Abstract

**Purpose:** Parkinson’s Disease Nurse Specialists (PDNS) play a vital role in delivering personalized care to individuals affected by Parkinson’s disease (PD) and their families. This paper explores the multifaceted responsibilities of PDNS in managing and providing comprehensive care for the unique needs of PD patients. Additionally, it delves deeper into the specialized qualifications and training opportunities available for PDNS, with a particular focus on the United Kingdom’s National Health Service (NHS).

**Method:** A systematic review of literature and publications from reputable sources, including PubMed, The Lancet, Parkinson’s Europe, and Parkinson’s UK, has been conducted to gather pertinent information and insights regarding the crucial role of PDNS in enhancing the quality of life for PD patients. It also includes reviewing the latest PDNS learning pathway guidelines and the EU’s PD care manifesto.

**Results:** A growing number of PD patients and families face communication difficulties with healthcare professionals, particularly consultants. There is a lack of awareness about the disease and its symptoms, which results in delayed diagnosis and inconsistent care plans. During consultations, there is a mismatch between the information provided and the information desired. Publications emphasize the critical roles of PDNS in the delivery of personalized care plans, emphasizing the importance of effective patient-provider communication for optimal plans.

**Conclusion:** Effective communication and understanding of PD patients’ and their family members’ circumstances and emotional well-being contribute to informed care plans. PDNS play diverse roles in providing comprehensive patient and family support. They serve as primary contacts, walking alongside patients in their PD journey. It is vital for PDNS to cultivate a trusted relationship and receive ongoing support to enhance their skills. Government and charities hold critical roles in raising awareness and creating learning opportunities for PDNS and healthcare professionals. Research shows low shared decision-making in European PD care plans, leading to treatment inconsistencies. The European Union recognizes the importance of funding further research, stressing knowledge sharing for well-informed and standardized care plans, benefiting PD patients and families.

**Keywords:** Parkinson’s Nurse Specialist, PDNS, Personalized PD Care, Parkinson’s Care Plans, TCM in Parkinson’s

1. Introduction

Parkinson’s Disease (PD) was first described by Dr. James Parkinson in 1817. He first described the symptoms related to “the shaking palsy” as he named the disorder [1]. It manifests with a progressive deterioration of motor and non-motor functions, causing tremors, rigidity, postural instability, pain, anxiety, and depression [2].
PD affects individuals of all ages, races, and cultures, with a higher prevalence in those over 60 years old, and a smaller proportion occurring in individuals under 50[3]. It presents with a wide range of motor and non-motor symptoms, impacting the quality of life for patients and their families[4]. PD needs long-term, individualized management because it presents in various ways. Patients are typically more satisfied when treated by a PD specialist than a general neurologist[5]. Therefore, the European Parkinson’s Disease Association (EPDA) highlights the pressing need for tailored care plans to address the diverse challenges faced by People with Parkinson’s (PwP) and their families and caregivers.

While PD remains incurable, medical and non-medical interventions can help slow its progression and improve patients’ quality of life[6]. Developing care plans tailored to each patient’s specific needs is essential to ensure the best possible outcomes[7]. The EPDA, the leading Parkinson’s association in Europe, addresses various challenges faced by people with Parkinson’s (PwP) and their caregivers in their research initiative ‘My PD Journey.’ These challenges include timely diagnosis, limited accessibility to advanced care, the need for research resources, and increased awareness of the disease’s impact. Recognizing these challenges will contribute to better care delivery, thus improving the quality of life for patients and their support networks[8].

1.1. Definition of personalized care

Personalized care is a collaborative process between healthcare providers and patients. It is often needed in ‘chronic condition management’[9], wherein healthcare providers and patients identify the symptoms and difficulties caused by their conditions and develop a tailored plan for addressing these issues. At the core of personalized care, there are a series of conversations where both parties are actively involved and being listened to.

People with long-term illnesses, such as Parkinson’s, play an important role in monitoring and managing their conditions. This involves monitoring physical, psychological, sensory, or cognitive limitations[10], and it can be complicated and often requires confidence and knowledge from the patients and their families. Healthcare providers are responsible for developing strategies to engage, support, and empower people with long-term conditions so that they can remain the active party in improving their daily lives[9].

1.2. The importance of patient empowerment

21 years ago, in 2002, in his report entitled ‘Securing our Future Health: Taking a Long-Term View,’ Wanless highlighted the importance of self-care over the next 20 years. He argued that self-care would be one of the best examples of how a ‘partnership between the public and the healthcare service can work.’ Healthcare providers can support the promotion of healthcare by providing patients, as well as the general public, with appropriate information, skills, and equipment to take a more active role in the diagnosis, treatment, and maintenance of well-being[11]. Parkinson’s Europe recommends taking a couple of weeks to cool off after their initial diagnosis and then revisiting healthcare providers to ask any questions they may have. Since PD is a highly individual and personal condition that everyone experiences differently, the organization encourages PwP and their caregivers to learn to embrace change, adapt, and take active roles in self-care. For instance, an analogy is used involving playing golf: rather than playing the usual 18 holes, it is advised to play nine holes, opt for a shorter walk than usual, and make healthier dietary choices to lead a fulfilling and high-quality life.

Studies have suggested that patients who actively engage in managing their illnesses (i.e., recognizing their roles in self-managing their conditions and being better informed about their conditions and symptoms, which boosts their confidence to do so) experience improved health and a better quality of life[12][13]. Empowering patients with skills and knowledge for self-managing their conditions will not only enhance their health conditions and general well-being but also have positive effects on the economy. In his 2001 letter to the United Kingdom (UK) Chancellor, Wanless emphasized that the UK’s healthcare system was lagging behind other
countries due to budget constraints and poor spending. He also highlighted the challenges posed by an aging society and underscored how providing better healthcare for older individuals can positively impact the national economy[11].

Several organizations have introduced models for managing chronic illnesses; however, “The Chronic Care Model(CCM)[14],” proposed by the Center for Accelerating Care Transformation(ACT Center) in Washington DC in collaboration with the American College of Physicians(ACP), has had the most significant global impact. This model emphasizes the relationship between patients and healthcare providers while highlighting the imperative of overhauling existing care plans for individuals with long-term illnesses, as shown in <Figure 1>. The proposed shift moves away from a predominantly reactive system, where responses are triggered only when a person’s condition worsens, to a proactive and holistic approach that investigates the root causes of changes. The model encourages active patient participation, enhancing their understanding of their conditions and empowering them with a stronger voice in the decision-making process related to their care plans. The responsibility of healthcare providers lies in equipping patients with the knowledge, skills, and confidence for self-managing their health conditions[15][16][17]. At the core of the CCM, meaningful conversations take place, with proactive and empathetic healthcare providers ensuring that patients are actively engaged and motivated to participate. With increasing life expectancy, a growing number of individuals will encounter chronic illnesses, necessitating specially tailored approaches to integrate unique needs and symptoms into their care plans.

**Figure 1.** The chronic care model, by the American college of physicians(ACP)[14]. Developed by the center for accelerating care transformation(ACT center), formerly known as the MacColl center for health care innovation.

The ACT Center emphasizes the significance of patient empowerment and values the involvement of patients and their families as partners rather than merely recipients of care. The center summarizes that when healthcare providers acknowledge the importance of connecting with patients and attentively listening to their stories with empathy, they will develop a deeper understanding of the underlying issues and gain more informed insights into how to effectively address them.

**1.3. The importance of parkinson’s disease nurse specialists in personalized care**

Parkinson’s Disease Nurse Specialists(PDNS) play crucial in providing individualized care for those impacted by PD and their families. PDNS are specialized nurses with advanced training
beyond basic qualifications, addressing unique needs of PD patients, offering varied responsibilities like pharmacotherapy and emotional support, following a ‘biopsychosocial approach’ first established by Rosemary Maguire in the UK in 1989[18]. Across different countries, the qualifications, prerequisites, and job designations for these specialized nurses differ notably. In the UK, their diverse responsibilities encompass a range of tasks, such as aiding patients and caregivers, delivering specialized nursing expertise, offering education and financial guidance, and overseeing care coordination, including referrals and advance care strategizing[19].

Across different countries, the qualifications, prerequisites, and job designations for these specialized nurses differ notably. In the UK, their diverse responsibilities encompass a range of tasks, such as aiding patients and caregivers, delivering specialized nursing expertise, offering education and financial guidance, and overseeing care coordination, including referrals and advance care strategizing[19]. Serving as the primary point of contact for PD patients and their families, PDNS walk alongside them throughout their PD journey. It is vital for PDNS to cultivate a trusted relationship and to receive ongoing support to continue enhancing their knowledge and skills to help educate and empower their patients.

Government organizations and charities hold critical roles in raising awareness and creating environments where continuous learning opportunities are available for PDNS and other healthcare professionals. Research has revealed that shared decision-making remains low in PD care plans across Europe, resulting in inconsistencies in treatment approaches. The EU recognizes the importance of funding further research and emphasizes the necessity of sharing knowledge and experiences to facilitate the implementation of more well-informed and standardized care plans for PD patients and their families.

Nonetheless, it wasn’t until 2017 that specific nursing protocols for PD were established[8]. Furthermore, due to the limited availability of PDNS, patients across Europe typically experience waits exceeding 4 months before being able to consult with them[5]. Hence, this research aims to investigate the state of PD care in Europe, including the UK where PDNS was initially introduced, and deliberate on the potential trajectory for advancing PD care.

2. Examining the Current Situation of Parkinson’s Disease Care in Europe

2.1. Inconsistencies in Parkinson’s disease care

The EPDA’s ‘My PD Journey’ research initiative led by experts including Professor Ray Chaudhuri MD FRCP DSC, highlights inconsistencies in available therapies and treatments for PD patients across the European Union(EU)[3]. This lack of consistency often hinders access and developing personalized care for PwP. Personalized care plans that cater to the unique needs of PwP and their families are crucial for managing PD effectively[2]. It is also important to address that PD is affected by the emotional state of the PwP, and the demand is continuous therefore an individual adaptation of the medication is highly recommended[2].

The EPDA’s research project, “The subjective experience of Parkinson’s disease: A qualitative study in 60 people with mild to moderate Parkinson’s in 11 European countries,” aimed to identify gaps in Parkinson’s care and seek out national examples of good practice that could be applied in other regions. The research was conducted by an independent organization on behalf of EPDA, and was presented to the EU’s stakeholders and decision-makers in Brussels in April 2015. The initiative included a qualitative research study that involved in-depth interviews with 60 individuals with Parkinson’s in 11 European countries, including Denmark, France, Germany, Hungary, Ireland, Italy, Netherlands, Slovenia, Spain, and the United Kingdom. All participants were in the mild to moderate stage of the disease and were able to participate in the interviews without relying on others[21].
2.2. Delay in diagnosis: understanding the experiences of people with Parkinson’s

PD is the second most common neurodegenerative disorder, and the number of patients is projected to double over the next generation, making PD one of the leading causes of neurological disability globally[22][23]. Significant progress has been made in understanding the pathogenesis and epidemiology of PD in different populations. However, the cause of the disease remains enigmatic, and there is no proven cure or preventive therapy.

Accurately and promptly diagnosing PD remains a challenge, particularly when it comes to identifying the disease in its earliest stages[24]. The existing clinical diagnostic criteria and biomarkers do not provide a definitive diagnosis during these initial stages, leading to suboptimal accuracy until the condition fully manifests[25].

When considering the experiences of PwP in the diagnosis process, the majority of participants expressed that they did not seek help immediately, with some waiting for up to two years before seeking medical assistance. The early signs of Parkinson’s were often misinterpreted as ‘stress or tiredness from a viral illness[21]’ or attributed to nerve problems. Tremor, being one of the prominent symptoms associated with Parkinson’s, raised concerns among these participants. For example, a participant from Sweden described ‘stiffness’ resulting from his office job, where he sat at a desk for long hours. On the other hand, another participant from Italy, who had a nephew with Parkinson’s, noticed that his symptoms were so different from his nephew’s that he did not consider it to be Parkinson’s. This particular participant did not experience tremor[21].

In European countries, most participants sought diagnosis from their primary care practitioner. While some were fortunate to receive an early diagnosis and were promptly referred to secondary care by their primary care practitioners, others faced delays as some doctors failed to address the seriousness of their symptoms. For instance, one patient from Ireland waited three years for a correct diagnosis, and his symptoms were often dismissed[21].

In some cases, patients with PD in Slovenia opted for private healthcare due to extended waiting times for diagnosis through the national healthcare system. On the day of diagnosis, patients receive prescribed medication, but concerns were raised about inadequate information regarding medication side effects during the consultation. A Danish participant emphasized since PD is a highly individual disease, there is a need for healthcare professionals to make personalized, more informed decisions rather than generalizing their symptoms[21]. Within a few years of medical therapy, most PwP develop complications and these complications are unpredictable. This also includes psychiatric side effects such as delusions, hallucinations and nightmares[26] when increased in severity, these side effects may pose challenges in providing optimal care[27].

2.3. Communications challenges with specialists

According to the EPDA’s latest PD observation study, it is evident that a significant number of patients experienced difficulties in effectively communicating with their healthcare professional, especially the senior consultants. Several participants from Slovenia and Germany reported feeling unheard and dismissed when receiving their PD diagnosis[21]. This first negative experience led them to feel hesitant about openly discussing their feelings and concerns about the disease or asking questions about their symptoms during their follow-up consultations[21]. On the other hand, some participants had more positive experiences, having informative and productive consultations with their specialists, with some consultations lasting over an hour. However it is evident that most participants highly appreciated the presence of a PDNS during their appointments, as they felt more comfortable and at ease discussing concerns and asking questions with the PDNS rather than the consultants[21].

In Sweden, a Swedish nurse named Sunvisson, who worked in a neurological rehabilitation ward during the 1980s, noted that “there was no nursing literature written on PD in the 1980s.”
She further addressed her astonishment at observing rapid changes in the mobility of her patients with PD. While some of these changes could be attributed to medication, others remained unexplained [28]. With the endorsement of the ward’s administration, Sunvisson was authorized to conduct in-depth interviews with PwPs and their families, to better understand their experiences and their coping strategies for the diminishing mobility and non-motor skills in their daily lives [28].

Sunvisson argues the significance of the nurse’s role in fostering a personal connection with PwP and their families. She writes, “An illness is an embodied experience” [28] which permeates every facet of our lives every day. She asserts, “We need to become attuned to this person’s rhythm of time...[28],” highlighting this as the foundation upon which personalized PD care can be initiated. She emphasized the importance of the willingness to understand the personal ways in which PwP navigate their illness and monitor the changes in their physical and emotional well-being. Such attributes are crucial in building a sense of trust between PDNS, PwP and their families.

3. The Role of Parkinson’s Disease Nurse Specialists

3.1. History of nurse specialists

Extended nursing role was first introduced in the 1940s when American nurse, Frances Reiter, coined the term ‘Nurse Clinician’ which she used to define a nurse who developed their knowledge and clinical competence beyond that of their ‘basic’ nursing training, but whilst still continuing ongoing clinical practice [29].

The first nurse specialist for PD, Rosemary Maguire, was appointed in the UK in 1989 [18]. She later developed a course at Plymouth University on ‘Specialist care of people with Parkinson’, for which she received an MBE (Member of the Most Excellent Order of the British Empire) [27]. In 1992, a small team of five PDNSs set up the Parkinson’s Disease Society with a mission to improve standards of care for PwP [30].

3.2. Understanding the role of nurse specialists in the United Kingdom and Sweden

Today, PDNS, as well as nurses specializing in neurology, undergo additional training and obtain experiences beyond their foundational nursing qualifications to address the unique needs of PD patients [18]. The specific qualifications, requirements, and job titles for the nurse specialist vary significantly across countries [31].

Notably, within the UK, PDNS holds the responsibility of providing not only pharmacotherapy but also emotional and social support, contributing to what is referred to as a ‘biopsychosocial approach’ to PD management [19]. Their multifaceted roles encompass numerous functions, including providing support for patients and caregivers, offering educational and financial advice, specialized nursing skills, and coordinating care, which entails referrals and advance care planning [20].

Among the myriad responsibilities undertaken by PDNS, the need for emotional support and empathy emerges as a common theme identified through the focus group studies, constituting critical elements in fostering patient-centeredness for both PwP and their caregivers [32]. Sunvisson’s interviews with PD patients and their family members, conducted in Sweden, echo the significant role PDNSs play in assisting patients and caregivers in accepting life-altering changes, setting goals, and strategically planning for the progression of the disease.

Functioning as the primary point of contact for PwP, the PDNS plays the role of guiding them throughout all stages of the disease stages. It is their responsibility to not only understand and connect with patients but also to educate and empower them.
3.3. Training opportunities for PDNS

Until 2017, there were no nursing guidelines in place for PD, and interventions were primarily based on routine clinical practices, as there was not enough evidence to support the benefits of nursing intervention[8]. Consequently, such circumstances resulted in inconsistencies in delivering both standardized and personalized care. Training PDNS is critical in formulating and implementing well-informed and personalized care strategies for PwP and their families. Significantly, patients and their caregivers have emphasized the importance of establishing effective and meaningful communication with PDNS and consultants, as this fosters a better understanding of the disease and facilitates appropriate modifications in the care plan[8].

Given the escalating demand for specialized care, it is imperative to provide support to PDNS in accessing continuous training and learning opportunities. This will aid in further refining their skills and expertise, enabling them to deliver more comprehensive and collaborative care for all those involved in supporting PwP.

However, it is important to note that identifying suitable training opportunities can be challenging for PDNS. To address this issue, Parkinson’s UK provides a training program designed for the orientation of new PDNSs. In 2018, Parkinson’s UK introduced a fresh learning pathway to guide and recommend areas for additional growth and learning for both novice and experienced PDNSs. The Parkinson’s Competency document outlines the necessary expertise and abilities that PDNSs need to possess in order to effectively oversee the care of individuals with PD in various healthcare contexts[20][33].

In addition, Parkinson’s UK and the Parkinson’s Academy have collaboratively developed a dedicated learning pathway exclusively for PDNS, published in July 2023. This comprehensive roadmap compiles all available professional development resources for PDNS and tailors the learning material according to the nurse’s specific band levels. The courses offered within this pathway are aligned with Parkinson’s nurse competencies and the National Health Service (NHS) Knowledge and Skills Framework. By emphasizing the importance of continuous learning and development, this pathway aims to ensure the delivery of the highest standard of care for Parkinson’s patients and their families[7].

One crucial component of the learning pathway is the inclusion of non-medical prescribing modules. In the UK, nurses, midwives, pharmacists and other allied healthcare professionals (AHPs) who have completed an accredited prescribing course and registered their qualifications are able to prescribe[34].

UK’s NHS primarily focuses evidence-based conventional treatment and medications to treat PD. While traditional Chinese medicine (TCM) and complementary and alternative therapies may be used alongside mainstream treatment, they are usually considered as supplementary rather than the primary form of treatment[20]. The regulation of TCM in the UK is overseen by the Association of Traditional Chinese Medicine and Acupuncture (ATCM). Patients who are interested in exploring TCM and other complementary therapies must discuss their options with their healthcare team, including the PDNS to ensure safe and coordinated healthcare. It is the healthcare team’s responsibility to advise patients on the potential benefits as well as the risks of incorporating TCM or other alternative medical treatments into their overall treatment plans to help them make informed decisions based on their individual health needs.

The largest charity in the UK dedicated to PD, Parkinson’s UK, acknowledges that there is limited scientific evidence suggesting that complementary therapies can slow, stop, or reverse the progression of Parkinson’s. Nevertheless, they have received feedback from numerous patients who report positive experiences with complementary therapies[20]. Many of the charity’s local groups arrange complementary therapy sessions during their regular meetings, encouraging members to explore these options. However, the charity refrains from endorsing any specific form of therapy and also patients are advised to discuss any additional treatments they intend to incorporate with their healthcare team, while also researching the Medicines and Healthcare products Regulatory Agency (MHRA) to ensure the safety of medicines and medical devices.
The UK government established the Complementary and Natural Healthcare Council (CNHC) to provide support and regulation for certain therapies, including the Alexander technique, aromatherapy, Bowen therapy, massage therapy, reflexology, Reiki, and Shiatsu. However, registration with CNHC remains voluntary, and not all practitioners of these therapies choose to be registered.

PD patients often speak with their primary care practitioner, specialist or PDNS to get advice in finding a suitable therapist. Some people speak to friends, family friends or local charity groups. Some practices offer complementary therapies under NHS and these therapies can include acupuncture, aromatherapy, massage, osteopathy and chiropractic treatments. However not all practices offer such treatments. Primary care practitioner can have training in complementary therapy or can refer patients to a therapist registered on the NHS. The Parkinson’s charities in the UK also encourage carers to seek complementary therapies, so they can look after their own physical and mental health.

In 2020, an observational study titled "Traditional and Complementary Medicine in a Nephrology Department: Practitioner Knowledge and Advice" was published on PubMed. This study captures particular interest as it tracked 62 practitioners in Spain, among whom 32.26% had received TCM training across various specialized fields. Furthermore, a 41.93% integrated TCM into their patient care practices, while a substantial 67.74% recommended TCM practitioners to their patients. What stands out is that a significant majority, comprising 62.90%, endorsed the inclusion of TCM in clinical practice. In addition, a substantial 77.42% advocated for adding TCM training into formal health education programs. Interestingly, a 27.42% of practitioners noted patient inquired for more information about TCM, and half of these practitioners were aware of the potential interactions between TCM and conventional treatment modalities [35].

4. Conclusion

In conclusion, the dynamic nature of PD calls for a shift towards personalized management, considering an individual’s specific symptoms and characteristics [6]. While the idea of nurse specialists in PD care is relatively new, there’s a growing acknowledgment of the crucial roles PDNS play in creating personalized care plans for PwP and their families. Although achieving tailored care plans might seem distant, it could start by cultivating a strong patient-provider relationship. This can involve improving diagnostic conversations to be more personal and compassionate, listening attentively to their needs and changes, observing their environmental influences closely, and more. Echoing Sunvisson’s view that an “illness is an embodied experience,” [28], healthcare professionals, especially PDNS, must take a comprehensive approach to address the diverse needs of individuals [36]. To attain this goal, it's essential to provide PDNS with continuous learning and training opportunities. Moreover, establishing standardized nursing guidelines and dedicated learning paths tailored to PD can be instrumental in achieving this vision.

5. References

5.1. Journal articles


5.2. Books


5.3. Additional references


[34] https://www.rcn.org.uk/ (2023).

6. Appendix

6.1. Author’s contribution

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