



## Understanding the role of the Parkinson's disease nurse specialist in the delivery of apomorphine therapy



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### ARTICLE INFO

#### Article history:

Received 29 October 2016

Received in revised form

20 November 2016

Accepted 22 November 2016

#### Keywords:

Parkinson's disease

Parkinson's disease specialist nurse

Apomorphine

Multidisciplinary team

### ABSTRACT

Optimal care of Parkinson's disease (PD) patients should involve a multidisciplinary team (MDT) of which a PD nurse specialist (PDNS) is a key member. The role of a PDNS is particularly prominent in the care of advanced PD patients suitable for apomorphine because, in addition to nursing skills, apomorphine treatment requires liaison, training, interaction and coordination with patients, caregivers and other members of the MDT as well as the interface with primary care physicians. The therapeutic success of apomorphine therapy depends not only upon the pharmacologic drug response, but also on how well the patient understands his/her disease and how to handle the therapy. In this respect, a PDNS is a vital member of the MDT who provides education and training, support, and is available for consultation when problems arise. In this article, we review the literature on the contribution of PDNSs in both continuous subcutaneous apomorphine infusion and intermittent subcutaneous apomorphine injection and highlight the various beneficial aspects of PDNS care, supported by scientific evidence when available. Despite a low level of published evidence, there is strong clinical evidence that the impact of PDNSs on the management of apomorphine therapy is vital and indispensable for the success of this treatment.

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### 1. Introduction

Recent evidence suggests the efficacy of a multidisciplinary care team in the management of Parkinson's disease (PD) [1,2]. This is particularly true in the care of advanced PD patients, where the PD nurse specialist (PDNS) plays an important role in enabling patients to adjust to the different types of therapy offered, extending from oral medications to infusion therapies (both apomorphine and levodopa carbidopa intestinal gel) and deep brain stimulation.

A holistic healthcare model in PD focuses on patient-centered outcomes supported by multidisciplinary professionals, but the PDNS is involved in all aspects of PD care starting right from diagnosis, assisting patients through the various types of treatment, addressing non-motor symptoms (NMS), initiating palliative care, and finally, following death, supporting caregivers and bereaved families. PDNSs not only provide the nursing skills required for the management of PD, but act as the pivotal liaison for the PD patient and the MDT, collaborating, interacting and coordinating with other care providers to ensure the holistic model of care is provided. The inclusion of PDNS support delivers a more comprehensive care by providing professional competence, nursing support, continuity of contact, and emotional support [3]. The networks of PDNS are now well established, providing

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considerable cross-cutting knowledge based initiatives that result in the development of pathways of advanced therapies. However, the nurses' involvement should be tailored to individual patients. In this article, we describe the role of the PDNS in the apomorphine treatment of advanced PD patients by reviewing relevant literature, together with expert inputs from international tertiary PD centers that have extensive experience in apomorphine treatment.

## 2. The concept of Parkinson's disease nurse specialist

The concept of training nurses with a special interest in PD, or PDNSs, has been proposed for more than 20 years to allow the provision of specialized nursing services in all clinical, educational, and professional aspects of PD care [4–7]. Community nursing teams are usually responsible for the day-to-day management of PD in the community, supported by training from a PDNS [8]. However, the setup, organization, prescribing role, and availability of nurses involved in the management of PD varies across countries, subject to different policies and resources. Recently, the trend to include a PDNS as part of the multidisciplinary care team for PD has spread to many countries and regions and has highlighted the diverse roles provided by PD nurses in the various settings in which they practice, depending on the specific local needs and organizations.

## 3. Parkinson's disease nurse specialist as a recognized status

The PDNS status is officially recognized in the UK where training is formally provided with support from the UK Parkinson's Disease Society ([www.parkinsons.org.uk](http://www.parkinsons.org.uk)) and Parkinson's Disease Nurse Specialist Association ([www.pdnsa.org](http://www.pdnsa.org)). According to the UK's national clinical guideline for diagnosis and management of PD (NICE guideline), the key roles and responsibilities of a PDNS are: 1) making and receiving referrals to create integrated and responsive service for PD; 2) admitting and discharging patients; 3) managing caseloads; 4) providing information, education, and support to patients in their homes, in clinics and in hospitals; 5) prescribing medicines and treatment and monitoring the effectiveness of changes; 6) using the latest information technology (IT) to triage PD patients; and 7) using IT to identify patients at risk [9]. In addition, PDNSs are also available in Thailand, Denmark and the Netherlands whose experts are represented in this review. Nurses with specialized PD knowledge also work in many other countries, such as the other Nordic countries, Germany, Australia, and the USA. The role of a PDNS also has been extended to support specific advanced therapies. Many centers in the UK, Denmark and Thailand have specific PDNS who specialize in DBS, apomorphine, or levodopa infusion therapy, and effectively run the coordination of such services [6,10]. Clinical experiences suggest that availability of a PDNS leads to greater adherence to advanced therapy as well as maintenance of therapy [11]. In North America, PDNSs are attached to specialty clinics, and are funded by research grants and specific funding from foundations (e.g. the National Parkinson Foundation) through their outreach and Center of Excellence programs [4]. In some cases, nurses are trained on the job and the amount of autonomy given will depend on the philosophy of the director. Some are exclusively associated with clinical trials and others have taken on the role of educator and counsellor for patients attending routine clinics.

## 4. Evidence-based on the role of Parkinson's disease nurse specialist

Despite the diverse and essential roles of the PDNS as described above, the evidence supporting the effectiveness of PDNSs still

remains inconclusive, largely due to limitations in study design, interventions and outcome measures used [12–15]. Another reason for a lack of efficacy may be because the studied outcomes are broad and not specific to certain types of intervention (e.g. apomorphine treatment). Nevertheless, patients, caregivers and physicians frequently have the clinical impression that PDNSs make a definition contribution to the care of patients with PD [13]. The clinical experience of the authors is that PD patients from centers with experienced PDNSs have a much better adherence to therapy. A good example is with apomorphine therapy, in which the PDNS plays a role in all therapeutic steps, beginning with the selection process and continuing on through initiation of treatment, maintenance of therapy, troubleshooting problems, and provision of regular education, consultation, and psychological support to both patients and caregivers [16]. Therefore, in this article, we review the literature on the contribution of PDNSs in both continuous subcutaneous apomorphine infusion (CSAI) and intermittent subcutaneous apomorphine injection (ISAI). However, before going into the details of the PDNS's role in apomorphine treatment, it is important to first understand the concept of multidisciplinary team (MDT) as the optimal care model in PD.

## 5. Multidisciplinary team as the optimal care model in PD: an emphasis on nurse's role

Optimal care in PD no longer is viewed as a one-to-one physician-patient relationship. With the current understanding of the complexity and heterogeneity of motor and non-motor symptoms, comorbidities and polypharmacy in PD, it is now clear that one treating physician alone cannot deliver a comprehensive management of this disorder. A number of recent studies also support the concept of integrating all the participating disciplines into a streamlined care team with the PD patients at the center, supported by a single or group of dedicated coordinators [1,17,18]. However, the nature of multidisciplinary treatment may vary across countries and even between centers within a given country [19]. In this respect, the PDNS's role can be viewed as a multidisciplinary one as he/she acts as a professional as well as the person who is close to the PD patient and is able to work in an interdisciplinary environment consisting of experts from different health professions, either in a community or hospital-based setting (Fig. 1) [5,12,20]. Many PDNSs run their own clinics, make home visits, refer to other experts and coordinate care packages according to a patient's needs (Fig. 2). In some centers in Denmark, PDNS even have a restricted

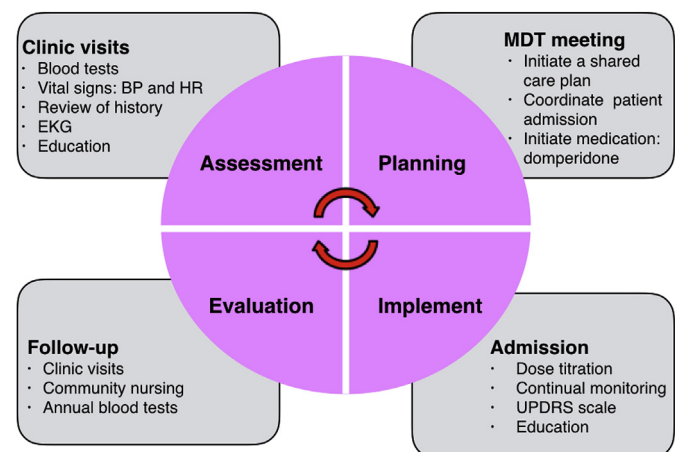


Fig. 1. The diagram illustrating the role of Parkinson's disease nurse specialist list. MDT: Multidisciplinary team.

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