications described the role of PDNS, and this is summarized in Table 2. It is clear that PDNS can perform many roles, but there is a wide interpretation about their functions between countries and between local institutions.

Table 2
Summary of possible roles for PDNS

Nursing role
- Information and education [2, 8, 9, 12–14, 21–25]
- Management of symptoms and medication [3, 9, 12–14, 21, 22, 24, 25]
- Support/advice to patients and caregivers [12–15, 24, 26, 27]
- Prevention (for example: screening to prevent crisis) [8, 12, 14, 15, 22, 24]
- Care coordination/case management [3, 9, 12–15, 22, 24, 25]
- Multidisciplinary collaboration [12–14, 22, 24, 25, 28]
- Palliative care [15, 29, 30]
- Support with advanced therapies (deep brain stimulation, apomorphine and carbidopa-levodopa enteral suspension infusion therapies) [31–34]

The Guideline Development Group defined primary tasks for the PDNS which can be seen as minimum standard care for patients with PD and their caregivers. PDNS should at least:

- provide information and education;
- support patient and caregiver in self-management;
- screen and offer prevention;
- support patient and caregivers on psychosocial and existential domains;
- work in a multidisciplinary collaboration;
- perform specific nursing-technical intervention.

The PDNS is a graduated nurse (education level according to the European Qualifications Framework 6 or 7) with a certificate in Parkinson's Nursing. Furthermore, PDNS should achieve a standard of competences. We developed a competence framework

for PDNS based on the CanMEDS (Canadian Medical Education Directives for Specialists-systematic). Finally, a PDNS should follow two PD-specific teaching courses each year to stay informed and competent.

The Guideline Development Group defined that PDNS should have a sufficient case load (i.e., they should support a sufficiently large number of PD patients to maintain adequate expertise). Specifically, the Guideline Development Group developed recommendations to guarantee continuity of care by describing a minimum caseload as well as a minimum number of working hours. PDNS working in an outpatient clinic should work at least 12 hours per week. PDNS working in another setting, for example home care, should work at least 8 hours per week. Only one international report described the caseloads of PDNS and recommended an average of 300 patients per specialist nurse [10]. However, one survey showed that PDNS often have an unmanageable caseload and in some cases see double the recommended caseload of 300 [11]. In the Netherlands, caseloads vary widely, with an average of 350 unique patients per 1 Fulltime Equivalent (FTE). The present guideline now recommends a caseload of at least 150 PD patients (based on 12 hours per week) and a maximum of 370 PD patients (based on 1 FTE).

The present guideline identified care coordination as an important topic for PDNS. PDNS are a key player in the multidisciplinary care for patients with PD. Furthermore, a Dutch multidisciplinary treatment guideline and other literature in PD emphasize that PDNS should preferably assume the role of care coordinator [12–15]. However, many PDNS lack time to do this adequately, and the presently high caseloads allow them to deliver only the minimum standard care. The present guideline emphasizes that a care coordinator should be someone who has a close relation with the patient and family caregivers, and should have specific competences as, e.g., knowledge of local (PD) services, skills in maintaining dialogues, prioritization, interagency communication, good at managing tensions and contradictory demands. Other healthcare disciplines could also assume the role of care coordinator, such as the general practitioner, general home care nurse or dementia case manager. The Guideline Development Group defined five specific core tasks:

1. Assessment of care needs for patients and caregivers. The care coordinator performs

a basic assessment concerning aspects of the medical, physical, mental and social domain.

2. Developing a patient-centered plan. The care coordinator composes a multidisciplinary and patient-centered care plan, based on the outcome of the assessments, and as prioritized by the patient and caregiver. In this patient-centered plan, actions are described and agreements about who is doing what and when are registered.
3. Navigation and monitoring. After the patient-centered plan is established and put into action, there will be regular contacts between the care coordinator and the patient, caregiver and healthcare professionals about the progress in realizing the plan and in monitoring the effects on patient and caregiver.
4. Collaboration with other healthcare professionals. The care coordinator stimulates collaboration between healthcare workers based on the patient-centered plan. If necessary, the care coordinator will organize (online) multidisciplinary meetings. Furthermore, the care coordinator plays a pivotal role in the information exchange and timely referral to other healthcare workers.
5. Advocacy. The care coordinator stands up for the patients' and caregivers' preferences within the care process and selection of the most appropriate service. Therefore, care coordinators should not be limited to organizational boundaries in allocating services.

FORMAL APPROVAL

The guideline was formally approved and disseminated by the Dutch Nursing Society as their official guideline. The full guideline is available in Dutch (<http://www.venvn.nl/Portals/1/Nieuws/2016%20Documenten/richtlijn%20vpk%20zorg%20bij%20parkinson.pdf>).

The guideline considered the literature until April 2014. Several papers have appeared since the publication of the guideline [16–20]. None of these studies existed of an RCT, and one systematic review reported the state of research related to PD conducted by nurse scientists during a 10-year period [20]. However, the level of evidence of the recommendations provided in our guideline was not altered by the results of these studies.

CONCLUSION AND FUTURE DIRECTIONS

The evidence for nursing care in PD is limited. Current recommendations for this nursing guideline were based on a small number of studies with variable quality. No specific nursing intervention have been tested, and only three RCTs evaluated the role of nurses in PD. By integrating current evidence with clinical expertise, plus patient and caregiver values, we have developed practice recommendations which were developed systematically according to EBRO [6]. Although available evidence was limited, the guideline provides recommendations that are based on the best available evidence and which are applicable in daily practice. Specific nursing interventions include provision of information and education, symptom management, medication management, support for caregivers, care coordination and palliative care. Furthermore, the guideline provides a firm basis for future research. Such research requires appropriate methods to optimize the scientific value. An important issue is the lack of good qualitative as well as quantitative studies on nursing interventions in PD. Furthermore, future studies need to be adequately powered, with a follow-up of at least 6 months to determine the duration of any observed improvements.

Implementation of the guideline in the Netherlands started in 2016. A few strategies have been developed for this purpose. Specifically, the guideline forms the basis for a 10-day teaching course for PDNS and for generic nurses trainings. Furthermore, the guideline is combined with a website (<http://www.parkinsoninzorg.nl>). This website is available for PDNS and generic nurses and provides a quick reference card, assessment instruments and a video. We hope that this first guideline for nursing in PD will help to contribute to the quality of care offered by Dutch PDNS.

A central element of the ParkinsonNet concept is delivery of care according to evidence-based guidelines [5]. We have meanwhile developed nine professional guidelines, for a range of professional disciplines, as well as a multidisciplinary guideline. All guidelines were written initially in the Dutch language, and four of these (namely those for speech therapists, dietetics, occupational therapists and physiotherapists) [35–38] have meanwhile been translated into English, and these English versions are now freely available (<http://www.parkinsonnet.info/guidelines>). We are planning to also repeat this

procedure for this specific nursing guideline, thus aiming to contribute to an international standard for PDNS.

ACKNOWLEDGMENTS

This work was supported by the Dutch Parkinson Association [2013]; and the Foundation Nuts Ohra [grant number 1204.075, 2013].

CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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