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Review

Parkinson's Nurses Are Crucial for the Management of Parkinson's Disease: 2007–2024

Sue Thomas[a,*], Emma Edwards[b] and Christopher Kobylecki[c]
[a]*Parkinson's Academy Sheffield, Sheffield, UK*
[b]*Livewell Southwest Parkinson's Nurse Team, Plymouth, UK*
[c]*Manchester Centre for Clinical Neurosciences, Northern Care Alliance NHS Foundation Trust, Salford, UK*

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Abstract.
Background: The role of the Parkinson's nurse specialist (PNS) has grown significantly over the last three decades and in the UK now recognized as pivotal in the delivery of services to people with Parkinson's (PwP).
Objective/Methods: The goal of this study was to evaluate the PNS role and the evidence base for its value in managing Parkinson's through a review of the available literature.
Results: PNS are valued by patients, families, and other professionals, and while westernized countries have embraced these nurses as an essential part of Parkinson's management, low-and middle-income countries do not have the resources to develop posts.
Conclusions: The common theme through the small number of studies that exist about the PNS is that the role has clinical benefits but there is little evidence, particularly from a service management perspective, of economic value. Lower income countries also have other health priorities that may overshadow development. More studies are required to establish a solid evidence base for the value of PNS roles.

Keywords: Parkinson's disease, Parkinson's nurse specialists, quality improvement, service development

INTRODUCTION

Parkinson's disease is a degenerative brain disease associated with motor and non-motor symptoms (NMS) including pain, fatigue, bladder and bowel problems, sleep disorders, dysphagia, and saliva control [1]. Motor impairment and complications such as dyskinesia contribute to limitations in mobility, health-related quality of life (QoL) and increasing care requirements [2]. Many people with Parkinson's (PwP) also develop dementia and other neuropsychiatric disturbances such as apathy, anxiety, depression, and psychosis [3]. Overall, the consequences of Parkinson's disease impact on stress and carer burden.

Globally disability and death due to Parkinson's disease are increasing faster than for any other

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[*] Correspondence to: Sue Thomas, Parkinson's Academy Sheffield, 1 The Edge, Hillsborough Barracks, Langsett Road, Sheffield S6 2LR, UK. Tel.: +44(0)7801143122; E-mail: sue.thomas@healthcare-consulting.org.uk; ORCID: https://orcid.org/0000-0002-9224-7726.

neurological disorder [4]. Prevalence has doubled in the last 25 years and global estimates in 2019 show over 8.5 million individuals with Parkinson's disease and suggest 5.8 million disability-adjusted life years, an increase of 81% since 2000 [4]. In addition, 329,000 deaths, representing an increase of over 100% since 2000 were recorded [4].

The impact of Parkinson's disease varies depending on age at diagnosis, with young-onset Parkinson's disease impacting a person's QoL and role played in society and family [5], contrasting with later-onset Parkinson's disease which has a greater impact on patient safety and QoL [6]. Regardless of age at onset PNS have a crucial role to play in supporting PwP.

We highlight why PNS are crucial to the management of PwP utilizing published literature and published viewpoints.

METHODS

A review was undertaken of national and international literature using MEDLINE and Cumulative Index to the Nursing and Allied Health Literature (CINAHL) relating to the PNS role; evidence, descriptors of working practice and global reach. Comprehensive electronic searches were undertaken using the following MeSH and search word terms "Parkinson's disease", "Parkinsonian disorders", "Nurses", "Nurse Specialists". The search was restricted to the English language literature. Further literature was obtained by reviewing reference lists.

In additional to this literature, the authors reviewed policy documents and reports from voluntary sector organizations and professional societies. Given the lack of randomized controlled trials (RCT) in this area the authors sought to focus more on the development and implementation of the PNS role rather than the effectiveness of PNS intervention. We also concentrated on literature where the main focus was on nurse intervention as opposed to where the nurse intervention was part of a multidisciplinary intervention study.

RESULTS

The role of the nurse specialist in the UK

The nurse specialist role in the UK evolved in the 1970s [7] and is often described as a combination of four elements: clinical, education, research, and consultation [8]. This description perhaps oversimplifies and negates the hidden work that nurse specialists perform, for example, in improving and redesigning services, clinical 'rescue' work, the coordination of care and brokering on behalf of patients to ensure appropriate and timely care [9]. Rescue work is performed primarily by nurses to prevent negative patient events, for example to ensure constipation is addressed and provide education to prevent reoccurrence.

The range of nurse specialist roles generally in the UK has increased over time as the value of the role has been recognized with multiple models needed to provide deeper understanding of the unique characteristics of each role depending on the area of practice. For example, the focus of the role may be in a specific population group (e.g., younger or older people, a care setting (e.g., palliative care) or a location (e.g., hospital, community, telephone service or care home). Fulton (2021) states no one model is best; the best model is the one that explains the phenomenon of interest [10].

The UK National Institute for Health and Care Excellence (NICE) Guideline for Parkinson's states that PwP should have access to a PNS specifically for: 1) regular access for clinical monitoring and medicines adjustment, 2) a continuing point of contact for support including home visits when appropriate, and 3) a reliable source of information about clinical and social matters of concern [11].

The 2022 UK Parkinson's Audit found that 95.1% of the 6,489 PwP attending elderly care and neurology services could access a PNS [12]. The majority who responded to the audits' Patient Reported Experience Measure (PREM) questionnaire (80.3%) felt that the amount of contact with their PNS met their needs, similar to the percentage who felt this about their Parkinson's specialist doctor (78.7%). These numbers are likely to be an outlier for many Westernized developed countries but the results are useful to highlight the PNS gap that exists in other countries and the need to address this.

Development of the PNS role in the UK

Access to a PNS following a Parkinson's disease diagnosis in the UK has provided significant benefits to patients over the last three decades [13]. The role has developed into a model of expertise in specialist nursing care that supports PwP at every stage of the disease. The PNS is often the healthcare professional that coordinates patient care referring on to the interdisciplinary team who can then offer non-pharmacological management and symptomatic relief of motor and non-motor symptoms [14].

The first PNS post in the UK was developed in Cornwall in 1989 after a community study showed PwP had several NMS such as constipation and altered sleep patterns which could be anticipated and proactively managed through specialist nurse intervention [15]. The wider development of the role was then spearheaded by the charity Parkinson's UK [16], aiming to improve prognosis and reduce the impact of the condition on both patients and families. The charity supported a 'flagship' team of nurses with specialist knowledge in Parkinson's disease to improve care standards and services. Since these nurses came into post the numbers of PNS have grown significantly and there are now 515 PNS in the UK [17] found in both community and acute settings. This development has largely been due to the fact that Parkinson's UK provided the NHS with funding to implement PNS posts for up to two years which enabled rapid expansion of the role. The funding was only provided if the NHS agreed to continue with the role thereafter but this did enable the role to be nurtured and protected until benefits could be demonstrated [16, 18]. Aside from subjective patient-expressed benefit, service commissioners anecdotally reported improvements such as increased neurology service capacity, reduction in waiting times and reduction in emergency hospital admissions resulting from the PNS interventions [19].

Evaluation of the PNS role

Although the PNS role has been in place for some three decades there is still very little RCT evidence of efficacy; consequently nurse value is frequently questioned by health services that seek to demonstrate value in terms of patient outcomes and cost efficiency [16]. The role is however multidimensional in nature with a lack of defined parameters of outcomes and value due to the multiple roles of the PNS. Nonetheless the Royal College of Nursing and Parkinson's UK made the case several years ago for maintaining and expanding the PNS and other condition-specific roles arguing a leading role for the PNS in ensuring patients get the best care possible [19].

In 2002 a two-year RCT of a community-based PNS role was conducted [20], involving 438 general practices and a total of 1,859 PwP. The primary outcomes measured clinical outcomes, mortality, patient wellbeing, healthcare costs, medication, and onward referrals; PNS had little effect on clinical condition but did improve subjective wellbeing at no additional cost compared to patients supported by their General Practitioner. The trial intervention used nurses who had only recently trained in care of PwP so with hindsight benefits may have been minimized by the nurses' lack of experience.

In a further RCT, Reynolds et al. (2002) compared outpatient services led by a consultant neurologist only, PNS only and PNS/consultant follow up with frequency of contact based on patient need [21]. The collaboration between the two professionals was beneficial and the nurses' longer consultations enabled greater attention to be paid to patient concerns, but the authors concluded that while the PNS expertise was valued the increased cost of the nurses meant they could not be recommended.

In 2006, 89 PNS were surveyed to examine job specifications, perceptions of service delivery and views about assistance [22]: 80.9% had completed specialist training, 60.7% had been in post for more than five years and 32.6 % were non-medical prescribers. They described their major barriers to service delivery as lack of time, administrative support, and heavy caseloads. The study concluded that although the nurses provided high-quality disease-specific care, they were concerned about their ability to maintain this.

An evaluation in Northern Ireland [23] examined the perceived effectiveness, acceptability, and efficacy of PNS among PwP and the multidisciplinary team. A key finding was of the value of the PNS in both acute and community settings, but there was a clear need to clarify the role of the PNS as perceived by other healthcare professionals who could in turn promote the service to their patients.

A Swedish study demonstrated the PNS role provides tailored and competent care to alleviate symptoms, but that PNS required practical skills, theoretical knowledge of Parkinson's disease and the ability to provide emotional support [24].

More recently RCT data from a study in Germany demonstrated that compared to standard care, an integrated approach with individually tailored care plans and home visits improved patient QoL, motor and non-motor features over a six-month period [25]. Future studies need to address the cost-benefit ratio and whether positive effects can be maintained long-term. These findings were also supported in a Canadian study which highlighted that integrated care and self-management support is promising for its feasibility, impact, and a sustainable cost in PwP [26].

Global adoption of the PNS role

While the PNS role and nurse training is well established in countries, for example, the USA, Canada, and Germany [27–31], there is poor PNS availability in low and middle income countries [32] with the median number of neurological nurses varying from 0 per 100,000 population for low income countries, including those in Africa, to 5.04 per 100,000 for higher middle-income countries, together with central and eastern Europe [33].

One of the wider issues in terms of PNS development is the global shortage of nurses, estimated to be almost six million. WHO *State of the World's Nursing* report confirms the critical role of nursing in achieving universal health coverage and documents 80% of the nursing workforce work in countries with 50% of the world's population [34]. To put this in context the African continent has one percent of the world's healthcare workers (most of whom are nurses) but 25% of the global burden of disease. Much of the nursing time here is devoted to addressing important issues like the initiation of retroviral treatments for HIV [35]. For specialist nurse practice, half of the world's countries do not have access to educational pathways to train specialist nurses, and for Parkinson's disease this may be compounded by the fact that neurological nursing as a speciality is not recognized in 41% of countries surveyed for the WHO Neurological Atlas [33].

The lack of government expenditure on health in developing countries also contributes to the deficit in PNS posts globally. Funding is frequently inadequate, and lack of health insurance coverage means that PwP must pay for their own basic health care and medication. Again to put this into context, only 23% of countries worldwide had neurologists in rural areas in 2017, while levodopa, the most effective medication for Parkinson's disease [36], was only consistently available in primary care in 34% of the 110 countries surveyed for the WHO Neurology Atlas [33], none of which were low income countries. Limited access to treatment means PwP cannot receive even the most basic therapy let alone a PNS.

Education likely represents a good return on investment through improved patient management, but these is also need to acknowledge local models of care which may not include PNSs because of nurse shortages. In India, an interdisciplinary community model of care is delivered in 65 support centers which promotes self- management to improve independence and QoL. In Uruguay, a therapeutic, rehabilitation and educational program has been developed which additionally demonstrates the importance of the community in management of Parkinson's disease. PNS could be instrumental in developing and supporting more resources like these globally if such posts were available.

Recognizing the need for greater awareness and improved education in Parkinson's disease, a Movement Disorders Task Force was established in 2012 and a first African PNS course, attended by nurses and therapists from six countries in Africa, was developed [37]. Following the success of the course similar courses have been held in Ghana, South Africa, Ethiopia, and Tanzania [38].

Clearly funding is a major issue in PNS development and insight into how PNS posts develop is useful and as in the UK external funding if often used. In Australia the Department of Health employed 49% of PNS while the pharmaceutical industry employed 21% to assist with device-assisted therapies for complex patients [27].

Crucial elements of the PNS role

Lennaerts et al. (2017) [39] have developed a guideline outlining seven areas that define the PNS role, which has led to clinical practice recommendations in nine key areas (Table 1). These guidelines are currently being evaluated in the Netherlands [40], and a further realist four-phase economic evaluation is being undertaken in the UK [41], which will increase the current knowledge base of the PNS role. However, lack of consistency in the way PNS work is a complication in assessing PNS benefit. While prescribing is seen as an essential part of the role, some PNS practice without this recordable qualification and do not prescribe. For those PNS that can prescribe, some can only prescribe within a certain agreed framework, while others can prescribe more robustly, such as infusion therapies, drugs for mental health complications, and autonomic challenges. This is also reflected in other parts of the world such as Australia.

Many PNS also manage patients with atypical parkinsonian syndromes including multiple system atrophy, progressive supranuclear palsy, and corticobasal syndrome. PNS can have a key role in identifying features that indicate an alternative diagnosis and in providing these patients with a holistic care approach.

There is growing awareness that the delivery of integrated personalized care provided by an interdisciplinary team is also necessary to meet the needs

Table 1
Core areas in PNS practice: role and recommendations (Lennaerts et al. 2017) [39]

Core practice areas of PNS role	Clinical practice recommendations
• Caseload, education, competencies, and care coordination	• Self-care
• Medication adherence	• Mental functioning
• Provision of information and education	• Mobility
• Coping	• Nutrition
• Caregiver support	• Sexuality
• Urogenital function	• Work
• Orthostatic hypotension	• Sleep
	• Palliative care
	• Complementary (integrative) care

Table 2
Pragmatic clinical scale conceptualized by MacMahon and Thomas (1998) [45] outlining the role of the PNS at each stage

Stage	Name	Aims	Priorities
1	Prodromal	• Screening to facilitate diagnosis. • Identification/recognition of motor symptoms in those with prodromal symptoms/at-risk cohorts.	• Provision of accurate information about Parkinson's disease.
2	Diagnostic	• To facilitate acceptance of diagnosis and education on lifestyle activities (e.g., exercise). • Titration of prescribed medicines. • Identification of 'red flag' features suggestive of an alternative diagnosis. • Referral to MDT as required.	• Provision of accurate, sensitive information. • Education in medicines compliance. • Educating patient and carer in self-management. • Directing PwP to research opportunities. • Monitoring for anxiety and depression.
3	Maintenance	• Relief of morbidity and prevention of complications. • Application of appropriate treatments for motor and non-motor symptoms. • Identification of 'red flag' features which may indicate an alternative diagnosis. • Early recognition and symptom management including mental health issues.	• Maintenance of good health, anticipatory care such as advice on medication, and referral to and liaison with the interdisciplinary team. • Monitoring for development of complications, e.g., impulse control disorders. • Directing PwP to research opportunities.
4	Complex	• Symptom management. • Management of motor and non-motor fluctuations with referral to MDT. • Referral for non-oral therapies where appropriate.	• Management of complicated drug regimes. • Identification of non-oral therapy candidates. • Directing PwP to research opportunities. • Advice and management of NMS including mental health issues and referral onto mental health team as required.
5	Palliative	• Relief of symptoms and distress in patients and carers. • Coordination of services.	• Support to community and specialist palliative care teams for management. • Patient, carer, and family support. • Titration of dopaminergic medication. • Bereavement support to carer/ family.

of PwP [42–44]. The PNS can be pivotal in providing coordination, ensuring referral and access to interdisciplinary care, coordinating care packages in addition to creating extra capacity by sharing patient management with movement disorders specialists.

MacMahon and Thomas (1998) outlined that patient priorities vary across the disease trajectory and conceptualized a four-stage pragmatic clinical scale (Table 2) outlining the role of the PNS within each stage [45]. An additional prodromal phase has now been included highlighting that non-motor symptoms such as anosmia, constipation, and rapid eye movement sleep behavior disorder may predict the development of motor Parkinson's disease [46].

The role of the PNS across these stages incorporates a range of clinically complex interrelated activities which include utilizing their specialist clinical skills and care coordination as well as education, advice, and support to both patients and their care

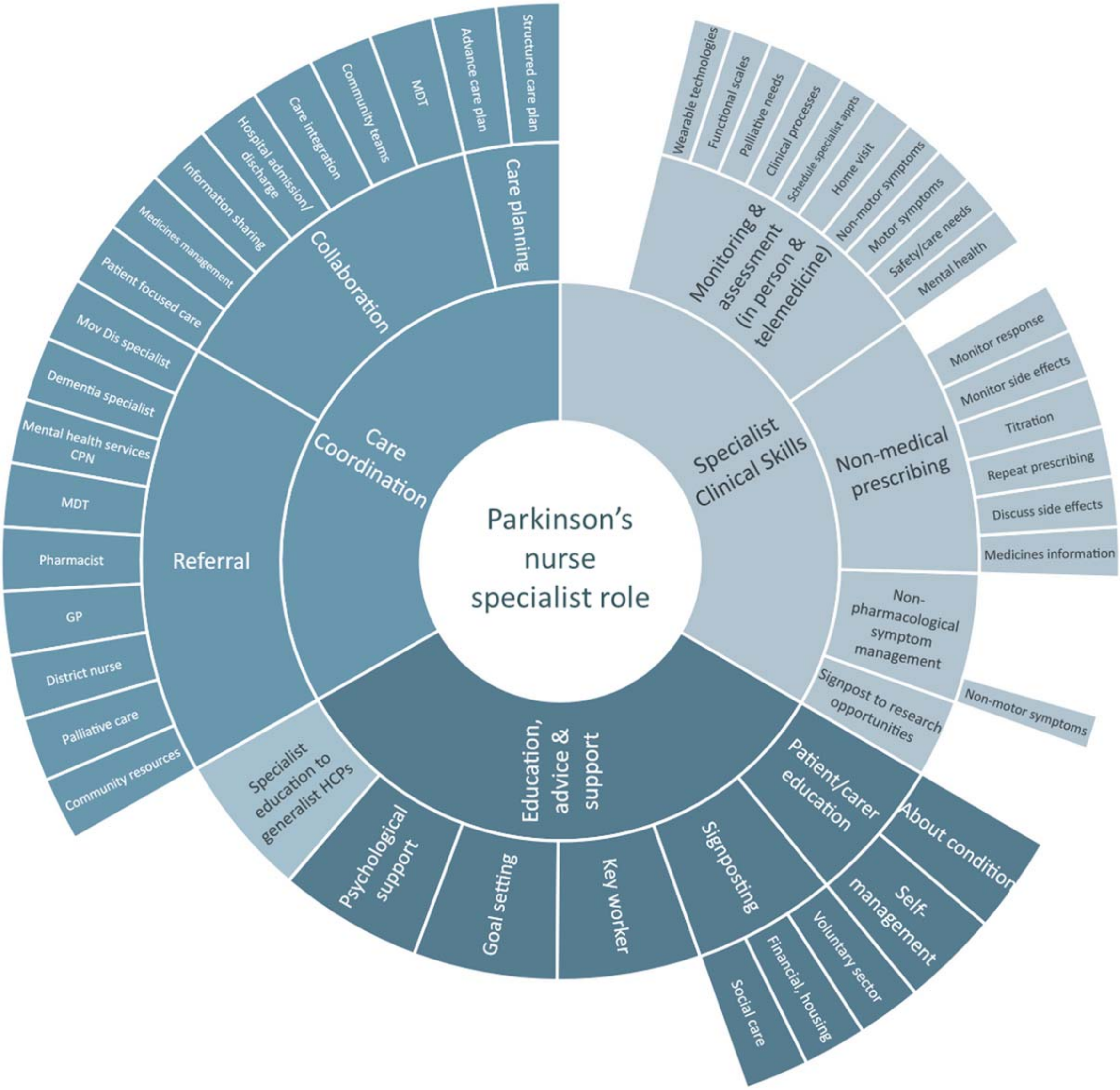

Fig. 1. The multidimensional elements of the PNS workload adapted from Tenison et al., van Munster et al., Lennaerts et al., and MacMahon & Thomas [13, 30, 39, 45]. CPN, community psychiatric nurse; GP, general practitioner; HCP, healthcare professional; MDT, multi-disciplinary team; Mov Dis, movement disorders.

givers [47, 48]. These three areas of clinical practice additionally include a variety of interrelated activities outlined in greater detail in Fig. 1.

The expertise and flexibility of the PNS in clinical practice is particularly significant across disease stages as well as helping PwP to become experts in self-management of their condition. A recently developed UK pathway [49] states that all patients with neurodegenerative movement disorders should have access to a specialist nurse throughout the course of the disease but that existing barriers related to this include inequitable care, lack of nurse prescribers, variation in nurse availability and inconsistent job roles.

PNS are part of a complex network of health and social care professionals and have the expertise to refer onto these and other agencies at the appropriate time. Most of the work is provided through nurse-led clinics, virtual assessments or telephone work, as well as community outreach or in-reach depending whether the nurse is working remotely or in an acute or community setting. The increase in monitoring technology solutions opens up opportunities for remote management and real-time support which can improve workforce capacity [50–55] but requires PNS to adapt to new ways of managing and analyzing clinical data. The PNS can perform many roles, but interpretation about their functions varies between countries and between local institutions [39]. Additionally, many specialist nurses of all kinds are without adequate administrative support with their time frequently spent on non-nursing activities and also subject to annual review processes to demonstrate their benefit which has a negative impact on their role [56].

CONCLUSIONS

The PNS role has grown over the last three decades with multiple configurations of working practice, job titles and ways of working across different settings. This development is not globally universal and more needs to be done to address nurse training, recruitment and retention in middle- and low-income countries. This will not be an easy task and will require commitment from governments as well as innovative ways to provide care.

There is a paucity of research evidence to substantiate the role of the PNS but rather than a linear set of the tasks illustrated in some of the literature, a multidimensional network of the interrelated activities PNS undertake is apparent. PNS manage caseloads of patients throughout all stages of the disease, and this is reflected in the complexity of the system of professionals and health and care groups they utilize to care for PwP. From a service perspective PNS provide additional capacity for movement disorders specialists and they are subjectively valued by PwP. The nurse invests time in empowering patients through teaching self-care and promoting self-management and although the types of nursing intervention may have similarities to other long-term conditions local studies have shown how prompt response to symptoms can reduce the need for emergency care.

The authors would state that the provision of Parkinson's disease care, as exemplified by the PNS model is a proficient, safety critical model of care that is essential to the functioning of interdisciplinary teams and other key professional groups. The benefits of the role are seriously undermined if PNS are deployed in routine, non-specialist nursing work, or elected for roles that lack a leadership component. The holistic care and timely interventions provided by a PNS not only help to reduce patient risk and morbidity but can also potentially prevent costly inpatient care episodes. Further scientific evidence of the PNS role in care models is desirable to generate a larger data pool supported by clearly stated theoretical concepts and well-designed evaluative studies but additionally serious policy discussion on how we will educate and supply more nurses to address the ongoing global needs in Parkinson's disease is required.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

DATA AVAILABILITY

The data supporting the findings of this study are available within the article.

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