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Carina Hellqvist and Carina Berterö

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

Short title: Support supplied by the Parkinson’s disease specialist nurse

Carina Hellqvist, RN, MScN
Department of Neurology, University Hospital, SE-58183 Linköping, Sweden
SWEDEN
Phone: + 46 070 1133343
E-mail: carina.hellqvist@lio.se

Carina Berterö, RNT,BSc, MScN, PhD,
Division of Nursing Science, Department of Medical and Health Sciences
Linköping University, SE- 581 83 Linköping, Sweden
SWEDEN
Phone: + 46 13 286974, 073 2702270 Fax; +46 13 123285
E-mail: carina.bertero@liu.se

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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: Four main categories were identified: professional competence, nursing practice, accessibility and psychological support. Taken together, these four categories illuminate different aspects of the overall support which combines skilled and professional practice tailored to the individual.

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.

Key words: Parkinson’s disease; nursing role; self-care; qualitative content analysis.
1. Introduction

Parkinson’s disease (PD) is a chronic neurodegenerative disease that is suffered by approximately seven to 10 million people worldwide (Parkinson’s 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’s Disease Foundation, 2013). 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. 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, 2012). 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 1,500 people are diagnosed with PD every year (EPDA, 2014, Parkinson’s Disease Foundation, 2013). The risk of developing PD increases with age and is somewhat higher for men than 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 (Parkinson’s Disease Foundation, 2013; Wirdefeldt, Adami, Cole, Trichopoulos & Mandel., 2011; Logroscino, 2005). 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 recognised 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, Lees, & Stern, 2011).

Motor symptoms of PD include tremor, rigidity, bradykinesia and postural instability (Parkinson’s Disease Foundation, 2013; Hoffman, Snyder, & Adler, 2006). There are no biomarkers for PD and the diagnosis is made by a clinical assessment of the patient’s symptoms (Halliday, Lees, & Stern, 2011). Good response to levodopa treatment supports a diagnosis of idiopathic PD (SWEMODIS, 2011). In the last fifteen 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 Swedish Parkinson’s Disease Association wanted a similar development and started a PD educational programme 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, Wilson-Barnett, & Richardson, 2000). Traditional care-oriented advice for dealing with physical symptoms (such as obstipation) is part of the PD specialist nurse role but providing psychological 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, Hasson, Kernohan, Waldron, McLaughlin, Cochrane, Chambers, 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 which contribute to increased pressure on the care-giver include psychiatric symptoms, hallucinations, depression and frequent falls (McLaughlin, Hasson, Kernohan, Waldron, McLaughlin, Cochrane, Chambers, 1998). A situation where the care-giver is unable to cope with the pressures is known to increase the risk of the patient being institutionalised 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 is 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 approach 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 favour 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 three 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; World Medical Association, 2008). According to Swedish law, ethical approval is not required for research studies conducted during advanced educational programmes, 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
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 to 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).

2.4. Data analysis

The transcripts were processed and analysed using inductive conventional content analysis according to Hsieh and Shannon (2005). The transcripts were read several times one after another to get a sense of the material in its entirety. The next step was to consider each interview as one unit for analysis. Each interview was then read carefully word by word to discover statements relevant to answering the purpose of the study. Codes capturing key thoughts were derived from the interview text and quotes directly from the text were sorted under relevant codes. The codes were sorted into larger groups depending on content and together they formed categories. Initially 10 categories were identified. A description of the
content of each category was formed and it was then clear that a number of categories were describing the same phenomena from different angles. These categories were then merged. In total four separate categories were identified as part of the overall support provided by PD specialist nurses.

2.5. **Validity**

To strengthen the validity of this study the interviewee sample was deliberately chosen to include PD patients from all H&Y-classified stages of the disease. This makes the results more likely to be valid for most PD patients and not just for patients at a certain stage of the disease. To improve the validity of the categories identified from the analysis, we included quotations from the original interviews. To test the face validity (how credible the result seems to a topic expert), a PD specialist nurse who was not involved in the study in any way has read through the interview texts and the results retrieved from the analysis (Polit & Beck 2012; Patton 2002).

3. **Findings**

The analysis resulted in the identification of four main categories: professional competence, nursing practice, accessibility and psychological support. All categories are distinct but related to each other and show different nuances of the same phenomenon – competent, professional practice, tailored for the individual. See Figure 1.

The findings are described below and illustrated with quotations from the PD patient and spouse interviews.

Please insert Figure 1 about here
3.1. Competent, professional practice, tailored for the individual

This comprehensive category of competent, professional practice tailored for the individual emerged from the interviews and highlights the importance of the PD specialist nurse’s work for PD patients and their spouses. In order to support PD patients and their spouses, the PD specialist nurse should have extensive factual knowledge of PD. In-depth knowledge of the disease’s progression, the different medical and surgical treatments available as well as their effects and possible side-effects is essential. The PD specialist nurse should have sufficient knowledge to be able to give PD patients and their spouses accurate professional advice when questions or complications arise regarding the disease or its treatment. Insight and an understanding that life with PD can be an enormous strain on both the spouse and the person afflicted by the disease are invaluable. The need for support which combines medical advice, information and psychological support is also of great importance, enabling the PD specialist nurse to handle the situation in the best possible way. PD patients and their spouses feel supported when the nurse allocates ample time to sit down with them and lets them tell in their own words how they experience the situation. By listening attentively, the nurse can evaluate patient needs and the actions required to make daily life with PD as easy as possible. To provide the best support possible the nurse should be able to listen to what each individual patient and spouse needs in the current situation and not generalise. Easy access to PD specialist nurse services is also important and will give PD patients and their spouses the feeling of trust, security and of being cared about as well as being cared for.

“I believe listening is important. To understand the complexity of the disease … even if the symptoms are the same in very many persons the experiences of the disease might be very different. Some make it a big deal and some try to ignore it and it is therefore important to talk to the person afflicted and listen to what he
says. It’s not everyone finds tremor to be the biggest problem. It can be a number of other things…” (Interview 5, Line 344-348)

3.2. Professional competence

Professional competence consists of three sub-categories; professional skills, personal approach and information/education. PD patients and their spouses say that the PD specialist nurse has extensive knowledge both of the disease itself and its impact on daily life. The nurse is able to answer questions that may arise concerning the disease and its treatment and is a source of information on the latest research and treatment options. A professional approach to the interaction with PD patients and their spouses is essential and it is very important to be treated with respect and listened to without any of the issues being diminished.

“She had extensive experience of people… she could give examples not just related to the medical diagnosis but also related to other people. I believe it’s important that it’s comprehensible. Not just some kind of diagnosis and in this stage of disease you’ll have to do this or that… She’s talking about the human being, the person, as well.” (Interview 2 Lines 568-572)

3.2.1. Professional skills

The interviewees made clear that extensive theoretical knowledge about PD including pathophysiology, symptomatology and disease progression as well as medical treatments and their possible effects and side-effects is crucial to the role of the PD specialist nurse. They also recognised that theoretical knowledge alone was not enough. Lengthy clinical experience working with PD patients and their spouses was an important complement to theoretical knowledge. A new and inexperienced PD specialist nurse although having good theoretical knowledge could not work as independently and answer patient and spouse questions as well as a more experienced colleague. An experienced PD specialist nurse can take anamnetic
information, make a clinical examination and evaluation of the patient’s symptoms and know what questions it is important to ask the patient and spouse.

“She has to have knowledge of the disease. Maybe… well it’s not that easy to know… But she has to kind of know what it’s all about. Know the progression. And if there’s anything new, treatments and so on… that can make it somewhat better.” (Interview 1 Line 203-205)

3.2.2. Personal approach

The participants said that the personal approach provided by the PD specialist nurse was greatly appreciated. If the nurse showed an interest and was committed to the interaction with patients and spouses this in itself could lead to feelings of ease and being cared for. It was also important for the nurse to provide enough time for patients and spouses to ask questions and tell their stories and to be able to see patients and spouses as individuals. Addressing patients and spouses by name established a personal rapport.

“It was very competent but also… no time-pressure. It was very calm coming into her room. And the contact… it was just such a good connection when you feel that this person is willing to give you the time needed. We can stay here asking all our questions. And we were there for a LONG period of time I can tell you that.” (Interview 2 Lines 453-455)

3.2.3. Education and information

The PD specialist nurse is a reliable source of information and education about the disease for PD patients and their spouses. Patients and spouses need information specifically related to the current stage of the disease. The interviewees feel that the PD specialist nurse understands the whole picture. The nurse can explain the diagnosis of PD and also knows how the disease will impact daily life both for the person affected and their spouse. Valuable information includes advice for patients and spouses about strategies and exercises to
maintain independence and to promote a good life in spite of the disease. The PD specialist nurse often works together with local patient organisations to inform and educate patients outside the hospital setting.

“The information we received at the onset of the disease was very helpful. Maybe information could be continued in some way… As disease progresses…information what to expect from the next stage of disease and what can be done to make things at home a little easier…” (Interview 3 Lines 341-343)

3.3. Nursing practice

The nursing practice category has two sub-categories: nursing tasks and teamwork. The interviewees have all experienced the practical work of the PD specialist nurse. The PD specialist nurse will have appointments with patients and spouses and also carry out visits to meet the patient and spouse in their home environment. The appointments are care-oriented, focusing on strategies to handle daily life. Usually the visits will include a conversation exploring the current situation for patient and spouse followed by a clinical assessment of the patient’s motor functions. The PD specialist nurse will help patients adjust treatment via medical pumps and DB stimulators. The nurse will also collect blood samples and measure orthostatic blood pressure.

The PD specialist nurse is seen by the interviewees as their main contact and link to the rest of the team involved in patient care. Contacts will be coordinated with other members of the team based on the individual patient’s needs – for a speech therapist, for example. The PD specialist nurse cooperates closely with the doctor in particular and will communicate information between the patient and the doctor. The interviewees recognise that if the PD specialist nurse and the doctor know each other well and have a relationship built on trust they can communicate well and counsel each other about issues concerning patients. On the other hand, if the PD specialist nurse and doctor do not know each other well, the
interviewees felt that the PD specialist nurse had less ability to make independent decisions and would have to ask the doctor’s permission. Even on medical issues the nurse should have the ability to make her own decisions. It is important for the PD patients and their spouses to feel secure and to be a part of the team and involved in decisions concerning treatment.

“The PD nurse and the doctor… they were.. they were what you would call a working team! They were a team where one would ask the other and being a nurse or a doctor by title… that didn’t matter! It’s your knowledge that counts! “

(Interview 6 Line 259-261)

3.3.1. Accessibility

This category consists of two sub-categories: security and continuity. Easy access to PD specialist nurse services and support is seen as being of great importance to all the interviewees. The knowledge that the PD specialist nurse is always in reach if problems arise ensures a sense of security and comfort for PD patients and their spouses. Having a familiar and trusted person to turn to, not having to be referred to someone new and not having to tell the whole story over and over again is comforting. Continuity of contact with the same PD specialist nurse creates feelings of confidence, trust and security and of being both cared about and cared for. The interviewees stress the importance of the PD specialist nurse and would feel excluded if this service did not exist. The PD specialist nurse initiates and maintains regular contact with patients and spouses, calls to see how the patient is doing and follows up on any changes in medication. Contact with the same PD specialist nurse over many years is valuable as the continuity makes the patients and spouses calm and makes the contact more personal.

“But the PDNS role in it all… it’s… what should I call it… It’s comforting because if you have a question you can always call. You have always someone
to ask… Well as I said before… It’s a lifeline! It’s security!” (Interview 6; lines 231-233, 390-391)

3.4. Psychological support

The psychological support category includes support aimed both directly at the patient and at the spouse and other family members. To be diagnosed with PD is a life-changing experience and often comes as a shock to both the person affected and family members. Often the diagnosis will bring on a major life-crisis and patients and spouses often struggle to accept changed life conditions and to adjust to living with a chronic neurodegenerative disease. The PD specialist nurse can guide and support patients and spouses through this process answering questions and listening to concerns and thoughts that might surface due to the changed conditions of life with PD. The nurse should be able to handle feelings of sorrow and anxiety when expressed by patients and spouses. The nurse should also provide calm advice and comfort in stressful situations. Psychological support helps patients and spouses set new goals in life and build a positive outlook for the future. The PD specialist nurse needs to instil courage and help patients not to worry about future difficulties. The PD specialist nurse has to be supportive as the disease progresses and affects more and more aspects of the spouse’s life.

The PD patient will need more help and support to handle daily life. It is important that the spouse and other family members are already involved and kept in the loop when a person is diagnosed with PD. The nurse should encourage spouses to attend doctor’s visits. Spouses often request support groups where they can meet and discuss issues with others in a similar situation. It is very important for the PD specialist nurse to recognise and acknowledge the day by day efforts made by a PD patient’s spouse to help their partner. One of the PD specialist nurse’s tasks is to inform spouses and family members that the need for help to deal with the normal activities of daily life will increase as the disease progresses.
“And then she said to me…Why are you so upset? And I answered; well you know I saw the Pope and my father also had Parkinson’s disease. But please you know we have completely different possibilities today. Completely different medications. You will not end up like your father and the Pope for a long, long time! “

(Interview 2 Line 564-566)

4. Discussion

This is one of the few studies to explore the professional role of the PD specialist nurse from the patient and spouse perspective. It is also the first to explore PD specialist nurse support services within Sweden. The spouses and patients in this study stated that expert theoretical knowledge of PD and the available treatments was crucial to the functioning of a PD specialist nurse. This finding that theoretical knowledge of the disease and the medical treatment available is crucial to the work of a PD specialist nurse is in line with several international studies (Hagell, 2007).

Clinical experience of meeting and interacting with PD patients and their spouses was considered equally important. The experienced PD specialist nurse was more confident in her own assessment and more independent in professional work and decision-making. The fact that confidence in the nursing role comes from clinical experience is supported by a study by Wilson Brooks, Kendall and Brooks, (2006), showing that extensive clinical experience makes specialised nurses better equipped to answer questions and demands from patients.

Several of the interviewees in this study expressed the view that to be able to improve the situation for the individual patient the PD specialist nurse should be up to date with and able to provide patients and spouses information on the latest PD research. In the United Kingdom, the Parkinson’s Disease Nurse Specialist Association (PDNSA) takes this one step further and specifies that one of the PD specialist nurse’s tasks is to initiate and be part of research (Parkinson’s Disease Nurse Specialists Association, 2013).
The interviewees stated that the PD specialist nurse should have respect for the individual and be interested in what the patient and spouse have to say. Taking the time to listen to the patient and spouse, being able to answer questions without time pressure helps patients and spouses feel that they are being looked after. This finding is in agreement with Reynolds et al., (2000) that PD specialist nurse patient appointments are usually longer and more focused on the individual patient’s needs and wishes. When PD specialist nurses take an empathetic approach they can ease patient worries and even ensure that some symptoms are relieved. Even such a small thing as addressing patients and spouses by their first names will create rapport and build feelings of recognition and trust. This finding is also confirmed by Axelrod, Gage, Kaye, Bryan, Trend, and Wade (2010), who describes the PD specialist nurse practice as an empathetic and patient-centred practice that is highly valued by patients and spouses.

This study shows that the PD specialist nurse provides information and answers patient and spouse questions about the disease. Information given by the PD specialist nurse focuses on explaining the whole picture and how the disease may impact daily life. Teaching strategies to make daily life as problem-free as possible and to maintain a good quality of life in spite of the disease is an important task for the PD specialist nurse. The interviewees in this study wanted continuous information relevant to each stage of the disease. The role of the PD specialist nurse in providing education, advice and information is well recognised in the literature (Reynolds et al, 2000; Axelrod et al; 2010; MacMahon & Baker, 1999). It is notable that PD specialist nurse consultations have a different focus to consultations with the doctor. Doctors will give medical information about the disease and the medical treatments available. The PD specialist nurse focuses on explaining the medical terms, giving practical advice to help patients and spouses handle the impact of the disease in daily life (Reynolds et al, 2000). This is in line with the findings in the present study.
The work of the PD specialist nurse also includes practical tasks. According to the interviewees, PD specialist nurses make home visits to examine and evaluate the patient’s health and motor functions. PD specialist nurses collect blood samples and measure blood pressure and help adjust the settings in DB stimulators and medical pumps. This practical role is described in some previous studies (Reynolds et al, 2000; Axelrod et al, 2010; MacMahon & Baker, 1999).

The findings of this study make it clear that the role of the PD specialist nurse includes coordination with the multi-professional team caring for the PD patient. Depending on the patient’s needs the PD specialist nurses will make arrangements for the patient to meet the physiotherapist, doctor, speech therapist or any other resource needed to improve the patient’s situation. Especially important is good teamwork between the PD specialist nurse and the doctor. If there is mutual trust the PD specialist nurse will have greater opportunity to make independent decisions and to take a greater responsibility in the patient’s care. (Reynolds et al., 2000; Carter, 2006).

Easy access to PD specialist nurse services and advice is valued highly by both patients and spouses. Knowing that the nurse is within reach with advice and help if needed gives the patient and spouse feelings of security and that they are being taken care of. Having contact with the same PD specialist nurse over a long period of time builds trust, recognition and ensures that contact is more personal. Previous studies (Reynolds et al., 2000; Van der Eijk, Faber, Al Samma, Munneke, & Bloem, 2011) also highlight accessibility to PD specialist nurse services, cooperation between the PD specialist nurse and patients and spouses and contact with the same PD specialist nurse for a long period of time as being of major importance to PD patients and their spouses.

Being diagnosed with PD is described by patients and spouses as life-altering. For some the diagnosis triggers a major life-crisis and many struggle to adjust to a new life with a
chronic disease. The PD specialist nurse should have detailed knowledge about reactions to crisis and be able to support patients and spouses through all stages of the disease; listening and answering questions and providing hope and support. These findings are in line with other studies describing the importance of the PD specialist nurse in providing psychological support to patients and spouses through all stages of the disease (MacMahon & Baker, 1999). Previous interview-based studies have shown that psychological support is considered to be a specific nursing skill by patients and relatives (Wilson et al., 2006). PD patients and their relatives considered it the most important nursing task together with guidance on how to manage life with a chronic disease (Van der Eijk et al, 2011). Supportive action directed primarily towards spouses and relatives is identified as one of the PD specialist nurse’s tasks in several other studies (Shim, Landerman, & Davis 2011; Mc Laughlin et al., 2010; Carter et al., 1998; Dyck, 2009).

The overall picture of the PD specialist nurse service to emerge from the findings in this study is summarised by the idea of competent, professional practice, tailored for the individual. This accurately describes the PD specialist nurse’s role in Sweden based on dyadic interviews with patients and spouses. In order to provide the best possible care and support to PD patients and their spouses the PD specialist nurse must have extensive knowledge and competence in several areas. The areas identified in this study are in line with the six main areas of support identified by PD patients and their spouses in another study (Van der Eijk et al., 2011). The patient-centred approach described in the study by Van der Eijk et al., (2011) could equally well describe the work accomplished by PD specialist nurses as shown in our study. Another study by Axelrod et al., (2010) presents the work of the PD specialist nurse as responsive and with a holistic focus on the entire life-situation for the patient and spouse. This is also in agreement with the findings of the present study.
4.1. Implications for practice

The findings of this study may provide nurses specialising in PD with a better understanding of what PD patients and their spouses value and desire in order to feel cared for. By acknowledging this, PD specialist nurses can improve their professional skills in ways that will best benefit the wishes and needs expressed by PD patients and their spouses. For a PD specialist nurse, working with a patient-centred approach, listening to the needs and wishes of each unique individual and involving them in decisions relating to their care in a supportive way, this is the greatest of challenges. The findings of this study may also strengthen PD specialist nurses in their professional role by helping them to recognise the competences and unique skills required. Further research could focus on how knowledge and self-care activities can be provided to PD patients and their spouses.

5. Conclusion

In conclusion, findings from this study reveal that PD patients and their spouses need and demand competent professional practice tailored for the individual. The support provided by PD specialist nurses is described as the ability to offer individually tailored and competent care with the aim of alleviating the impact of the disease on daily life. This kind of support demands that the PD specialist nurse has a number of skills and knowledge in several different areas. Practical skills and experience are important as well as theoretical knowledge about PD. As life with PD is often stressful for both the person afflicted and their spouse, the ability to provide psychological support is considered to be an important part of the support offered. PD specialist nurse services must be easily accessible.
References


Research Interviewing. London; Sage.

Swedish Code of Statutes (2003:460) om etikprövning av forskning som avser människor
(Ethics regarding research on human beings) retrieved from: www.notisum.se 3May, 2013.


Figure 1. Illustrating the role and support of the PD specialist nurse for PD patients and their spouses