Applied Nursing Research 28 (2015) 86–91

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

# Support supplied by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses

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ARTICLE INFO

Article history:
Received 28 February 2014
Revised 16 September 2014
Accepted 18 December 2014

Keywords:
Parkinson's disease
Nursing role
Self-care
Qualitative content analysis

ABSTRACT

*Aim:* The purpose of the study was to identify the role of the Parkinson's disease specialist nurse in providing support both for people with Parkinson's disease (PD) and their spouses.
*Background:* PD is a neurodegenerative disease with symptoms that affect many aspects of daily life. In Sweden, specialised nurses called Parkinson's disease specialist nurses (PD specialist nurses) have been working for over a decade to support PD patients and their families.
*Method:* A qualitative approach was taken using dyad interviews with each PD patient and spouse. The analysis was conducted using conventional qualitative content analysis.
*Findings:* The analysis resulted in the identification of one overarching category; competent, professional practice, tailored for the individual. Four categories: professional competence, nursing practice, continuity of contact and emotional support, are distinct but related to each other and show different nuances of the same phenomenon.
*Conclusion:* The work of PD specialist nurses in providing support to PD patients and their relatives should be tailored to individual patients and their families as well as including skilled nursing care to relieve the impact of the disease on daily life.

## 1. Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease that is suffered by approximately seven to 10 million people worldwide (Parkinson Disease Foundation, 2013). PD is a disease with both motor and psychiatric symptoms that affect many aspects of daily life not only for the patient but also for the patient's spouse (Parkinson Disease Foundation, 2013). In Sweden, specialized nurses called Parkinson's disease specialist nurses (PD specialist nurses) have been working for over a decade to support PD patients and their families. PD specialist nurses work in the outpatient clinics of larger hospitals throughout the country and play an established role in multi-professional teams of both neurologic and geriatric clinics (Vårdföreningen Movement Disorders, 2013). Although the PD specialist nurse role is well established in Sweden and their competence and work are acknowledged and valued by team members and patients, no studies of the PD specialist nurse service in Sweden have yet been carried out.

PD is the second most common neurodegenerative disease after Alzheimer's disease. The prevalence of PD in Sweden is between 15,000 and 20,000 persons and about 1500 people are diagnosed with PD every year (EPDA, 2014; Parkinson Disease Foundation, 2013). The risk of developing PD increases with age and is somewhat higher for men then for women. Genetic mutations have been linked to the development of early onset PD in some cases but for most cases the cause of the disease is still unknown (Logroscino, 2005; Parkinson Disease Foundation, 2013; Wirdefeldt, Adam, Cole, Trichopoulos, & Mandel, 2011). Initially the pathological process was considered to be a degeneration of the dopaminergic pathways only mainly in the substantia nigra, but it has since been recognized that other pathways are also affected notably the noradrenergic and serotonergic pathways (Halliday, Lees, & Stern, 2011). The pathology includes the presence of Lewy bodies. Lewy bodies are alfa-synuclein proteins that have been folded in an abnormal way and are therefore not degradable and which form lumps in the brain cells (Wolters, Van Laar, & Berendse, 2007). The diseased neurons then infect the neurons in the surrounding tissue (Halliday et al., 2011).

Motor symptoms of PD include tremor, rigidity, bradykinesia and postural instability (Hoffman Snyder & Adler, 2006; Parkinson Disease Foundation, 2013). There are no biomarkers for PD and the diagnosis is made by a clinical assessment of the patient's symptoms (Halliday et al., 2011). Good response to levodopa treatment supports a diagnosis of idiopathic PD (SWEMODIS, 2011). In the last 15 years more research has focused on the non-motor symptoms of PD namely depression, anxiety, hallucinations, obstipation, sweating, loss of weight and pain (Wirdefeldt et al., 2011).

Nurses with a special interest and training in PD (PD specialist nurses) have been active in the United Kingdom since 1992 (Reynolds, Wilson-Barnett, & Richardson, 2000). In Sweden, the

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http://dx.doi.org/10.1016/j.apnr.2014.12.008

Swedish Parkinson's Disease Association wanted a similar development and started a PD educational program for nurses. In both countries the PD specialist nurses are acknowledged and valued as part of the multi-professional team caring for the PD patient (MacMahon & Baker, 1999). In Sweden PD specialist nurses work in both neurological and geriatric outpatient clinics. For most patients the PD specialist nurse is the primary link to medical care as most PD specialist nurses have an open phone line that provides patients and their relatives easy access to PD specialist nurse services (MacMahon & Baker, 1999). The PD specialist nurse also offers care-oriented appointments for both patients and relatives in the outpatient clinic or in the patient's home. The role of the PD specialist nurse requires extensive knowledge of PD and its symptoms. It is essential for the nurse to be aware of the effects (and possible side-effects) of medical treatment in the form of tablets and drug pumps and also surgical treatment with deep brain (DB) stimulation. The PD specialist nurse will evaluate changes in medical treatment and ask the patient for feedback on effects and side-effects (Reynolds et al., 2000). Traditional care-oriented advice for dealing with physical symptoms (such as obstipation) is part of the PD specialist nurse role but providing emotional support for both patients and spouses is also an essential part of the work (MacMahon & Baker, 1999). A regular assessment of the patient's physical and psychological health needs is important since the progressive nature of the disease necessitates periodic adjustments to nursing care and medical treatment. The PD specialist nurse uses these assessments to identify needs that can be best catered for by other professionals such as physiotherapists or speech therapists, referring the patient to the appropriate care-giver (Reynolds et al., 2000). The PD specialist nurse will also work as an educator, teaching patients and their relatives and other care personnel about the disease, its treatment and its impact on daily life for both patients and relatives (MacMahon & Baker, 1999). Most PD patients are cared for in the home by their spouse who is also normally over 65 years of age. The spouse will normally be the primary care-giver, providing personal care and emotional support as well as taking on greater responsibility for practical household chores (McLaughlin et al., 2010). It is very important for the PD specialist nurse to pay attention to the spouse's general health and wellbeing including how they are coping with these additional burdens. Pressure on the primary care-giver will increase as the disease progresses. Key factors that contribute to increased pressure on the care-giver include psychiatric symptoms, hallucinations, depression and frequent falls (McLaughlin et al., 2010). A situation where the care-giver is unable to cope with the pressures is known to increase the risk of the patient being institutionalized in the future (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). The main goal of the PD specialist nurse is to improve the long-term prognosis of the disease for the patient and help to diminish its impact on the daily life of patients and their relatives. This goal means creating the best possible conditions for patients and their relatives to enjoy the best possible quality of life, to increase their sense of being in control and their ability to lead an independent life and perform self-care (MacMahon & Baker, 1999). As no earlier studies exploring the work of the PD specialist nurse have been identified, the purpose of this study was to identify and describe the role of the PD specialist nurse in providing support for PD patients and their spouses in Sweden.

## 2. Methods

### 2.1. Design

This study was conducted with a qualitative content analysis approach (Krippendorff, 2004) exploring the phenomena through qualitative dyadic interviews where PD patients and their spouses were interviewed together. Dyadic interviewing is appropriate when the participants have a close relationship and the interaction between the participants is important. Dyadic or simultaneous interviews change the balance of power in favor of the participants. The two participants can help each other to get their message across to the interviewer (Polit & Beck, 2012; Sophier, 1995). The ability to help each other out during the interview is particularly important for people with possible cognitive or speech difficulties. People in the advanced stages of PD often experience these types of difficulty. In qualitative interviews the aim is to explore the participants' perspective and their experience of the matter under study (Patton, 2002; Sophier, 1995).

### 2.2. Sample

The sample included PD patients and their spouses selected by PD specialist nurses from two separate neurological and geriatric outpatient clinics during the period from April 2012 to August 2012. The inclusion criteria for the study were a diagnosis of idiopathic PD and a minimum of one contact with the PD specialist nurse in the last 3 months as documented in the patient's case notes. Excluded from the study were patients with a diagnosis of atypical PD and patients living alone. Another inclusion criterion was that participants be able to understand and speak Swedish. After receiving written permission from the clinical directors of the clinics, the study was carried out in accordance with the Declaration of Helsinki and Swedish legislation for non-invasive studies (Swedish Code of Statutes (2003:460), 2003; World Medical Association, 2008). According to Swedish law, ethical approval is not required for research studies conducted during advanced educational programs, but all considerations in the study were made in accordance with ethical laws and guidelines. Letters with information about the study and its aim and a request for participation in the study were sent to 20 patients. Those who wanted to participate replied to the letter and were then contacted by phone. A suitability selection procedure was used to capture the widest diversity of experiences and perspectives possible (Patton, 2002). The suitability selection procedure consisted in choosing patients from all stages of the disease using the PD-specific Hoehn and Yahr scale (H&Y) which classifies disease severity in stages 1–5 according to the patient's symptoms (Chaudhuri, Healy, & Schapira, 2006). In total seven patients with their spouses gave informed consent and were included in the study (14 people). Five patients were men and two were women. Out of the seven patients included; three had had PD less than 10 years, two for more than 10 years and one patient less than 20 years. According to the H&Y scale; one patient was at stage 1, two patients were at stage 2, one patient was at stage 3 and one patient at stage 4.

### 2.3. Data collection

The data collection was conducted by qualitative interviews. An interview guide was designed to ensure that interviews remained focused on the purpose of the study which was to examine the PD specialist nurse role from the perspective of PD patients and their spouses. The questions were inspired by existing literature about the role of the PD specialist nurse. A pilot interview was conducted. After the pilot, the interview guide was revised since the questions concerning the role of the PD specialist nurse were too specific and made it difficult for participants express any opinion. The pilot interview was not included in the study.

The interview guide was revised to contain three broader and more general areas relating to PD specialist nurse support. These more general areas gave the participants a greater chance to share their feelings about PD specialist nurse support. The interviews began with open questions: “Please can you tell me about when you got your diagnosis”, followed by the next area; “Please tell me if the disease affects your daily life”, and ended with “What do you think is most important in your contacts with the PD specialist nurse?” This structure gave the interviewer a better opportunity to listen and follow up on interesting topics mentioned by the interviewees. Follow-up questions were: please tell me more, could you clarify, please give an example, etc. Each interview lasted between 45 and 90 minutes. The interviews were recorded and transcribed verbatim. The audio-recorded conversation transcripts were then used for the analysis (Kvale & Brinkmann, 2009).