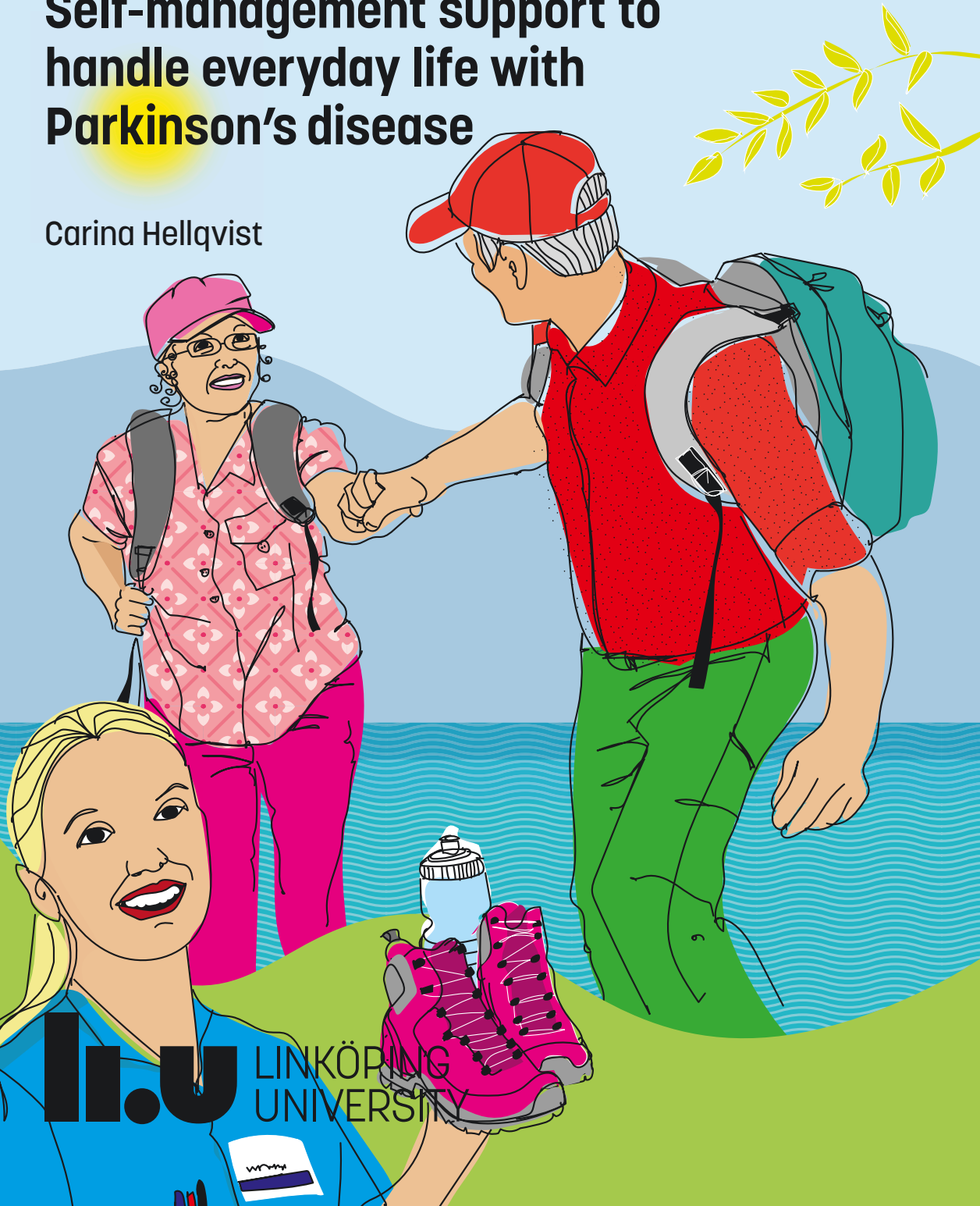


# Self-management support to handle everyday life with Parkinson's disease

Carina Hellqvist



Linköping University Medical Dissertations No. 1730

# Self-management support to handle everyday life with Parkinson's disease

Carina Hellqvist



Division of Nursing Sciences and Reproductive Health  
Department of Health, Medicine and Caring Sciences

Linköping University, Sweden

Linköping 2020

---

© Carina Hellqvist, 2020

Cover/Picture/Illustration/Design: Annelie Dorsell-Svensson

Published articles have been reprinted with the permission of the copyright holder.

Printed in Sweden by LiU-Tryck, Linköping, Sweden, 2020

ISBN 978-91-7929-907-1

ISSN 0345-0082

---

Till pappa!

“Here is a plea  
From my heart to you  
Nobody knows me  
As well as you do  
You know how hard it is for me  
To shake the disease  
It takes hold of my tongue  
In situations like these  
- Understand me....”

- Martin L. Gore



# CONTENTS

**PREFACE**

**ABSTRACT**

**POPULÄRVETENSKAPLIG SAMMANFATTNING**

**LIST OF PAPERS**

**LIST OF FIGURES AND TABLES**

**ABBREVIATIONS**

	<b>Page</b>
<b>1. INTRODUCTION</b>	<b>1</b>
<b>2. BACKGROUND</b>	<b>3</b>
2.1 Parkinson's Disease	3
2.1.1 Prevalence, incidence and risk factors	3
2.1.2 Pathophysiology	3
2.1.3 Symptoms and diagnosis	4
2.1.4 Disease progression and staging according to Hoehn & Yahr	5
2.1.5 Treatment	5
2.2 Living with Parkinson's Disease	6
2.3 The concepts of self-care, self-management, self-monitoring and self-efficacy	9
2.4 Self-management support and interventions	11
2.5 The Swedish National Parkinson School	12
2.6 The Parkinson's Disease Nurse Specialist	14
<b>3. THEORETICAL FRAMEWORK</b>	<b>17</b>
3.1 Dorothea Orem's self-care deficit nursing theory	17
3.2 Person-Centred Care - philosophical theory and clinical practice	19

<b>4. RATIONALE</b>	<b>23</b>
<b>5. AIMS</b>	<b>25</b>
<b>6. METHOD</b>	<b>27</b>
6.1 Designs	27
6.2 Participants and settings	28
6.3 Data collection	32
6.3.1 <i>Group discussions</i>	32
6.3.2 <i>Patient-reported questionnaires</i>	33
6.3.3 <i>Observation and follow-up interviews</i>	35
6.4 Data analysis and summary of findings (study I-III)	40
6.4.1 <i>Qualitative methods</i>	40
6.4.1.1 <i>Thematic analysis according to Braun &amp; Clarke (study I)</i>	40
6.4.1.2 <i>Constant comparative analysis according to Glaser (study III)</i>	43
6.4.2 <i>Quantitative methods</i>	45
6.4.2.1 <i>Methods of statistical testing for outcomes in and between groups (study II)</i>	45
6.4.3 <i>Overall analysis of studies included in the thesis</i>	46
<b>7. ETHICAL CONSIDERATIONS</b>	<b>49</b>
<b>8. RESULTS</b>	<b>51</b>
8.1 Person's efforts and struggles to accept, manage and adjust to everyday life with PD	51
8.1.1 <i>A changed reality</i>	51
8.1.2 <i>Finding a new path</i>	52
8.1.3 <i>The companions</i>	55
<b>9. DISCUSSION</b>	<b>59</b>
9.1 Discussion of the results	59

9.1.1	<i>The process of accepting, managing and adjusting to PD in everyday life</i>	59
9.1.2	<i>PDNS nursing support for PwPD and CP</i>	61
9.1.3	<i>Self-management interventions in clinical care to support PwPD and CP</i>	62
9.2	Applying the theoretical framework	65
9.2.1	<i>Overall description of the model</i>	67
9.2.2	<i>Self-care agency in PwPD and CP</i>	67
9.2.3	<i>Nursing agency</i>	68
9.2.4	<i>Prerequisites for the clinical encounter</i>	69
9.2.5	<i>The relational process of collaboration and partnership to handle impact of PD - Person-centred care in the clinical encounter</i>	70
<b>10.</b>	<b>METHODOLOGICAL DISCUSSION</b>	<b>75</b>
10.1	Strengths and limitations	75
10.2	Validity, reliability and trustworthiness	79
10.2.1	<i>Generalisability, validity and reliability (study II)</i>	80
10.2.2	<i>Trustworthiness (study I and III)</i>	80
<b>11.</b>	<b>CLINICAL IMPLICATIONS</b>	<b>83</b>
<b>12.</b>	<b>FUTURE RESEARCH</b>	<b>85</b>
<b>13.</b>	<b>CONCLUSIONS</b>	<b>87</b>
	<b>ACKNOWLEDGEMENTS</b>	
	<b>REFERENCES</b>	





## PREFACE

Working as an outpatient nurse specialising in the care of persons with Parkinson's disease (PD) for almost 15 years has given me ample experience of the impact of this long-term condition on everyday life. PD affects not only the lives of persons receiving the diagnosis, but also the persons around them like spouses, other members of the family and friends. PD is a long-term condition and symptoms progress over time involving constant adjustments of the persons living with the condition. It is important to develop strategies to handle new and changing symptoms to minimise the impact on, and disruption to everyday life. A vital part of my work as a specialised PD nurse is to provide knowledge about the symptoms and treatments of PD, and to give advice on how to handle both practical and emotional situations, which can occur in everyday life because of the condition.

Meeting so many persons who live with PD, and the persons close to them, has made me realise how unique each person is. Different persons react to and handle the situation in different ways. Some seem to find constructive ways to handle the situation while others seem to struggle considerably, with accepting the changes PD brings about in their life. This sparked my interest. How could I, in my work as a nurse, best support self-management and improve satisfaction with life for the persons affected by PD that I meet in my clinical encounters? I believe that persons with PD are capable of, and willing to be active participants in their own care, and that they wish to find strategies to enable them to continue living a fulfilling life. Specialised PD nurses can provide the guidance and support which is often required during this process.

When I was given the opportunity to become involved in this field of research, my wish was to improve my understanding of how persons with PD and their care partners experience living with and managing PD in their everyday lives. My hypothesis is that a better understanding of the processes, barriers and facilitators involved could also improve my ability, as a nurse, to provide the support needed.

As I wanted my research to be of benefit to persons affected by PD in clinical care, the findings of the thesis are also discussed and applied in relation to nursing theory and person-centred care. This was done to highlight important features of nursing in relation to the findings of this thesis, and to serve as guidance for nurses working in this field.

*Carina Hellqvist*



# ABSTRACT

**Background:** Being diagnosed with Parkinson's disease (PD) is a life-altering experience. The long-term condition requires continuous adjustments to the everyday life not only of the person affected, but also for care partners. There is still insufficient knowledge on how best to support this process of acceptance and adjustment to encourage self-management.

**Aims:** The aim of this thesis is to enhance the knowledge and understanding of self-management for persons with PD (PwPD) and their care partners. Furthermore, to investigate whether the self-management intervention Swedish National Parkinson School can be used as a tool to support self-management, and how nurses specialised in the care of persons with Parkinson's disease can tailor their support to encourage self-management in everyday life.

**Method and design:** Both qualitative and quantitative designs and methods were used in the three studies included in this thesis. Participants included a total of 209 persons. Of these, 127 were persons with PD and 75 were care partners. Participants with PD were largely in the middle stages of the disease. The time since diagnosis ranged from less than one year to over 20 years, and most participants had lived with the disease for around five years. Participants were cared for at five separate outpatient clinics, both geriatric and neurological, in three county and two university hospitals across Sweden. Data collection included observations, interviews, self-reported questionnaires and audio-recordings of the National Parkinson School in clinical care. The overall results of this thesis were obtained using a qualitative approach, where the results of the three studies were analysed using qualitative thematic analysis as described by Braun and Clarke (2006).

**Results:** In combining the results of the separate studies through thematic analysis three distinct but interrelated themes were evident. These described the processes and efforts of persons to accept, manage and adjust to everyday life with PD. The theme "A changed reality" involves participants' descriptions of how life changed after the diagnosis of PD. For many this was a shock, and both the person affected and their care partners experienced a variety of emotions such as anger, denial and hopelessness. It changed their personal identities, their perception of themselves as individuals and as a couple. They worried about what the future would hold, and the uncertainty was hard to accept and handle. One strategy for processing and beginning to acknowledge the new situation involved speaking openly about the diagnosis. The second theme "Finding a new path", involves a description of how,

after accepting or at least acknowledging, their new reality, participants started to find ways of managing the impact of PD on everyday life, incorporating it into their current life and identity. Many felt new knowledge was needed and turned to books and websites on PD. An intervention which was appreciated in terms of providing tools for self-observation and self-knowledge was the Swedish National Parkinson School. Participants later used these techniques to communicate and observe symptoms and healthcare needs. Being an active participant in life and performing activities such as physical exercise or other activities they enjoyed were also used as a strategy to feel satisfaction in life. Participants frequently worked out self-care and compensatory strategies to handle everyday tasks. Another strategy they found comforting and helpful involved retaining a positive mind-set and believing that a good future lay ahead. In the third category “The companions”, the participants described self-management in everyday life as a task they performed together. Management of PD was considered the shared responsibility of the person affected and the care partner, but was also influenced by others such as family members and close friends. The Swedish National Parkinson School provided knowledge as a form of common ground for the person affected and the care partner. During the Swedish National Parkinson School, the social interaction involved in exchanging experiences and feeling support from others in the same situation was considered helpful and was much appreciated.

**Conclusions:** Management of PD in everyday life involves both the person affected and the care partner. After the initial emotional reactions, alongside feelings of lost identity and an altered life, persons started to look to the future and were ready to find ways of handling the changed conditions of their everyday lives. Persons with PD and their care partners were now willing to learn more about PD and to find tools and strategies to help them manage its impact on their everyday lives. During this phase, they appreciated the support of the Swedish National Parkinson School intervention. In the intervention, they would meet others in the same situation to find support and exchange experiences. They also turn to healthcare for support in the process of self-management in everyday life. Nurses working specifically to support PwPD and their CP will need to tailor support taking into account the disease trajectory as well as the psychological processes involved in accepting and adjusting to PD to best fit the unique needs and wishes of every person with PD and their care partner.

**Keywords:** Parkinson’s disease, self-management, everyday life, self-care support, care partners, self-management intervention

# POPULÄRVETENSKAPLIG SAMMANFATTNING

Parkinsons sjukdom (PS) är en kroniskt progressiv sjukdom som drabbar centrala nervsystemet. I Sverige finns cirka 15000-20000 personer med PS. Medelåldern för insjuknande är omkring 65 år. Symtomen innefattar rörelsesvårigheter, balansproblem och skakningar men även psykologiska symptom till exempel humörförändringar, stresskänslighet samt sömnproblem, smärta och blodtrycksfall är vanligt förekommande. Bra medicinsk behandling finns för att lindra symtomen men behandlingen kan inte bromsa eller bota sjukdomen. Med tiden kommer symtomen, trots en väl anpassad behandling, att påverka vardagslivet. Personen med PS kommer att behöva mer hjälp och stöd av sina närstående, för att hantera sjukdomen i vardagen. Att få besked om PS är omskakande. Att så småningom kunna acceptera sjukdomen och hitta strategier för att hantera dess praktiska och känslomässiga påverkan i vardagslivet är avgörande för ett fortsatt gott liv med god livstillfredsställelse.

Denna avhandling fördjupar kunskaperna om hur personer med Parkinsons sjukdom och deras närstående hanterar sjukdomen i sitt vardagsliv. Avhandlingen undersöker också effekterna av patientutbildningen Nationella Parkinsonskolan för de personer som varit deltagare i den. Tre vetenskapliga artiklar ligger till grund för avhandlingen. I dessa har olika metoder använts för att samla in och analysera information. Bland annat har självskattningsskalor använts, intervjuer med personer med PS och deras partners samt observationer av vårdmöten har genomförts.

Genom att analysera resultaten av de tre vetenskapliga artiklarna framkom en beskrivning av personer med PS och de närståendes väg från diagnos till att så småningom att acceptera, hantera och anpassa vardagslivet. Denna process beskrivs genom tre teman. Det första temat ”En förändrad verklighet” innehåller beskrivningar av hur hela livet förändrades i samband med beskedet om PS. För många kom beskedet som en chock och följdes av starka känslor som förnekelse, ilska, sorg och oro. Beskedet förändrade den personliga självbilden och relationen mellan personen som drabbats och partnern. Att tala öppet om sjukdomen samt den oro för framtiden som den innebar var ett sätt att försöka förstå och acceptera den förändrade verkligheten med Parkinsons sjukdom. Efter den första omvälvande tiden började de allra flesta hitta sätt att hantera sin vardag och detta beskrivs i det andra temat ”Hitta en ny väg”. För att återfå känslan av kontroll och hanterbarhet

sökte personen med PS och de närstående medicinsk information om sjukdomen och behandlingar. Att hitta nya sätt och lösningar för att kunna fortsätta att utföra aktiviteter i vardagslivet var ett sätt att behålla självständigheten. Att ägna sig åt aktiviteter som ger välmående och livsglädje var en strategi för att kunna ha en positiv inställning till livet nu och i framtiden. Att vara deltagare i Nationella Parkinsonskolan upplevdes som ett bra stöd både för personer med Parkinson och deras närstående. De strategier för själv-observation och kommunikation som introducerades i Nationella Parkinsonskolan var uppskattade och användes fortsatt i vardagslivet för att registrera parkinsonsymtom och kommunicera dessa vidare till vården i samband med besök och uppföljningar. I det tredje temat "Följeslagarna" beskriver deltagarna att det är otroligt viktigt med stöd i form av familj, goda vänner och även stöd från hälso- och sjukvården för att kunna hantera livet med PS. Att hantera PS i vardagslivet är en gemensam uppgift där både personen som drabbats och den närstående är lika delaktiga. Nationella Parkinsonskolan gav dem en gemensam grund för förståelse av sjukdomen som de kan referera till och bygga vidare på tillsammans i vardagslivet. I Nationella Parkinsonskolan fanns också möjligheten att träffa andra i liknande situation för att utbyta tankar, erfarenheter och ge varandra stöd.

Sammanfattningsvis visar resultaten av denna avhandling att uppgiften att hantera PS i vardagslivet är något som involverar både personen som drabbats och dennes partner. Det ses som ett gemensamt uppdrag och ansvar som engagerar dem båda. Sjuksköterskor som arbetar specifikt för personer med PS behöver anpassa sitt arbete och stöd utifrån sjukdomens symtom men också med tanke på vilket stöd som behövs för att kunna acceptera och hantera vardagen. Sjuksköterskans arbete ska även inkludera stöd till partners och närstående och utföras med hänsyn till varje unik persons värderingar, önskemål och livssituation.

## LIST OF PAPERS

- I. Hellqvist, C., Dizdar, N., Hagell, P., Berterö, C., & Sund-Levander, M. (2018). Improving self-management for persons with Parkinson's disease through education focusing on management of daily life: Patients' and relatives' experience of the Swedish National Parkinson School. *Journal of clinical nursing*, 27(19-20), 3719–3728. doi:10.1111/jocn.14522
  
- II. Hellqvist, C., Berterö C., Dizdar N., Sund-Levander M., & Hagell P. (2020). Self-management education for persons with Parkinson's disease and their care partners - a quasi-experimental case-control study in clinical practice. (accepted for publication April 2020. *Parkinson's Disease* )
  
- III. Hellqvist, C., Berterö, C., Hagell, P., Dizdar, N., & Sund-Levander, M. (2020). Effects of self-management education for persons with Parkinson's disease and their care partners: A qualitative observational study in clinical care. *Nursing & health sciences*, doi:10.1111/nhs.12721. Advance online publication.





# LIST OF FIGURES AND TABLES

<b>FIGURES</b>	<b>Page</b>
<b>Figure 1</b> The seven themes of the NPS	<b>14</b>
<b>Figure 2</b> Flow of participants (study II)	<b>31</b>
<b>Figure 3</b> Initial thematic map (study I)	<b>41</b>
<b>Figure 4</b> Example of substantial coding (study III)	<b>45</b>
<b>Figure 5</b> Initial thematic map overall findings (study I-III)	<b>47</b>
<b>Figure 6</b> Model of the overall results of thesis: Building blocks for everyday management of PD	<b>57</b>
<b>Figure 7</b> Model of PDNS nursing care applied in Dorothea Orem's nursing theory	<b>66</b>
<b>TABLES</b>	<b>Page</b>
<b>Table 1</b> Overview of the studies included in the thesis (I-III)	<b>27</b>
<b>Table 2</b> Overview of participants and study locations (I-III)	<b>29</b>
<b>Table 3</b> Content of session 7 in the NPS	<b>33</b>
<b>Table 4</b> Interview guide (study I)	<b>38</b>
<b>Table 5</b> Observational guide (study III)	<b>39</b>
<b>Table 6</b> Example of data processing from text (study I)	<b>42</b>



# ABBREVIATIONS

CP	Care Partners(s)
HCP	HealthCare Professional(s)
MPT	Multi Professional Team
NPS	National Parkinson School
PCC	Person-Centred Care
PD	Parkinson's Disease
PDNS	Parkinsons Disease Nurse Specialist
PwPD	Person(s) with Parkinson's Disease
SCDNT	Self-Care Deficit Nursing Theory (SCDNT)
SMI	Self-Management Intervention(s)



# 1. INTRODUCTION

Changes in population demographics with a longer life expectancy in the general population, will also impact the number of persons in the community affected by long-term conditions. To be able to provide adequate care and support with limited resources and changes in the way healthcare is organised, there is a need to focus on strategies which support self-care provided in an outpatient setting (Rees & Williams, 2009; WHO, 2015).

Parkinson's disease (PD) is a common neurodegenerative condition affecting 1% of the population over the age of 60. A total of 6.1 million persons are affected by PD worldwide, and this number is expected to double over the coming decades, leading to increased costs and resource requirements (Dorsey & Bloem, 2018). Although good medical treatments are available to relieve the symptoms, PD is a long-term and progressing condition. As the disease advances, life with PD involves physical, psychological and social consequences for the person affected. It also impacts the lives of care partners (CP) and family. Although persons with PD (PwPD) need regular contact with healthcare to monitor symptoms and to adjust medical treatment, PwPD undertake everyday management and care themselves, together with their CP and family (Beudet et al, 2015; Shin et al., 2013). Uncertainty about the future and the progression of disease, as well as the constantly changing symptoms of PD, require PwPD and CP to adjust and adapt constantly. Self-management of PD is a constant struggle on both a physical and psychological level (Haahr et al., 2011; Sjødahl-Hammarlund et al., 2018).

There is still insufficient knowledge of the process of accepting and adjusting to life with PD in terms of the experiences of persons living in this situation. Several studies have illustrated how emotional support and support for self-management are important for PwPD and CP in the clinical encounters, but their needs and wishes remain largely unmet (Schipper et al., 2014; Vlaanderen et al., 2019; Kleiner-Fisman et al., 2013). More patient-centred research is needed, along with better-designed studies, to help understand how best to support PwPD and CP handle the impact of disease on everyday life. PwPD themselves, and their families, suggest that research areas could include topics like coping, stress management, social support, nursing care interventions, communication, self-care and multi-professional care (Shin & Habermann, 2017). Enhanced knowledge including the factors facilitating or preventing persons to positive adaptation to the new demands brought on by PD is vital to develop interventions in clinical care to provide support in this process.

This thesis focuses on improving knowledge of self-management of PD by exploring the experiences of PwPD and CP. It also investigates the Swedish self-management programme National Parkinson School (NPS) as a tool for support in developing strategies to promote self-management and satisfaction with life. The thesis further discusses the main results in relation to nursing theory and person-centred care. It elaborates on how these findings can be understood and introduced into clinical care, to guide nurses who support PwPD and their CP throughout all stages of the disease, as described by Hellqvist and Berterö (2015).

## 2. BACKGROUND

### 2.1 Parkinson's Disease

PD is a long-term progressive neurologic condition and the second most common neurodegenerative condition after Alzheimer's disease (Tysnes & Storstein, 2017). It was first described in writing by an English apothecary and surgeon, James Parkinson, in 1817 in his publication "An essay of the shaking palsy", describing the cardinal signs of this condition (Parkinson, 1817).

#### 2.1.1 Prevalence, incidence and risk factors

PD is diagnosed in about 1% of the population above the age of 60 making it an endemic condition in this age group. In Sweden, prevalence is estimated at 15000 – 20000 persons with around 2000 new cases diagnosed annually (Swedish national board on health and welfare, 2016). The risk of developing PD increases with advancing age and the average age of onset is between 65-70 (Tysnes & Storstein, 2017). Worldwide, it is estimated that there are about 6.1 million persons with PD, of whom about 2.9 million (47.5%) are women and 3.2 million (52.5%) are men (GBD, 2018). The number of PwPD worldwide is expected to increase and almost double in the coming decades. Improved medical treatment and a longer life expectancy in the general population mean that there will be a greater number of persons living with PD for many years of their lives (GBD, 2018). This will also lead to an increased need for healthcare resources.

The cause of PD has not yet been identified, but it is most likely to involve a combination of genetic as well as environmental factors. A number of parkinsonian genes have been identified but most persons developing PD have no such genetic variations (Kalia & Lang, 2015). Known environmental risk factors include exposure to pesticides, prior head injury, living in the countryside, drinking well water, use of  $\beta$ -blockers, consumption of dairy products, substantial emotional stress and agricultural occupations. Environmental factors which reduce risk include tobacco smoking, drinking coffee, drinking alcohol and long-term use of anti-inflammatory drugs and calcium channel blockers (Nag & Jelinek, 2019; Kalia & Lang, 2015). The risk of PD is also lower for persons that practice intense physical activity (Xu et al., 2010; Yang et al., 2015).

#### 2.1.2 Pathophysiology

Previously, the pathology of PD was considered exclusively to involve the death of dopaminergic neurons in a particular area in the mid-brain. This area, consisting of several nuclei and called the basal ganglia, is involved in



the coordination and performance of movements (Dickson et al., 2009). A 50% loss of the dopaminergic neurons in this area leads to tremors and difficulties with movements and these are the cardinal symptoms of PD. The death of the dopaminergic neurons is caused by aggregates of misfolded alpha-synuclein proteins, forming so called Lewy-bodies in the body of the cell. The pathology of Lewy-bodies is not specific to the brain, but can also be found in the peripheral nervous system and in cardiac, gastric and skin tissue. One hypothesis is that the sick neurons spread the misfolded proteins to other neurons close to them leading to the progress of Lewy pathology throughout the brain (Kalia & Lang, 2015).

A hypothesis on the spread of PD and Lewy pathology through the brain has been described by Braak and colleagues (2003), based on the general symptomatology seen throughout the disease trajectory. The Braak hypothesis describes how PD progresses in six stages. Stages 1-2 are considered to be prodromal disease with a variety of symptoms such as loss of smell, constipation and REM sleep disorder. Stages 3-4 are considered to be the clinical phase, where pathology in the mid-brain causes the distinct motor symptoms of PD such as rigidity and tremors. Stages 5-6 represent the advanced disease where Lewy pathology spreads to the cortex, with symptoms such as affected cognition and apathy (Braak et al., 2003).

With advancing knowledge of PD pathology, it is now clear that it is not just the dopaminergic neurons, which are affected. Cell loss also involves other neurons, which use various neurotransmitters, as well as protein aggregates other than Lewy-bodies. The complete pathology in PD is not yet fully understood (Kalia & Lang, 2015).

### **2.1.3 Symptoms and diagnosis**

The diagnosis of PD is still mainly based on the presence of clinical symptoms assessed by a neurologist specialising in movement disorders. No clinical tests or biomarkers are available to determine diagnosis. However, in clinical care dopaminergic imaging and lumbar puncture are often performed in order to rule out other diseases (Kalia & Lang, 2015).

Parkinsonian symptoms include bradykinesia (slow movements), muscular rigidity, rest tremor (often unilateral), and impaired gait and postural control. Bradykinesia as an absolute criterion and either rest tremor or rigidity or both must be present for diagnosis of probable PD. A positive response to medical treatments will further strengthen the probability of idiopathic PD (Postuma et al, 2015). The motor symptoms in PD can vary greatly between individuals and two subtypes of PD have been suggested, tremor-dominant and akinetic-rigid type (Kalia & Lang, 2015).

Persons affected by PD will experience motor problems but non-motor symptoms are also common. These include loss of smell, cognitive impairment and dementia, psychiatric symptoms like anxiety and hallucinations, sleep disorders and autonomic dysfunctions like orthostatic hypotension, pain, and fatigue. All PwPD will experience at least a couple of non-motor symptoms and these can often be the first presentations of disease in the pre-clinical, prodromal phase (Schapira et al., 2017). Non-motor symptoms can be pronounced in the more advanced stages of the disease and severely affect the quality of life for PwPD, their CP and their families (Kadastik-Eerme et al., 2015).

#### **2.1.4 Disease progression and staging according to Hoehn & Yahr**

As a way of describing disease severity, the five stages of PD according to Hoehn & Yahr (1967) are the gold standard, and are used in clinical care and research (Goetz et al., 2004). The five stages are based on observations of the natural progression of PD (Hoehn & Yahr, 1967) and describe the condition from mild to very advanced:

Stage I: Unilateral involvement usually with only minimal or no functional disability.

Stage II: Bilateral involvement without impairment of balance.

Stage III: Bilateral disease: mild to moderate disability with impaired postural reflexes: physically independent.

Stage IV: Severely disabling disease: still able to walk or stand unassisted.

Stage V: Confinement to bed or wheelchair unless aided (Hoehn & Yahr, 1967).

#### **2.1.5 Treatment**

Good medical treatments are available to reduce many symptoms of PD, but all treatments are only symptomatic and will not cure or slow down progression of the disease. There are three long-term goals in terms of treating persons with PD: to delay disease progression, to improve symptoms and to maintain functional capacity (Shin & Hendrix, 2013). PwPD require close and regular contacts with healthcare in order to adjust therapy as symptoms worsen, or when new symptoms occur as PD progresses.

There are several types of drugs, often used in combination to achieve the best possible control of PD symptoms. Most commonly used are drugs targeting dopaminergic receptors like L-dopa and dopamine agonists. In addition, several types of enzyme inhibitors such as MAO-B and COMT inhibitors are used to prolong the effects of the dopaminergic drugs. During the initial years following diagnosis medication often provides good symptom control (Kalia & Lang, 2015). However, as the disease progresses, medica-

tion often lead to side effects, including a fluctuating drug response, involuntary movements (dyskinesia), hallucinations and reduced impulse-control. Furthermore, non-motor symptoms often increase as the disease progresses, and these are usually less responsive to medication. For some PwPD oral medications are ultimately insufficient to provide acceptable symptom control with symptoms occurring in patterns which are totally unpredictable and fluctuate between parkinsonian symptoms and dyskinesias several times every day (Armstrong & Okun, 2020; Ravenek et al., 2017). For these persons alternative ways of administering anti-parkinsonian medication are sometimes required. To control symptoms in an acceptable way for these persons medication can be administered by using medical pumps, which ensure an even flow of medication over the day (Bhidayasiri et al., 2015; Pederesen et al., 2017). Some are also helped by implanting a deep brain stimulator to block the abnormal brain activity in the basal ganglia, which causes the difficulties of movement (Mansouri et al., 2018).

There are a number of non-pharmacological interventions available to improve long-time prognosis and preserve function for PwPD (Radder et al., 2017). Regular physiotherapy is a vital complement to medical treatment and should be undertaken by all PwPD. Regular physical activity can improve motor performance like balance and gait, functional ability and non-motor symptoms like pain, sleep, fatigue, mood and cognitive functions. It can also reduce problems of constipation and apathy (Ramaswamy et al., 2018). In addition there is growing evidence that physical activity can have neuroprotective effects, slowing down the progression of the disease (Paillard et al., 2015), but more studies are required needed to distinguish the types of exercise which are most beneficial and the amount and frequency of exercise needed to achieve this effect (Ellis & Rochester, 2018). Another intervention specifically targeting PwPD is the Lee Silverman voice treatment (LSVT). This method aims to improve the volume and articulation of speech, which are impaired in many patients (Mahler et al., 2015).

## 2.2 Living with Parkinson's Disease

Most PwPD live in their own residence for the main part of their lives. Even as the disease progresses over the years, and with a diagnosis of PD for 10 years or more, most PwPD still live in their own homes (Hassan et al., 2012). They rarely need to be admitted to hospital, and are cared for in the outpatient clinic. This usually involves visits to the treating physician and other members of the multiprofessional team a couple of times a year, to evaluate health status and adjust treatment (Lennaerts et al., 2017; Kalia & Lang, 2015).

Because PD is a progressive disease involving difficulties with movements and balance, and frequently psychiatric symptoms and cognitive decline, the impact on everyday life is inevitable (Sjödahl-Hammarlund et al.,

2018). Persons everyday lives involve activities and tasks persons engage in to look after themselves and use their mental, social, physical and spiritual capabilities in ways, and to an extent that is satisfying and health promoting to them (Håkansson et al., 2006). Everyday life include practical tasks common to most persons like eating, washing and walking but also involve social aspects and interactions with other persons in society. Everyday life is what we usually live and do and often take for granted until something prevents us from performing them. Which activities and interactions are considered included in everyday life is to a great extent variable to each unique person (Milbourn et al., 2014; Kang & Ellis Hill, 2015).

For most persons work plays an important role in their everyday life. Persons with PD often retire from work earlier, with the loss of income and the social interaction of the workplace. Early retirement is often related to an inability to meet demands of work due to the symptoms of PD (Murphy et al., 2013). Communication barriers, such as blurred speech and impaired facial expression due to rigidity of facial muscles can lead to communication difficulties and misunderstandings. This can affect personal relationships with friends and family members, and can lead to disease stigma in social activities. PwPD tend to have fewer close friends and visit them less frequently than other persons in the same age. It has been demonstrated that some PwPD lose friends when they are diagnosed with PD and they can also lose friends if they try to hide the diagnosis instead of speaking openly about it (Perepezko et al., 2019).

The obvious symptoms of PD include difficulties with movement, such as freezing of gait, dyskinesias, balance problems and tremors. These can be embarrassing causing feelings of being exposed and of shame so that PwPD and CP avoid social events (Fereshtenejad & Lökk, 2014; Thordardottir et al., 2014). The unpredictability of PD, where symptoms often change several times a day, makes PwPD unsure of how to handle situations, and this influences their social participation in a negative way (Ravenek et al., 2017; Thordardottir et al., 2014). PwPD tend to be less active in leisure activities after they are diagnosed. Their leisure activities become more solitary and less physically demanding then before diagnosis. Activities in a group format, arranged and tailored to PwPD and their specific condition, have been shown to be helpful in improving both social interaction and physical activity (Perepezko et al., 2019). These activities can include dancing, yoga and boxing. Strategies used by PwPD to help them handle everyday life include planning ahead, using aids and compensatory strategies to allow them to remain active, maintaining a positive attitude, using upward and downward social comparison and accepting support from family, friends and healthcare professionals (Sjödahl-Hammarlund et al., 2018; Thordardottir et al., 2014).

As the disease progresses motor symptoms and cognitive difficulties become more pronounced. Ten years after diagnosis, approximately 50% of PwPD have developed dementia, and already at the time of diagnosis around 30% experience mild cognitive impairment (Weil et al., 2018). As symptoms progress, PwPD become less independent and need more support to manage everyday life (Maffoni et al., 2019). The support of other persons is crucial in maintaining health and satisfaction with life (Ambrosio et al., 2019; Chenoweth et al., 2008), and PwPD living alone require certain attentions and support from healthcare professionals (HCP).

Many PwPD live and share everyday life with a spouse. Because of the known trajectory of PD, it is encouraged to involve and inform spouses and other members of the family already at the time of diagnosis (Lennaerts et al., 2017). In many cases, the spouse wants to be engaged, and often takes on the role of care partner (CP). By definition, becoming a CP involves acknowledging that handling of PD is a shared experience and responsibility (Bennett et al., 2017). The CP dyad is built on a relationship of commitment, trust and collaboration. Care is not simply something which CPs provide for the spouse affected by PD. It includes the mutual involvement and engagement of both (Bennett et al., 2017; Berg & Upchurch, 2007). Spouses are often CP but the concept is not restricted to this constellation. Anyone close, i.e. children, close friends or siblings, can become a CP. The CP dyad is an interdependent relationship where the persons involved look after each other in the best interests of them both (Bennett et al., 2017).

As PD progresses the roles within the CP dyad might change. More of the everyday tasks like housework, driving the car and paying bills may need to be undertaken by the person not affected by PD. In addition, in the more advanced stages of PD, the PwPD requires help with personal tasks such as dressing, walking, going to the bathroom and following medication regimens. It has been shown that CP need to plan ahead to enable them to cope with the situation, remain positive and maintain their own social and leisure activities. They turn to formal healthcare support and the support of family and friends in order to manage emotionally as well as physically. In the later stages of disease caring for PwPD can be both physically and emotionally demanding for CP. CP often try to find a balance in life, to care for both themselves and for the spouse affected by PD (Berger et al., 2019). In order to maintain mutuality in the relationship and to ensure that the CP dyad remains positive HCP have to assess needs and provide support for the CP too, to enable them to handle the situation and keep the feelings of self-efficacy and a positive outlook in life (Lennaerts et al., 2017; Berger et al., 2019). Symptoms in PwPD closely connected to increased burden on CP include frequent falls, cognitive problems and psychiatric symptoms like hallucinations, anxiety and sleep problems (Mosely et al., 2017). Strategies used by CP to cope can include accepting the situation, having patience, living in the

present, being positive, looking for information and maintaining their own leisure activities and social interaction with others (Navarta-Sanchez et al., 2017).

The positive outcomes of a dyadic care partnership for handling life with long-term conditions have been discussed extensively in the literature (Helgeson & Zajdel, 2017; Martire & Helgeson, 2017; Eilers, 2013; Berg & Upchurch, 2007). A well-functioning CP dyad not only has the potential to lead to improved medical outcomes but can also strengthen the relationship between the two partners and improve their satisfaction with life (Park & Schumacher, 2014; Tanji et al., 2008; Young-Mason, 2015). On the other hand, the relationship can become strained if the person closest to PwPD does not have the ability or the will to adopt a mind-set of shared responsibility, or take on the entire responsibility for care. This can lead to feelings of burden for both, less satisfaction with life and less favourable medical outcomes, especially for persons affected by neurodegenerative diseases such as PD (Sjödahl-Hammarlund et al., 2018; Eilers, 2013; Theed et al., 2017; Nilsson et al., 2015).

## 2.3 The concepts of self-care, self-management, self-monitoring and self-efficacy

Self-care can be defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being" (Orem, 1991: p 145). Self-care activities are conscious activities directed towards universal needs and goals in life to promote and preserve health. A person's ability to engage in self-care is influenced by internal factors such as motivation, belief in their own abilities, cognition, literacy and the ability to make decisions and act accordingly. Self-care is also influenced by external factors, such as culture, economy and religion and the availability of social support and resources (Matarese et al., 2018). In order to engage in self-care, a person must first possess the knowledge required to make a conscious decision about whether or not to engage in an act of self-care (Orem, 1991). Self-care is a broad concept, which involves all humans of all ages. The concept of self-care involves a number of related terms which are considered components of self-care, and whose aim is situation-specific acts of self-care (Richard & Shea, 2011).

Self-management is a concept involving the actions required for a person to control or adjust to disease. Self-management is defined as "the ability of the individual, in conjunction with family, community and HCP, to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of health conditions" (Richard & Shea, 2011: p 261). The

concept of self-management is frequently used in literature concerning persons living with long-term conditions (Richard & Shea, 2011). Self-management actions can be proactive or reactive. Proactive actions include evaluating changes in health status, adhering to a medical regimen and living a healthy lifestyle to prevent recurrence or worsening of symptoms. Reactive actions involve activities undertaken as the result of an event i.e. worsening of symptoms. Reactive activities might include a decision to take additional medication or seek help and advice from HCP (Matarese et al., 2018; Blok, 2017). The effects of good self-management skills include improved symptom and disease control, satisfaction with life, empowerment, a reduced need for healthcare and less economic strain on the healthcare system.

Self-monitoring is a central skill in the ability to undertake self-management. Self-monitoring includes observations, assessment and monitoring of i.e. physical symptoms and activities of e.g. daily living, as well as cognitive processes leading to self-awareness. In order to monitor themselves, persons need knowledge about the symptoms and characteristics of disease, as well as skills in detecting variations in health status. They also need the cognitive ability to reflect on the factors which can impact these. Self-awareness through self-monitoring can form the basis for self-management activities, and improve communication of healthcare needs and disease related symptoms in consultations with HCP (Wilde & Garvin, 2007). Self-monitoring and self-management should be seen as components of the broader concept of self-care (Richard & Shea, 2011; Wilkinson & Whitehead, 2009).

The most influential factor in successful engagement in self-care, including self-management of disease, is a person's own beliefs and confidence in the own ability to handle the current situation. This is referred to as self-efficacy. Bandura defined self-efficacy as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994: p 71). Self-efficacy is connected to specific situations, and a person can have high self-efficacy in one area of life but low self-efficacy in others. Persons believes in their own self-efficacy is influenced by a number of factors. These include earlier experiences of successfully mastering of similar situations, seeing other persons successfully manage them (role-models), encouragement from parents, teachers, coaches or other influential persons in their life, and the emotional state of the person, i.e. major depression or loss will hamper perception of self-efficacy (Bandura, 1997). Self-efficacy is considered both a mediator and a moderator of self-care (Lorig & Holman, 2003; Richard & Shea, 2011; Bandura, 1982). The term "self-care self-efficacy" has been used in the literature to describe a person's belief in their own ability to care for themselves. High levels of self-care self-efficacy are positively associated with better physical function, mental health and quality of life. In persons with long-term condition, they also lead to less distress in terms of symptoms and

a greater ability to adapt and manage the situation (Eller et al., 2018; Chenoweth et al., 2008).

## 2.4 Self-management support and interventions

A core aim of the nursing profession is to provide assistance, support and advice to persons suffering from ill health. Nurses have the medical knowledge and close enough contact with those affected by long-term conditions to know how it impacts their everyday lives. They are therefore well placed to provide self-management interventions and support (van Hooft et al, 2016; Chenoweth et al, 2008). Limited resources, changes in the organisation of healthcare and changes in population demographics involving a growing number of persons in the community affected by long-term conditions (Rees & Williams, 2009) have accentuated the need for nurses to facilitate and support self-care in outpatient care.

Self-management support (SMS) is considered one of the most important activities in outpatient nursing care. The purpose of SMS has been conceptualised as “enabling people to live (and die) well with their long-term condition(s)” (Morgan et al., 2017: p 53). “Living well” not only involves managing disease, but is also recognising a broader perspective, i.e. supporting the development of a persons’ autonomy and self-efficacy, and promoting patient-led goal setting and shared decision-making between partners in clinical care. This includes a person’s own views of what is important in life, in the present and in the future (Morgan et al., 2017).

Self-management interventions (SMI) are complex educational interventions designed to help persons with long-term conditions deal with the impact of disease in everyday life. They involve factors such as symptom control, medication regimens and emotional reactions. To be considered a self-management intervention the intervention should target cognitive processes and inner motivation and not simply improve knowledge of the disease and medication. Self-management interventions often include techniques for setting goals, self-monitoring symptoms, problem solving and action planning (Lorig & Holman, 2003; Jonkman et al., 2016).

SMIs for persons with long-term conditions vary significantly in design, length and style of provision. Interventions can be provided individually, in a small group format or using a dyadic approach involving both the person affected by the disease and a CP. A dyadic approach is often used in interventions targeting older persons, persons with neurodegenerative conditions, cancer or, heart failure, and in pediatric care (Beaudet et al., 2015; Martire & Helgeson, 2017). SMIs can be offered and carried out by HCP or lay-lead instructors, or both. Although most interventions take place through personal



meetings the advances of technology in healthcare has helped to introduce app and web-based SMIs targeting specific age or disease groups (van der Eijk et al., 2013; Bashi et al., 2018). A number of generic SMI programmes are available which have been developed to suit most persons with long-term conditions regardless of medical diagnosis. Some programmes on the other hand are tailored to specific persons with a certain diagnosis (Stenberg et al., 2016). Recent research indicates a need to tailor SMI interventions to the intended recipients, and suggests that these tailored interventions sometimes have a more favourable outcome than generic programmes. The desired SMI outcomes, as well as the tools and techniques used to assess the outcomes, also vary significantly between studies investigating their effects (Warner et al., 2019; Pappa et al., 2017; Kessler & Liddy, 2017).

The “Self and Family Management Framework” developed by Grey and colleagues (2006, 2015) is a general model which describes self-management for persons living with long-term conditions. It emphasises that self-management to a large extent is carried out in the social context of family. Management of long-term conditions need family members to accept and incorporate the condition into their regular family routines and their everyday life. The model describes facilitators and barriers for self and family management. It also describes the processes involved in managing disease and the outcomes of successful self-management for the person, the family and for healthcare. The “Self and Family Management Framework” can be used to guide research and development of SMIs for persons living with long-term conditions (Grey et al, 2006, 2015).

## 2.5 The Swedish National Parkinson School

The Swedish National Parkinson School (Nationella Parkinsonskolan: NPS) was developed in 2013 and is an SMI tailored to PwPD and their CP. The NPS is an adaptation of “Patient Education for Persons with PD and their carers” (PEPP), developed by the European EduPark consortium in 2002 (Smith Pasqualini & Simons, 2006). The NPS was developed on the basis of PEPP. It was translated and adapted as a collaboration between representatives of healthcare, PwPD and CP and the pharmaceutical industry (Carlborg, 2013a, 2013b). The majority of the content of the NPS is similar to that of PEPP, but it has been adapted and revised to suit delivery in the context of the Swedish healthcare services. The NPS also places an even greater emphasis on the importance of shared resources to handle life, as it is delivered entirely as a dyadic intervention.

The NPS is based on the idea that if PwPD and CP are to be able to undertake the required self-management activities, they first need knowledge about PD and an understanding of how it can affect their lives. Knowledge and self-awareness act as a platform for accepting and understanding changing life situations. Replacing negative thoughts with constructive ones helps manage difficulties. This leads to a more positive perception of life and can improve life satisfaction. Self-monitoring plays a central role in the NPS, and is introduced as a tool to enhance self-awareness. The goal of the NPS is to provide PwPD and their CP with the knowledge and cognitive strategies needed to improve their ability to manage everyday life and thereby promote life satisfaction. The main focus of the NPS is on how to continue living a fulfilling and satisfying life in the presence of PD. This is done by enhancing awareness own thoughts, feelings and actions in relation to the impact of PD on their everyday lives. How PwPD and CP choose to relate to disease and their changing life situation greatly affects their ability to maintain good satisfaction with life, despite the difficulties. The introduction of techniques for self-monitoring and self-awareness in the NPS gives participants the tools needed to initiate life changes.

The NPS consists of seven two-hour sessions. During each session, PwPD and CP meet in a small group with a certified educator. The certified educator is an HCP with extensive experience of supporting PwPD and CP, as well as medical knowledge of PD. Each session has a certain structure, which begins with an introduction involving facts and information on a topic related to everyday life with PD. This is followed by group discussions relating to the information which has been presented. Group discussions focus on participants' own experiences and thoughts, and provide an opportunity for peer learning and support. The new knowledge presented during the session is afterwards applied to the participants' own life situation through practical exercises and home assignments, which are discussed and followed up during the next session. Each session of the NPS ends with a 15- minute relaxation exercise.

The NPS has been operational in clinical practice in Sweden since 2014 (Carlborg, 2013a, 2013b). However, the effects and outcomes of the NPS programme have never been tested thoroughly or in a structured scientific manner.



**Figure 1:** The seven themes of the Swedish NPS.

Introduction, Self-monitoring, Stress, Anxiety & depression, Commu- cation, Enriching activities, My life with PD.

## 2.6 The Parkinson's Disease Nurse Specialist

Nurses specialising in providing support and care to PwPD and CP are found in all parts of the world. The role of the PD nurse specialist (PDNS) is recognised as a vital aspect of good quality care for PwPD in many countries. Guidelines and frameworks which describe the PDNS service, the compe- tencies needed, and the interventions included in the PDNS role are available in Great Britain and the Netherlands (Lennaerts et al., 2017; Parkinson's UK, 2016). The role and function of PDNS within the Swedish healthcare setting have also been described in a previous study (Hellqvist & Berterö, 2015). There are many similarities between countries in terms of PDNS work and differences are often due to the organisation of healthcare in different coun- tries.

In order to provide high-quality care and medical treatment to meet the complex needs of PwPD, their CP and families, the Swedish healthcare au- thorities recommend that PD care be organised in multi-professional teams (MPT) (Swedish national board on health and welfare, 2016). MPTs involve close collaboration between different HCPs with extensive knowledge and experience of PD. The members of an MPT can vary in different healthcare settings, but usually will include a physician, physiotherapist, occupational therapist, dietician, speech therapist, nurse and psychologist. Members of the

MPT work together to optimise and evaluate treatments, and to discuss the treatment options available to ensure the best possible help and care for PwPD. The MPT will customise care according to each person's specific needs (Pedersen et al 2017). MPTs work in outpatient clinics at regional and local hospitals throughout the country. They can be found in the fields of neurology, rehabilitation and in geriatric medicine (Swedish national board on health and welfare, 2016. Swedish Movement disorders society, 2019).

In many cases the PDNS is considered the coordinator of the MPT and vital to the success of the teamwork. Close and regular contact with the other experts in the MPT, as well as with PwPD themselves, enables them to collaborate actively in assessing and adjusting care plans (Hellqvist & Berterö, 2015). The PDNS supports PwPD in implementing care plans and medical regimens in their everyday lives. PDNS also follow up on care plans, in collaboration with PwPD and CP, and discussing them with the other members of the MPT. The evaluation focus on outcomes and need of adjustments (Hellqvist & Berterö, 2015; Bhidayasiri et al, 2015; Pedersen et al 2017).

A PDNS has extensive medical knowledge and often many years of experience in the field. For most PwPD, CP and family members, the PDNS is the most accessible person and the contact person when they need guidance or advice about issues concerning symptoms or treatment (Hellqvist & Berterö, 2015). The PDNS role involves clinical, educational and professional areas (Hagell, 2007). Support from PDNS working in the Swedish healthcare settings has been described by PwPD and CP themselves as providing "Competent and professional practice, tailored for the individual". PDNS services includes providing emotional support, offering continuity of contact, providing professional medical support and information and carrying out nursing interventions (Hellqvist & Berterö, 2015). The holistic support offered by PDNS is valuable for PwPD, CP and their families from the time of diagnosis and throughout the disease. Easy access to PDNS services is vital, and should be available to all PwPD, CP and their families (Swedish national board of health and welfare, 2016; Hellqvist & Berterö, 2015).

PDNS nursing interventions include monitoring physical and psychological symptoms, and assessing the effects and side effects of treatments (Reynolds et al., 2000; MacMahon et al., 1999). Recent studies highlight the importance of PDNS support and accessibility for the success of, and adherence to medical treatments for PwPD (Pedersen et al., 2017; Bhidayasiri et al., 2015). A vital part of the PDNS support is to provide knowledge and give advice to PwPD and CP in order to promote self-care and improve life satisfaction. The educational role of a PDNS also includes providing advice and knowledge to other HCPs who are not specialised in the area but who are involved in supporting and caring for PwPD, e.g. staff in nursing homes (Chenoweth et al., 2008; Pedersen et al., 2017).



## 3. THEORETICAL FRAMEWORK

### 3.1 Dorothea Orem's self-care deficit nursing theory

A theory by nursing theorist and educator Dorothea Orem involves assumptions about the nature of nursing and the components involved in the nursing process. Grand nursing theories can be used to understand the nature of nursing as well as serving as practical guidance for nurses in their clinical work. Orem's self-care deficit nursing theory (SCDNT) is an action theory with clear specifications for nurse and patient roles. The grand theory includes three minor and interrelated theories: the theory of self-care, the theory of self-care deficit and the theory of nursing systems.

The theory of self-care involves three vital concepts; self-care, self-care ability and self-care demands. Orem defines self-care as practicing activities which individuals initiate and perform on their own behalf in terms of maintaining life, health and well-being (Orem, 2001). Self-care activities are conscious actions which are goal-oriented and have a special focus. In order to engage in self-care activities, a person must first possess the knowledge needed to make an informed decision whether or not to carry out a self-care action. Self-care ability involves a person's collected abilities and power to carry out self-care actions. Self-care is a learned ability which is influenced by environmental factors and develops during the course of life. It can decrease as the individual grows older, or as a result of disease or illness. Self-care ability includes all human abilities which are necessary in terms of engaging in self-care actions. Self-care demands are the activities required for a person to be able to maintain life, health and well-being. Orem divides self-care demands into three areas: a) universal demands, which all people need, for example adequate amounts of food, sleep and rest; b) demands involved in preventing or coping with regular life events such as role changes as a result of death or birth; and c) self-care demands which arise for people with illness and disability who are under medical care. A person must be conscious of the existing self-care demands and needs, which have to be addressed in their current situation, if they are to engage in appropriate self-care activities (Orem, 2001).

The theory of self-care deficits suggests that there is always a relationship between a person's self-care ability and self-care demands, and that these can be in balance or insufficient in one or a number of ways. Self-care deficits occur when this relationship is un-balanced and a person's self-care ability is insufficient to meet existing self-care demands. According to Orem, the presence of a self-care deficit is the only legitimate reason for nursing. There must be an existing self-care deficit or a potential self-care deficit in the future (i.e. a progressive disease) for nursing actions to be required. If

there is no self-care deficiency, there is also no need for nursing care. The main goal of nursing action is to help persons regain a balance between self-care demands and self-care abilities, and thereby become independent in managing their own self-care.

Orem describes the role of nursing practice in the theory of nursing systems (Orem, 2001). This theory incorporates two important concepts; nursing agency and nursing systems. Nursing agency involves a nurse's accumulated skills and abilities, defined by Orem as "... a set of developed and developing capabilities that persons who are nurses exercise in the provision of nursing for individuals or groups" (Orem, 2001: p 289). Nursing ability is a complex acquired ability which is learned and practised consciously and for a purpose. Nursing ability varies between nurses, and is dependent on education, experience, and the ability to engage in intrapersonal relationships and care for other persons.

Nursing systems are the conscious and goal-oriented actions designed and performed by nurses to meet person's self-care demands and improve their self-care agency. Nursing actions can involve acting in the place of a patient, guiding the patient to action, supporting the patient mentally or physically, providing education and knowledge, and adjusting the environment to enhance a patient's own ability to carry out self-care actions. Nursing systems incorporate all activities and interactions between nurses and patients in the clinical encounter (Banfield, 2011). Nurses can provide nursing support on three different levels, depending on the magnitude and degree of the self-care deficit of the patient.

Educational and supporting systems are nursing actions for patients who have the ability to care for themselves but are in need of guidance, emotional support or education in terms of managing the new demands brought on by disease. This level of nursing intervention is found primarily in outpatient care settings. The partially compensatory nursing systems are needed for persons who can carry out self-care activities to meet some of the self-care demands and participate in care, but who cannot meet all these demands by themselves. Nursing actions are required in some areas related to disease in order to compensate for this. Wholly compensatory nursing systems are needed for persons who are not able to meet even the basic universal self-care demands or participate in their own care. Nurses help patients meet all existing self-care demands needed to keep them alive and promote well-being (Orem, 2001).

### 3.2 Person-Centred Care - philosophical theory and clinical practice

Person-centred care (PCC) acknowledges the human interactions which take place in healthcare encounters primarily as encounters between human beings, and not just clinical encounters between patients and healthcare providers (McCormack & McCance, 2010). Being a “patient” is a role, and a limited part of a whole person which only exists within the healthcare context. The concept of a patient is traditionally focused on the objective body and ill health in this body. Although for many nurses, the role of nurse is perceived as an integrated and vital part of themselves, it is in fact a role primarily evident and practiced in the healthcare context and in encounters with persons in need of nursing care (Kristensson Ugglå, 2014).

The concept of a person is much broader, and aims to see the person in their entirety not just the body or the disease. The concept includes the values and preferences of a person, as well as the life situation and everyday context in which the person lives (Ekman et al., 2014; Britten et al, 2017). According to the philosopher Paul Ricoeur, personal identity consists of two parts which he calls *Ipse* and *Idem*. *Ipse* is the self, or personal identity and soul, and *Idem* represents the more objective human body. These two are interconnected and exist simultaneously. *Ipse*, or personal identity, is developed and shaped and changes constantly as a result of interactions with other persons (Ricoeur, 1992).

One definition of PCC is that “individuals’ values and preferences are elicited and, when expressed, guide all aspects of their care and support their realistic health and life goals” (American Geriatrics Society Expert Panel on Person-Centred Care, 2016: p 16). PCC is carried out through a dynamic relationship between the persons involved and engaged in care. This includes the person in need of care as well as their family, friends or other persons who are important to them. It also include all relevant providers of care and support. This collaboration between persons informs decisions about care in terms, and to the extent, of the wishes of the person in need of care. HCPs are seen as active participants involved in the mutual interactions taking place in healthcare encounters and not merely the providers of medical treatments and care (McCormack & McCance, 2010).

PCC is not about making the patient a "customer" of care, giving the patient all the rights to decide and choose medical tests and treatments. A person-centred approach is based on a partnership and collaboration between experts (Sharma et al., 2015). Persons in need of care are experts on their own life situation, symptoms and the impact of the illness of their everyday lives. They are also experts on their hopes and wishes for the future. HCPs



are experts with knowledge about the organisation of care, medical information on disease and specific treatments, and has the clinical experience of having met many persons in similar situations (Ekman et al., 2014).

According to Ricoeur (1992) persons always interpret, and try to find meaning in the world and the context in which they live. Their interpretation of the world is developed in interaction with other persons and consists of both explaining and understanding. The interpretation space is a dynamic and changing place, where experiences gained in a situation are interpreted by a person and form the basis for new understandings about the world (Kristensson Uggla, 2014). In a PCC relationship, this can be the bridge between the body of the natural sciences (explanation) and the soul of the human sciences (understanding) (Ricoeur, 1992). In the intrapersonal meeting between a nurse and a person with a disease, a partnership can form when their realities, knowledge and expectations are confronted and tested against each other. This process in itself can lead to increased understanding, and change the perception of reality in both the nurse and the person affected by disease (Kristensson Uggla, 2014).

PCC is based on seeing human beings as relational, always involved in interactions and relationships with other persons and always equal as humans. In PCC, patients are seen as capable partners with the ability and the will to take responsibility for themselves and for their own life, but also with an inherent vulnerability which is part of being human and which should not be regarded only as a weakness (Ricoeur, 1992). A capable person will need emotional as well as practical care and support from other persons in order to manage vulnerability in times of hardships. In PCC practice, the aspects of what constitutes a person and a human as described above, in terms of the philosophical views, standpoints and characteristics should form the ethical, moral and practical guidance for all care activities (Kristensson Uggla, 2011).

The foundation of PCC as practised in clinical care is the patient's own perception of health and illness, and the impact on everyday life. In the clinical encounter, the patient's story or narrative is the basis for seeing the "person" and not just the patient (Ekman et al., 2011). By listening to the patient's story, human resources and opportunities can be identified which can form the basis of a mutual understanding and a therapeutic partnership. There are important aspects to assess in the personal story in order to establish a therapeutic relationship and these are the persons own experiences of illness and health including their personal beliefs, goals, values and preferences for treatment. Assessment of the person's health literacy (in example the own knowledge of how and when search medical advice from healthcare) and language literacy. Also the knowledge of person's preferences when it comes to receiving information of their own health and care and to what extent there is a social network of i.e. care partners or other persons close and to what

extent the person wish them to be involved in care (Sharma et al., 2015). The personal narrative is constantly shaping and changing over time and need to be assessed and reassessed continuously in the clinical encounters (Sharma et al., 2015; American Geriatrics Society Expert Panel on Person-Centred Care, 2016).

The relationship between HCPs and patients is underpinned by central values such as mutual respect and understanding of the patient's self-esteem and will (Ekman et al., 2014; American Geriatrics Society Expert Panel on Person-Centred Care, 2016). The partnership formed through the person-centred meeting can lead to a joint understanding of how the present situation is experienced and the needs and resources available. To improve patient satisfaction with care and the results of interventions and treatments, shared decision-making is one of the primary goals of PCC. Person's capabilities and wishes to engage in shared decision-making can vary but HCPs should promote involvement in care whenever possible. To enhance the opportunities for involvement in care HCPs should openly share information about available alternatives for treatment including risks and benefits in a style and at a level appropriate to the person's literacy level. To be easily accessible for advice and discussion and to consciously work to empower patients to be involved in decisions (Sharma et al., 2015).

The therapeutic relationship resulting from a patient-centred care approach can be the foundation for nursing interventions such as writing a personal care plan. In the care plan, the person's experience of their own life situation, values and preferences are equally important as the nurses' evidence and experience-based knowledge of pathophysiology and treatment. The care plan is documented in the patient file, and will include information on what was agreed, the goals set and the interventions planned to reach them. Documentation of the care plan makes it possible to evaluate progress and revise it if necessary (Ekman, 2014). The provision of PCC nursing care in clinical practice also include active coordination of care. This includes education and information sharing to other service providers involved in the person's care. The care plan should therefore be easily available for the persons themselves and for other HCPs involved in caring for the person. The goal is to provide seamless support for the person over organisational and professional borders (American Geriatrics Society Expert Panel on Person-Centred Care, 2016).

Nine important themes explaining dimensions of PCC were identified in a recent review of research studies published between 2000 and 2017. These themes were empathy, respect, engagement, relationship, communication, shared decision-making, holistic focus, individualised focus and coordinated care (Håkansson Eklund et al., 2019). These dimensions were also present in the descriptions of patient-centred care meetings, but the philosophical foundations and goals of patient-centred and person-centred meetings differed.

Person-centred care focuses on the human being primarily as a person, not a patient, even in the context of care. The goal is to make life meaningful for the person, taking into account the whole life situation and not just a functional aspect of life in the context of managing disease (Håkansson Eklund et al., 2019; Buetow et al., 2016).

## 4. RATIONALE

PD is a long-term and degenerative condition which impacts everyday life for PwPD, CP and their families. Self-management skills are essential in reducing the impact of the disease, and in maintaining satisfaction with life and physical and psychological well-being. There is a large knowledge gap in terms of the importance and effects of non-pharmacological treatments and interventions which focus on psychosocial strategies and education in managing the impact of PD for PwPD and CP. Research is therefore needed to provide a better understanding of the usefulness and outcomes of these interventions. A better understanding of self-management and of the factors which facilitate or hinder this process could also be of use in tailoring nursing interventions to support PwPD and CP in their everyday life.



## 5. AIMS

The overall purpose of this thesis is to enhance knowledge and understanding of self-management as experienced by PwPD and CP. This includes improving understanding of the usefulness of the self-management intervention Swedish National Parkinson School (Nationella Parkinsonskolan, NPS) when provided in clinical care. The thesis will examine its use in supporting PwPD and CP in developing strategies to improve self-management of disease. It will also explore how reasonable the suggested benefits of the NPS are in terms of increasing participant's satisfaction with life and their ability to manage everyday life. This thesis also elaborate on how nurses specialising in the care of PwPD and CP can support self-management within the framework of nursing theory and a person-centred approach.

The specific aims of the studies are as follows:

**Study I:** To identify and describe experiences valuable for managing daily life after participation in the NPS self-management intervention.

**Study I:** To explore the applicability of the “Self- and family management framework” by Grey and colleagues for PwPD and their relatives.

**Study II:** To assess outcomes of the NPS from the perspective of the participants using self-reported questionnaires regarding, e.g., life satisfaction, self-reported health status, emotional well-being, health directed behaviours, social integration and support.

**Study III:** To study whether PwPD and CP implemented the strategies of self-monitoring included in the self-management intervention NPS and use them in clinical encounters with healthcare professionals.



## 6. METHOD

### 6.1 Designs

A variety of designs and methods were used in this thesis. The individual studies were conducted to explore, from different perspectives, the experiences and effects of the NPS programme to support self-management in participants (study I-III). An overview of the studies included in this thesis is presented in Table 1 below.

Table 1:

Overview of the studies included in the thesis: designs, methods and analysis

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>
Design	Qualitative group discussion study	Quantitative quasi-experimental case-control study in clinical care	Qualitative observation study with follow up interviews
Sample	5 group discussions involving 25 PwPD and 17 CP	Intervention group: 48 PwPD and 30 CP  Control group: 44 PwPD and 25 CP	10 PwPD and 3 CP
Data collection	Audio recordings of group-discussions during the final NPS session.	Self-reported questionnaires administered before and after participation in the NPS (intervention group) or at 7 weeks	Observations of routine clinical visits with treating physician. 3-15 months after participation in the NPS.



		standard care (control group)	
Data Analysis	<p><u>Step I:</u> Inductive thematic analysis according to Braun &amp; Clarke (2006)</p> <p><u>Step II:</u> Deductive application of findings using "Self- and Family Management Framework" (SFMF Grey, 2015).</p>	Descriptive statistical analysis within and between groups, using Mann-Whitney U, Chi <sup>2</sup> and Wilcoxon signed-ranks tests.	Constant comparative analysis according to Glaser (1965, 1978)
<p><b>The overall results of the thesis:</b></p> <p>The results presented in this thesis combine findings of all the studies (I-III) in order to illustrate the broader meaning and interpret the results as a whole. The overall results were obtained using a qualitative design, which analysed data using thematic analysis according to Braun &amp; Clarke (2006). This is described in detail in the data analysis section.</p>			

## 6.2 Participants and settings

The participants in the studies were PwPD and CP listed in outpatient clinics at five county and university hospitals. Broad inclusion criteria were generally used for participants in all studies, so that the results would reflect clinical reality rather than a restricted study selection. Table 2 presents an overview of the participants and settings for each separate study (I-III).

**Table 2 :**  
**Overview of participants and study locations included in studies I-III**

Study	Number of participants (PwPD/CP)	Study location	Age range in years (median)	Gender (n) Male/female	Years since diagnosis (median)	Hoehn & Yahr stage (n)	Marital status n (%)	Educational level (n)
<b>I</b>	42 (25/17)	Five outpatient clinics in different parts of Sweden.  (3 county and two university hospitals)	68-73 (71)	PwPD: 11/14  CP: 9/8	3-7 years (4.5)	I: 3 II: 13 III: 9 IV: 0 V: 0	M/LT: 41 (98%)	PS: 13 HS: 12 UD: 17
<b>II</b>	147 (92/55)  <b>IG:</b> 78 (48/30)  <b>CG:</b> 69 (44/25)	Five outpatient clinics in different parts of Sweden.  (3 county and two university hospitals)	<b>IG:</b> PwPD  65-75 (71)	19/29	2-7 years (5)	I: 3 II: 20 III: 19 IV: 6 V: 0	M/LT: 52 (88%)	PS: 15 HS: 19 UD: 25
			CP 68-77 (72)					19/11
			<b>CG:</b> PwPD 64-75 (68)	30/14	3-8 years (7)	NC	M/LT: 41 (85%)	PS: 12 HS: 8 UD: 15
			CP 67-74 (69)					7/18

III	13 (10/3)	One Swedish uni- versity hospital	68-79 (75.5)	PwPD: 4/5  CP: 1/2	2-7 years (4.5)	I: 2  II: 2  III: 5  IV: 1  V: 0	M/LT:  10 (77%)	PS: 4  HS: 6  UD:3
-----	--------------	--------------------------------------	-----------------	--------------------------------	--------------------	--	-----------------------	--------------------------------

Range is presented in quartiles (q1-q3)

PS = Primary School

HS = High school

UG = University Degree

IG = Intervention group

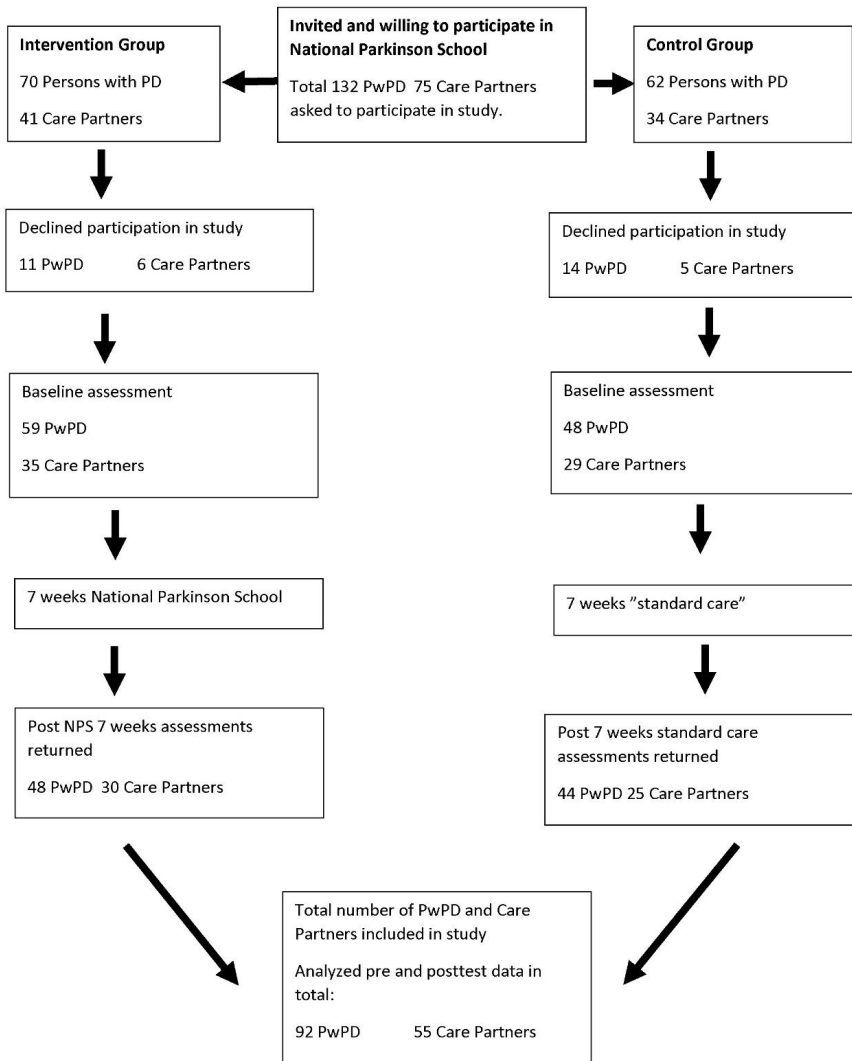
CG = Control group

NC = Data Not Collected

M/LT = Married or Living Together

**Study I** included participants involved in the NPS programme at five geriatric and neurological outpatient clinics in central and southern Sweden. Both county and university clinics were represented. There were no inclusion or exclusion criteria for participation in the study. Participants were enrolled in the NPS programme and had been selected by staff for participation in the NPS on a solely clinical basis. The final session of the NPS was audio recorded in its entirety. The session was not in any way modified for the purpose of this research study, as the aim was to capture the clinical reality and value of the NPS programme. All group discussions were recorded in a conference room used for the NPS at the participating clinic. The groups consisted of the NPS educator and 8-12 participants, involving both PwPD and CP. In total 42 participants were included in the study. PwPD were mainly in mild to moderate Hoehn and Yahr stages of the disease, and no one was in stages IV or V, which designate severe disease (Table 2).

**Study II** included participants from five geriatric and neurological outpatient clinics across Sweden. PD related health, general health status, caregiver burden, proximal outcomes of self-management education, satisfaction with life and fatigue were assessed using self-reported questionnaires. A matched control-group was recruited for comparing findings. Data were collected before and after participation in the NPS, or before and after seven weeks of standard care for the control group. Data were compared between and within groups. A total of 92 PwPD and 55 CP were included in the study (Figure 2). In the NPS group, there were 48 PwPD and 30 CP. The control group consisted of 44 PwPD and 25 CP. PwPD in the intervention group were largely in the middle stages of the disease, corresponding to Hoehn & Yahr stages II-III (Table 2).



**Figure 2:** Flow of participants through study II

**Study III** involved PwPD and CP who had previously been participants in the NPS programme. Participants were recruited from one geriatric and one neurological outpatient clinic connected to a university hospital in the southern part of Sweden. In total, 10 PwPD and three CP participated in the study. Purposeful and consecutive sampling was used. Two PwPD declined to participate due to a heavy symptom burden. The length of time which had passed from participation in the NPS to the time the data were collected varied from three to 15 months. Three geriatricians and five neurologists granted permission for observing routine patient visits. All PwPD had been familiar with their physician for some time. Data were collected by observing a standard clinical consultation with the treating physician in the outpatient clinic. The follow-up interview with PwPD and CP was conducted directly after the visit in a separate room. The physician was not present during the follow-up interview. Participants in this study were mainly in mild to moderate stages of PD according to Hoehn & Yahr (Table 2).

## 6.3 Data collection

### 6.3.1 Group discussions

In study I, the last session of the NPS” My life with Parkinson’s Disease” was audio-recorded in its entirety. This session is a standard part of the NPS programme. Under the guidance of the NPS educator, who is also present, the participants are asked to look back at the contents and techniques discussed in the previous NPS sessions. The session includes a reflection by participants on the contents and value of the programme as a whole, and on whether and how the knowledge and techniques acquired through NPS can be of use in their everyday lives (table 3). The session was not in any way modified for the purpose of the study, as the aim was to capture the clinical reality and value of the NPS programme. Before the start of this session, the researcher gave some brief information about the purpose and use of the recording and placed a recording device in the room. The researcher then left the room so that the dynamics and interactions of the group would not be affected by the researcher being present. Each group discussion lasted about two hours and generated between 25-40 pages of transcribed text. Data were collected between August 2015 and June 2016.

**Table 3:** Content of session 7 of the NPS “My Life with Parkinson’s Disease”

- **Short summary of the contents of the previous six sessions:**
  1. Introduction to PD and reactions to diagnosis and long-term disease
  2. Self-monitoring as a way of enhancing self-knowledge and promoting change
  3. Stress management
  4. Addressing feelings of depression and anxiety
  5. Communication
  6. Enriching activities – how they can increase satisfaction with life
  
- **NPS educator introduces questions and promotes discussion:**
  - Which session was the most interesting for you and why?
  - What has been of most use to you in your everyday life?
  - Did you discover something new when you did the home assignments and applied things we discussed in the NPS in your own life?
  - Have you been able to change anything for the better in your life using the knowledge from the NPS?

### 6.3.2 Patient- reported questionnaires

In study II, patient-reported questionnaires were used to collect data, and these data were then compared to those of a matched control group. The questionnaires used were both generic and PD-specific. The PD questionnaire (PDQ-8) was only used for PwPD and the Zarit Burden Interview (ZBI) was used exclusively for CP. To reduce the risk of confounding factors, all participants were asked to fill in a short form to confirm whether there had been any changes in their medication, or any outstanding events, which had made them, feel particularly happy or sad recently. Disease staging according to Hoehn and Yahr, was also documented for the PwPD in the NPS group at baseline. Sample size was calculated using G\*Power version 3.1.9.4 (Faul et al., 2007) and estimated from a previous study investigating the minimal important difference in the PDQ-8 scores (Luo et al., 2009). To detect a significant effect at least 35 were needed in each group. To compensate for attrition and uncertainties in the estimates, the aim was to include a sample size twice that number.

Seven self-reported questionnaires were used in this study.

**The PDQ-8** is a PD-specific questionnaire, which assesses perceived PD related health status (Jenkinson et al., 1997). It consists of eight items summarised into a total score, which is transformed to a 0-100 range, where higher scores indicate worse health status.

**The EQ-5D** is a generic instrument with five items, which describe and assign values to states of health (EuroQoL Group, 1990). It yields a utility value which represents how each combination of responses has been valued by representatives of the general population, from 1 (perfect health) to 0 (dead), as well as negative values representing states of health considered worse than death (Dolan 1995). This study used the experience-based scoring algorithm proposed by Burström et al. (2014).

**The ZBI** (Zarit Burden interview) is a generic scale designed to evaluate the burden of family caregivers (Zarit & Zarit, 1987). This study used the 12-item short-form of the ZBI (Bédard et al. 2001) previously tested with caregivers of PwPD (Hagell et al. 2017). A total score is calculated ranging from 0 to 48, where higher scores indicate a greater burden.

**The heiQ** (Health Education Impact Questionnaire) is a generic instrument designed to evaluate the efficacy of self-management education across settings for persons with various long-term conditions (Osborne et al., 2007). The heiQ consists of 40 items across eight domains. Items are scored from 1 (“strongly disagree”) to 4 (“strongly agree”), and total scores within each domain are also expressed between 1 and 4. Higher scores indicate better self-management, except for the area “emotional well-being”, where scoring is reversed. A Swedish version of the heiQ has been evaluated but not specifically tested with PwPD (Kumlien, 2018). In addition, the heiQ-Program evaluation questionnaire was used at follow-up. This questionnaire was designed to evaluate participants’ perceived quality of program delivery (Osborne et al., 2007). In this study, the heiQ-Programme evaluation questionnaire was extended by adding two questions specific to the NPS. These asked participants if their expectations of patient education had been fulfilled, and if the education had improved their understanding of PD.

**The LiSat-11** (11-item life satisfaction questionnaire) is a generic instrument regarding satisfaction with the current life situation as a whole as well as within 10 specific areas (Fugl-Meyer et al., 2002). Higher scores indicating greater satisfaction. The questionnaire has previously been used to assess satisfaction with life in PwPD (Gustafsson et al. 2015; Rosqvist et al. 2017).

**The PSF-16** (16-item Parkinson Fatigue Scale) is a PD specific rating scale for assessing fatigue in PwPD, but it is also considered useful for persons who do not have PD (Brown et al., 2005; Hagell et al., 2012; Nilsson et

al., 2013). Items are summarised into a total score between 0 and 64, where higher scores indicate greater fatigue.

Participants that had been invited by HCPs in clinical care to attend the NPS programme were also contacted by the researcher over the phone with information about the study and its purpose. If they were willing to participate self-reported questionnaires and a background information sheet were sent by post.

Participants in the intervention group received questionnaires and a background information sheet, before the start of the NPS. Participants filled in the questionnaires, which were collected in person by the researcher at the participating site just before the first session of the NPS programme. Collecting the questionnaires in person gave participants the opportunity to clarify any uncertainties they might have had filling in questionnaires and ask further questions about the study. After the last session of the NPS, the same questionnaires were sent to participants as a post-intervention assessment. Participants filled in the questionnaires in their own homes at a time they found suitable, but no earlier than one week before the NPS for baseline and two weeks after the NPS for post-test data.

The control group received written information about the study, and if they were willing to participate, they filled in the same questionnaires, background information sheet and the form investigating confounding factors. Questionnaires were sent to them by post at baseline, and again after 7 weeks of standard care. Participants were provided with the researcher's contact information if they had further questions about the study or the self-reported questionnaires. Data were collected between 2015 and 2017.

### **6.3.3 Observation and follow-up interviews**

Non-participant observation is valuable as a way of collecting data, and as a technique for understanding and observing actions, roles, processes and interactions. It allows the researcher to witness these processes directly as they occur in the intended setting. In interviews, participants can reason and discuss these things, but observations can study how something is actually done in practice (Walshe et al., 2011). Observations can highlight disparities between reported practice and actual practice, and can deepen understanding of what works in clinical care and what does not. It is of great value in improving understanding of influences on structures and processes, and on the actions of healthcare staff and patients. This can help evaluate the care delivered, which, in turn, can improve the outcomes of care for patients (Handley et al., 2019).



The main focus of study III was to investigate whether the knowledge and techniques of self-monitoring and communication introduced and practised in the NPS programme could be observed in clinical care. These are to be considered the distal outcomes and benefits suggested by the NPS programme to enhance the quality of healthcare. Non-participant observations of clinical care were chosen as a suitable method for studying this. To complement the researcher's observations follow up interviews were added which captured the participant's experiences in their own words. Routine standard clinical care encounters were observed between the treating physician, and PwPD and CP who had been participants in NPS. Participants were informed observations would focus on the interaction in the clinical encounter. Participants were contacted by phone and also received written information about the study.

A semi-structured observational guide was developed to cover the basic elements of interaction and practice, as well as the topics of interest related to the contents of the NPS programme (Table 5). The researcher was guided by, but not restricted to this document during the observations (Guba & Lincoln, 1994). Data were collected through field notes and transcribed as close to the time of collection as possible. Before the consultation started, participants were informed once again about the purpose of the study and the two-part method of data collection. Each observed consultation lasted about 45-60 minutes. The researcher collected observational data as a silent observer, taking notes as the clinical encounter unfolded. To reduce the influence on the interaction between physician and PwPD, the researcher sat in a corner of the consultation room.

In study III, follow-up interviews were also used to enrich observational data collected during the clinical encounter between PwPD, CP and the treating physician. This gave participants an opportunity to express their own perceptions of the encounter and the feelings about it. A semi-structured interview guide was developed for the purpose, influenced by Kvale (2009), which contained five questions (Table 4). The interview guide was tested in a pilot interview and found suitable for use. No revisions were made, and the pilot interview was included in the study. The researcher asked probing questions if necessary, to encourage participants to explore their answers. In total, 10 interviews were conducted.

If the care partner was present, the interview was dyadic. Dyadic interviews involve interviewing both partners together. This style of interviewing can be used if the partners have a close relationship to each other, and if the interaction and collaboration between the partners are of interest to the researcher. In these situations, dyadic interviews can result in richer data and improved understanding of joint actions and processes. Dyadic interviewing as a methodology recognises the social and interactional life world of humans (Caldwell, 2014). Persons constantly interact with others, which helps

them form their perception of themselves and their life world. For persons affected by long-term conditions, collaboration with friends and family and CP is fundamental in coping and handling everyday life.

Dyadic interviews can give participants an opportunity to help each other in the interview situation, filling in gaps in information of what is told. This contributes to a joint narrative, which gives the researcher a better understanding of the information considered important for the couple, and gives a better sense of the meaning of what is told (Polak & Green, 2016). The presence of the other partner can also contribute to a more equal power relationship for participants, making them feel more comfortable in the interview situation. PwPD can experience problems communicating both verbally and non-verbally, as rigid muscles can make articulation difficult and can lower the volume of the voice. In addition, changes in cognition due to PD can sometimes make it difficult for PwPD to find the words and maintain the flow of a conversation.

Data were collected through observations and interviews between April 2016 and January 2018. Ten PwPD and three CP were included in this study, and 10 clinical encounters were observed in total. The length of interviews ranged from three to 22 minutes, and the majority were about 15 minutes long. Data were collected three to 15 months after the participation in the NPS.

**Table 4.** Interview guide for study III

<b>Follow- up interview with PwPD and CP (if present) after observation of a clinical care encounter.</b>
<p data-bbox="190 493 442 524"><b>Interview questions</b></p> <ul data-bbox="231 560 968 1033" style="list-style-type: none"><li data-bbox="231 560 968 633">- “Can you please tell me how you experienced the meeting with the physician? “</li><li data-bbox="231 660 968 697">- “Did the meeting turn out as you had expected?”</li><li data-bbox="231 760 968 833">- “Did you prepare yourself in any way before the meeting with the physician?”</li><li data-bbox="231 860 968 897">- “What are your feelings now just after the meeting?”</li><li data-bbox="231 960 968 1033">- “Did you have an opportunity to talk to the physician about things that are important to you?”</li></ul>

During the interviews the researcher would use probing questions such as: How do you mean when you say...? Can you please tell me more about...? Can you give an example? These questions aimed to encourage participants to go deeper into something they had said. All interviews included in the study (III) were audio-recorded and then transcribed verbatim before analysis.

**Table 5:** Observational guide study III

<b>Observational guide for clinical consultation with physician</b>
<p>The consultation is observed as a whole –with focus on certain aspects, as follows:</p> <ul style="list-style-type: none"><li>- Is the PwPD accompanied by a care partner?</li><li>- Does the physician invite the PwPD/care partner into the conversation?</li><li>- Are PwPD /care partners actively involved in discussion with the physician about medical treatment and rehabilitation?</li><li>- How long (estimated) do the physician and PwPD/ care partner each speak?</li><li>- Have the PwPD /care partners brought notes / documentation on what they wish to discuss with the physician?</li><li>- Do PwPD / care partners address non-motor symptoms during the consultation?</li><li>- Is there any evidence that PwPD/care partners have been using self-monitoring techniques (i.e. registering symptoms or medicine intake) prior to the consultation?</li><li>- Do PwPD/ care partners mention strategies for relieving stress / anxiety and worsening PD symptoms?</li><li>- Do the care partners ask for support?</li><li>- Are physical activity and rehabilitation discussed?</li><li>- Is the future discussed, including strategies for dealing with problems that may arise?</li><li>- How much of the time is spent looking at the medication list /medical record?</li><li>- How do the physicians / PwPD / care partners place themselves in the room?</li><li>- Does the physician summarise the conclusions of the consultation, i.e. what has been decided or adjusted?</li><li>- Does the physician invite further questions / discussion from the PwPD/ care partners?</li></ul>

## 6.4 Data analysis and summary of findings (I-III)

### 6.4.1 Qualitative methods

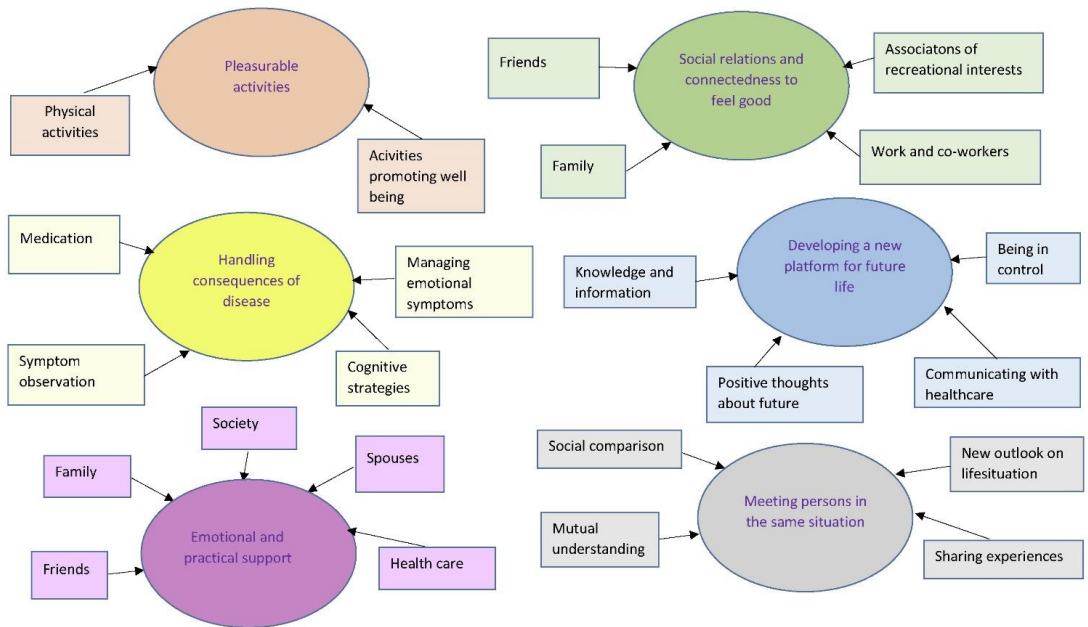
A variety of qualitative methods were used to analyse data included in this thesis. Some qualitative methods are mainly used as means of organising data, finding patterns and describing what is present in data, while others can also be used to interpret data at a more abstracted and latent level, to discover underlying meanings and themes. The choice of method is dependent on the focus and aim of the research question. In this thesis, thematic analysis (study I and overall analysis of studies), and constant comparative analysis (study III) were used. Study I combines inductive and deductive perspectives applying the findings from the analysis to an existing generic model of self-management in long-term conditions (Grey, 2006, 2015). Study III takes an inductive approach, with no underlying theory to guide analysis.

#### 6.4.1.1 *Thematic analysis according to Braun & Clarke*

In study I, data were analysed in two steps. First, the transcribed material was analysed inductively using thematic analysis and following the steps described by Braun and Clarke (2006). Thematic analysis is a flexible method of identifying and analysing patterns within a dataset, but it also allows findings to be interpreted and conclusions to be drawn at a more abstracted level. The second part of the analysis involved a deductive process, which applied the inductive findings from step one to the “Self and Family Management Framework” developed by Grey and colleagues (2006, 2015). This framework identifies the facilitators, barriers and processes involved in self-management as well as the proximal and distal outcomes of self-management for individuals, families and society. Thematic analysis was suitable with the ability to compare findings, and to interpret them further for exploring the applicability and usefulness of a general model of self-management for PwPD and their CP.

In the first step of inductive analysis, the transcribed group discussions were read several times and initial ideas and thoughts were noted. A more thorough reading of each transcribed group discussion generated initial codes, which were grouped into tentative themes (Table 6). Throughout the analysis, the contents of each identified theme were clarified further. The initial steps of the analysis and the creation of thematic maps were undertaken by three researchers separately. The results of the individual analysis were then discussed among the researchers, and this informed the development of an initial thematic map with six themes (Figure 3). The initial thematic map was then further analysed and the themes were refined. Themes which described the same phenomenon but from different angles were combined. Three final themes of interest to the research question were identified.

The three themes are “Exchanging experiences and feeling support”, “Adjustment and acceptance of PD for managing daily life” and “Promoting life satisfaction”. These themes are the final result of the inductive analysis (study I). The contents and meanings of the final themes were then verified and confirmed once again in the body of raw data by actively re-reading the five transcribed group discussions several times.



**Figure 3:** Initial thematic map with six themes developed during analysis according to Braun & Clarke (study I)

**Table 6:**

Example of data processing from text to theme using thematic analysis according to Braun & Clarke 2006 (study I)

<b>Data extract:</b>	<b>Coded for:</b>	<b>Codes merging to form themes:</b>
<p>" There was a lot that was confirmed and I suddenly realised that... well this has been going on for quite a while without me knowing about it. It was a moment of clarity for me."</p>	<p>1: Knowledge 2: Symptoms 3 : Learning 4 : Making meaning</p>	<p><i>Adjustment and acceptance of PD for managing daily life</i></p>
<p>" I took notice of what you said last time. That you should put your energy into things that you are able to achieve and not the things that you cannot do. That's a good strategy!"</p>	<p>1: Cognitive strategy 2: Sharing 3 : Positive thoughts 4 : Adjusting 5 : Psychosocial resources</p>	<p><i>Adjustment and acceptance of PD for managing daily life</i></p> <p><i>Exchanging experiences and feeling support</i></p>
<p>" I'm a golf player and I really enjoy it. But then I wonder how long I can continue playing. I'm not as good anymore"</p>	<p>1: Activity to promote well-being 2: Physical activity 3: Fear of future 4: Adjusting 5: Emotions</p>	<p><i>Adjustment and acceptance of PD for managing daily life</i></p> <p><i>Promoting life satisfaction</i></p>

The second step of analysis was undertaken in a deductive manner. The three themes retrieved from analysis were then applied deductively to the “Self and Family Management Framework” by Grey and colleagues (2006, 2015). This deductive approach was used to test the applicability of the general framework specifically for PwPD and CP, as this had not been done before. The themes and descriptions of the contents derived from the inductive analysis were compared to the model, searching for similarities and differences to ascertain whether the framework fit the experiences of self-management and self-management interventions in terms of PwPD and CP attending the NPS. If applicable, the framework of Grey and colleagues could also be used to guide research, and to design and improve self-management interventions such as the NPS for PwPD in the future.

#### **6.4.1.2 Constant comparative analysis according to Glaser**

In study, III transcribed observations and follow-up interviews were analysed using the constant comparative method as described by Glaser (1965). Constant comparative analysis (CCA) can be used when the purpose is to study general social and interactional processes and behaviours rather than the experiences of individuals. In CCA, researchers take an inductive approach, and the results develop from evidence contained in the raw data. CCA is often used as a part of the process of formulating a new theory, following the procedures of Grounded Theory studies, but it can also be applied separately as a systematic method of gathering and interpreting qualitative data (Fram, 2013). In study III CCA is used in the latter way.

The data were transcribed shortly after they had been collected. They consisted of field notes on observations of the clinical encounter and the follow up interviews. All data involving the same participant, whether from observation or interview, were considered as one dataset and analysed as such. After the transcriptions had been checked for accuracy against the original recordings and field notes the transcribed material was distributed continuously to the other two researchers involved in the analysis. The process of analysis was continuous, and data were collected and analysed side by side (Glaser 1978).

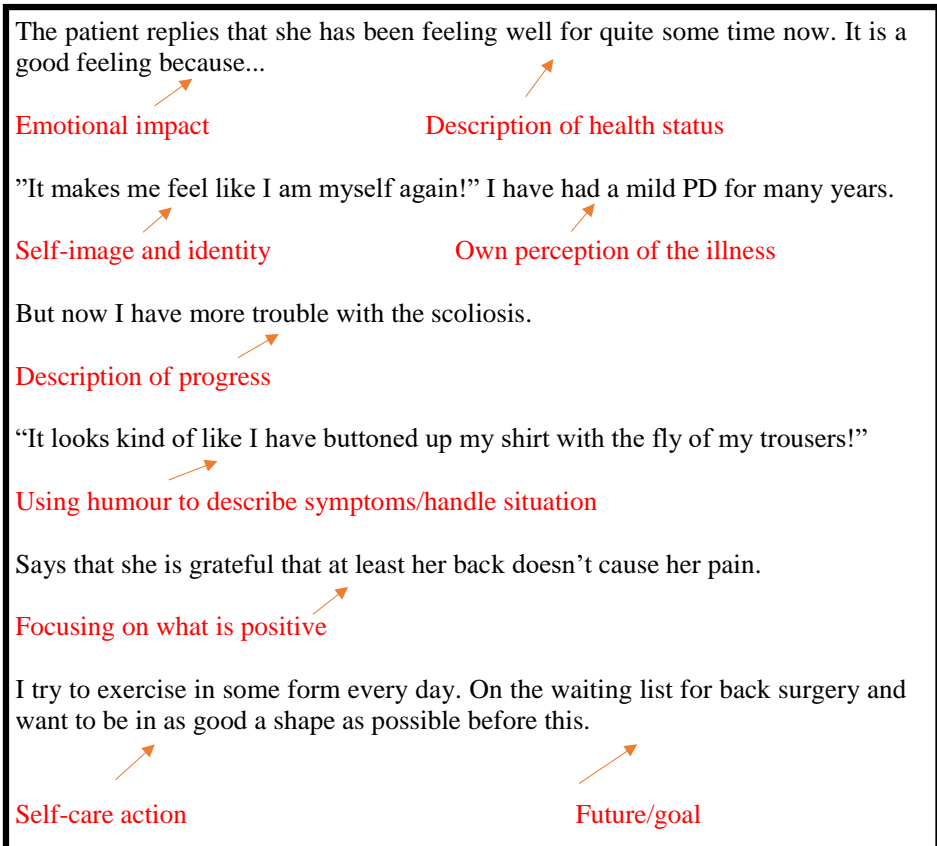
Through open-coding procedure, each dataset was read thoroughly to identify words or phrases relevant to the research question. Relevant parts of the text were marked and given substantive codes describing the process or behaviour which was found or expressed (see figure 4 for an example of substantive coding of field notes). The substantive codes from each dataset were then compared to the substantive codes of every other dataset. Comparing substantive codes clarified patterns and similarities between codes, enabling categories to be formed and labelled at a more abstracted level (Glaser, 1965).



The contents of each category were described and the categories were then compared and checked against each other, against the substantive codes and back to raw transcriptions of data. This ensured that they were meaningful and fit properly, and that they could be traced back to the raw material (Glaser, 1965). Three researchers performed these steps in the analysis independently.

In the final steps of the analysis, the researchers met to discuss their findings and compare results. By comparing all the categories found by each researcher using the theoretical coding procedure, the relations between the categories were clarified and described. This process also resulted in the identification of an overarching core category.

The overarching core category “Awareness of own abilities strengthens mutual understanding and communication in the healthcare encounter” is the essence and meaning of all data analysed and brought together in study III. The core category comprise three subcategories representing important features included. These are “Self-observation in everyday life”, “ Self-care activities to promote health” and “Managing the emotional impact of PD (study III).



**Figure 4:** Example of open substantial coding in an extract of field notes. Substantive codes in red text (study III)

## 6.4.2 Quantitative Methods

### 6.4.2.2 *Methods of statistical testing for outcomes in and between groups*

In study II, data from self-assessment questionnaires were analysed using IBM SPSS version 23 (IBM Corp., Armonk, NY, USA). Because of the ordinal nature of the questionnaire data as well as a non-normal distribution non-parametric tests were used to analyse data (Fowler et al., 2013). Four separate groups were analysed altogether, PwPD and CP in the NPS inter-

vention group and PwPD and CP in the control group. Background characteristics in the four groups were presented using descriptive statistics such as frequencies, percentages, medians and quartile ranges (Petrie & Sabin, 2013).

For the self-reported questionnaires, baseline and follow-up data were compared and tested for all four groups. The Mann-Whitney U test and Chi<sup>2</sup> tests were used to test between-group differences at baseline and follow-up. To test for within-group changes over time between baseline and follow-up scores, the Wilcoxon signed-ranks test was used (Petrie & Sabin, 2013). The level of statistical significance was set at  $P < 0.05$  in all analyses (Kirkwood & Sterne, 2003). Results show that after participation in the NPS PwPD reported improved self-reported health status on both PDQ-8 and EQ5D. There were also improvements in two domains of the heiQ; “Constructive Attitudes and approaches” and “Skill and Technique acquisition”. A trend towards improved scores in the other questionnaires following participation in the NPS was found, but these failed to reach statistical significance. No improvements were found in the CP group. The control group, including both PwPD and CP, exhibited a pattern of deterioration over seven weeks of standard care with some of the scores reaching significance (study II).

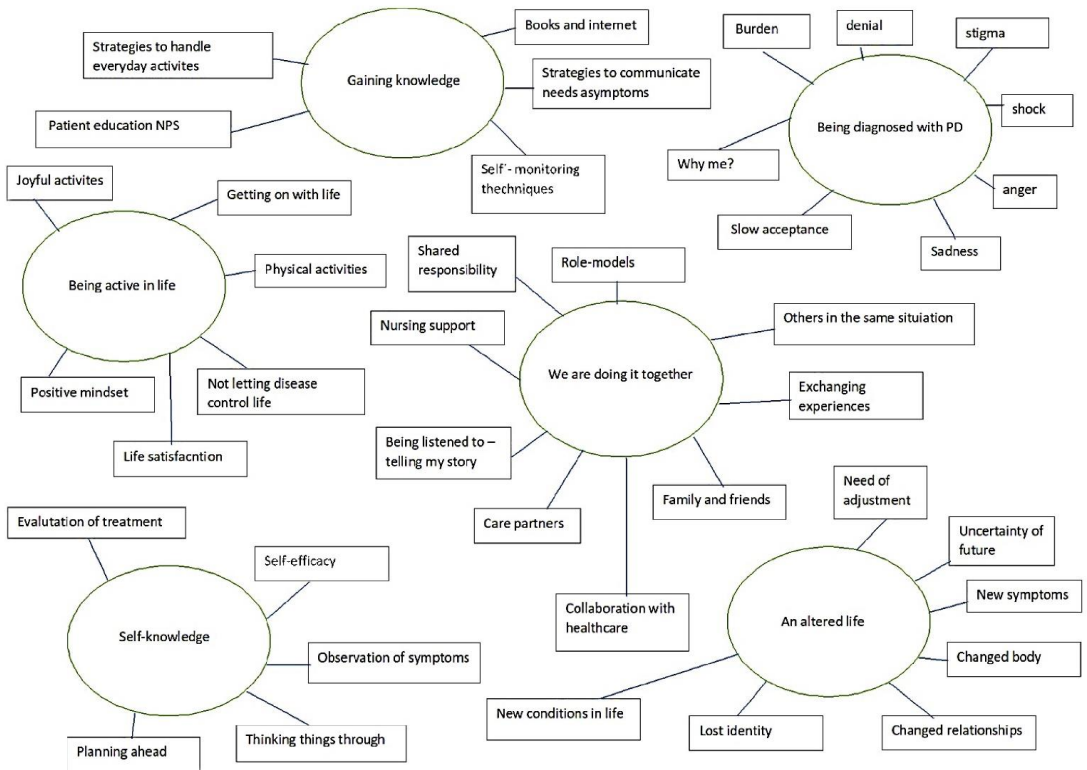
#### **6.4.3 Overall analysis of studies included in the thesis**

The main results in this thesis are the combined findings of all the studies (I-III), brought together to form a new whole. The focus of the analysis was to gain an understanding of the experiences of PwPD and CP in terms of self-management in everyday life. Analysis adopted a realist semantic approach to highlight the experiences and meanings of the reality of life as described by participants. Qualitative thematic analysis, as described by Braun & Clarke (2006), was found to be a suitable approach. Thematic analysis is flexible and not tied to a specific theory or philosophy. It can also be applied to several types of data and combinations of data sources. It is well suited for applied research carried out in the practical reality of healthcare settings (Braun & Clarke, 2014).

The author of the thesis personally analysed and interpreted the findings by following the six steps of thematic analysis and the 15-point checklist of criteria for good thematic analysis (Braun & Clarke, 2006). An inductive approach was taken with no pre-existing framework or hypothesis guiding the analysis, so that analysis remained close to, and reflected the actual words and experiences the participants expressed in the studies.

During the analysis, the findings of all three studies were first read several times, and notes were taken of initial thoughts about the contents of the body of data as a whole. The next step involved coding data of interest in each study, to explore the specific focus of analysis, i.e. self-management of

PwPD and CP. The codes were then compared and related codes were sorted into broader themes. Initially six themes (see figure 5) were identified but after these were refined, some themes were combined, as they were found to describe different angles of the same phenomenon. The final themes were named, and the contents of each theme were described in a short text to summarise them. Naming and conceptualising themes helps to interpret and understand their meanings as well as their relationships to one other. The final themes were checked against the initial codes and the original text of the full dataset, to confirm that they fit and could be identified in the initial data. The final thematic map consisted of three related but separate themes describing self-management in everyday life from the perspective of PwPD and CP (Figure 6). This final thematic map, illustrated by figure 6, is the combined result of all studies included in this thesis, and is presented and further explained in the results section.



**Figure 5:** Initial thematic map which forms part of the analysis of the overall findings of study I-III in the thesis



## 7. ETHICAL CONSIDERATIONS

All studies included in this thesis were conducted according to the ethical guidelines established by the World Medical Association in the Declaration of Helsinki (WMA, 2013). Permission to conduct the studies was also obtained from the regional ethical review board (EPN) in Linköping (Reg. no. 2014/497-31, 2015/458-32, 2016/166-32, 2017/264-32). As a nurse and researcher designing the studies included in this thesis, the author constantly reflected on the three ethical principles, autonomy, (which involves respect for persons), beneficence and justice, as stated in the Belmont report (US department of health and human services, 1979). These ethical principles guided the research work throughout the studies (Judkins-Cohn et al., 2014).

Before data were collected, written permission was obtained from the heads of the participating clinics. All participants in the studies was provided with oral as well as written information about the study, except for the control group in study II who only received written information about the study. Written information used ordinary language, with no complex medical or research terminology to promote understanding (Tamariz, 2013). This followed the guidelines for this type of information stated in the Swedish law of research ethics concerning humans (Lag 2003:460).

All participants (studies I-III) were informed that participation was completely voluntary, and could be cancelled at any time without having to state reasons for doing so (WMA, 2013). They were also provided with contact information including a phone number for the researcher and were encouraged to contact the researcher if they had any questions or concerns about the purpose or design of the study, or if they wished to withdraw their consent to participate .

For studies II and III, oral and written consent were obtained from all participants, with the exception of the control group in study II, where only written consent was obtained. For study I, only oral consent was obtained from the participants for collecting data through audio-recorded group discussions. They were informed that results would be presented at a group level and that no individuals would be able to be identified in the transcription of data or in the presentation of results. They were also offered the opportunity to decline to participate in the study.

In study II, participants in the control group received a 50 SEK voucher for a convenience store for taking the time to participate. This was considered to be an appropriate amount as an incentive to participate without being considered unethical coercion (Resnik, 2019). No other incentive for

participation was offered for the intervention group in study II or the other studies (I, III).

Many PwPD experience cognitive as well as communicative challenges as the disease progresses. This makes them a particularly vulnerable group, and this was taken into account when asked to participate in the studies (Levine et al., 2004; WMA, 2013). Dyadic interviews and collecting data in the presence of a CP can strengthen personal integrity, as the CP can support and help in these situations if necessary. Another strategy for reducing stress and easing strain for both PwPD and CP involves giving participants the opportunity to take part in data collection in their home environment when possible.

Participants can find data collection through self-reported questionnaires a burden if questionnaires are too lengthy or if the same study issues several questionnaires (Andresen, 2000). Participants often have to fill in questionnaires twice to provide baseline and follow-up data. This was borne in mind in designing study II and questionnaires were chosen carefully to limit the burden of the package as a whole.

All collected data were coded, and transcriptions contained no personal information. The encoding lists and raw data were only accessible to the author, and were stored in separate locked cabinets. All findings are presented in a way, which makes it impossible to trace the information back to the individual participants. All personal data were processed according to the General Data Protection Regulation (EU) 2016/679.

## 8. RESULTS

### 8.1 Persons' efforts and struggles to accept, manage and adjust to everyday life with PD

The results of this thesis are the overall findings from studies I-III and describe the efforts of persons in terms of accepting, managing and adjusting to everyday life with PD, as well as the process they followed to do so. This includes their experiences as participants in the NPS programme, offered in clinical care as a way of supporting them in this process. The findings are summarised in three separate, but related themes: *A changed reality*, *Finding a new path* and *The companions*. The contents of each theme is described with examples from the original studies.

#### 8.1.1 A changed reality

Being diagnosed with PD is a life-altering experience. For many, receiving notice of a progressive neurological disease comes as a shock. It changes the basic conditions, foundations and expectations of life and the future for PwPD, CP and their family. Accepting PD as a part of life is a gradual process. Both PwPD and CP describe experiencing all kinds of emotions ranging from denial and anger to sadness and hopelessness in the time following diagnosis (study I).

As PD is a progressive disease, and medical treatment is only symptomatic, PwPD and CP know that over time the burden of symptoms will increase. The worries and fears concerning how rapidly symptoms will progress and whether they will affect mental and cognitive abilities are a burden (studies I, III). For PwPD who have already been living with the diagnosis for several years, the impact of the disease has already forced them to adjust their lives and the activities they used to enjoy. Participants in the studies worried that they would eventually have to give up these activities altogether (study III). They also noted that PD had taken over their life completely. All that was left was to try to handle and cope with the disease throughout the day and night, and this left no room for anything else (study III). The uncertainty of what life would be like in the future was difficult for PwPD to accept and handle (studies I, III). PwPD also shared how new or progressing symptoms would sometimes throw them back into a new crisis, involving feelings of not being in control. This reaction to new symptoms affecting



their everyday life was experienced as similar to the initial shock at diagnosis, but in most cases was not as articulated or lengthy (study I).

Some participants felt that PD had changed their feelings about themselves, their personal identity, and how they viewed themselves. Many had noticed these changes not just on a psychological level but also on a more distinct level. They found they were less tolerant of stressful situations which occurred in everyday life, and that their thoughts and actions were noticeably less flexible. This reduced flexibility was a result of PwPD now having to focus on one thing at a time, and being less capable of doing several activities simultaneously. They also found it challenging to be in environments with lots of stimuli (study III).

Speaking openly about the disease was one way in which PwPD started to process the new situation in terms of accepting the disease as a part of their life. Participants noted that the information they shared was depended on the situation and who was asking. They had both good and bad experiences of how speaking openly about PD affected the way other persons in society viewed them. In some cases, other persons were more tolerant and helpful when they knew about the disease. In other cases, they pitied the person with PD or were uncertain about how to act around them. It was experienced as a stigma of “being ill” (study I).

To make life more comfortable, and to ease the strain of their own life situation both PwPD and CP used upward and downward social comparisons. Downward comparisons included expressions like, “there is always someone worse off than me”. Upward social comparisons included mentioning the good medical treatments available nowadays to ease the symptoms of the disease and how these have been developed and improved in recent years. Participants also expressed how grateful they were that, although PD is a long-term condition, it is not fatal, and there are other diseases with a much worse prognosis. Meeting and talking to other PwPD who had already lived with the disease for many years and were still living good and fulfilling lives, was encouraging and helpful in the process of handling difficult emotions (studies I, III).

### **8.1.2 Finding a new path**

After the initial shock, most PwPD and CP slowly started to find a more balanced way to handle life under the new circumstances. They started to look to the future and plan for it, moving forward in life with a new outlook on their reality (study I). The ability of PwPD to handle disease involves a number of interlocking inner personal factors, such as motivation and belief. However, it is also greatly dependent on, and influenced by environmental factors, including social support, attitudes in society and healthcare resources. Environmental conditions can either support or hinder self-care, and are closely linked to the ability to manage disease (studies I-III).

When PwPD and CP began to accept, or at least acknowledge, the new life situation they were also ready and willing to find ways of handling it and reducing the impact and disruption PD had brought to their everyday life (studies I-III). Many felt the need to acquire new knowledge about Parkinson's disease and its symptoms in order to relate to the new life situation (studies I-III). Improved knowledge of PD included the treatments available and also keeping updated on the latest research made them feel more in control of their lives. Information was gathered from books and a number of internet sources such as patient organisations, internet discussion forums and information provided by HCPs (studies I, III).

In this thesis, data were collected from PwPD and CP who were, or had previously been, participants in the NPS self-management programme. The NPS is an intervention which provides PwPD and CP with knowledge and techniques they might find useful in the process of finding a new path in life (studies I - III). Through analysis of the data, a number of strategies used by participants to handle everyday life with PD were revealed. The NPS provides support in introducing and practising techniques of self-monitoring, as a way improving self-awareness and evaluation of symptoms and medication. Learning these techniques was particularly valuable for PwPD and CP who had been diagnosed fairly recently, and who were seeking a constructive way of dealing with PD in everyday life (studies I-III). One strategy used by participants in the NPS was to think through situations known to cause stress and worry, and to make a plan of action on how to handle this situation the next time it occurred, so that they felt more prepared and in control of the situation (study I).

After taking part in the NPS, PwPD and CP continued to use strategies of self-observation and symptom registration in their everyday lives. Study III showed that PwPD and CP had adopted strategies of self-monitoring and self-observation, and had incorporated the use of these techniques into their everyday routines to improve their self-awareness (study III). PwPD and CP also used self-observation as a way of explaining and describing their health status and needs in clinical encounters with treating physicians (study III). For more experienced PwPD, the self-monitoring strategies introduced in the NPS were not new. As a part of their experience of living many years with PD, they had already developed strategies similar to self-monitoring such as keeping a journal to improve their understanding of their symptoms and the effects of PD treatment (study I).

Being an active participant in one's own life is considered crucial to maintaining a balance of both body and mind, and is discussed in the NPS. Participants' activities towards maintaining this balance included physical, mental, cultural or spiritual pursuits. Focusing on activities that were enjoyable to them promoted feelings of happiness, and prevented them from wor-

rying or feeling hopeless and sad (studies I, III). What is considered enjoyable differs considerably between persons, but participants in the NPS noted that they often enjoyed spending time with family and friends, being out in a natural environment, walking in the woods or gardening. Creative activities were enjoyed by many and included painting, cooking and singing (studies I, III).

Physical activities were undertaken partly because they were enjoyable, but also because they were heavily promoted by HCPs as a way of maintaining muscular strength, balance and motor functions. This was discussed extensively by participants in the NPS (study I), and was also recognised as a strategy they maintained after the programme to promote health and well-being (study III). PwPD themselves recognised that engaging in physical activity was a way of improving their long-term prognosis, and they prioritised it as a way to handle PD and not letting the disease control their life (studies I-III). Both PwPD and CP noticed the clearly positive effects of physical training and exercise for both body and mind. Regular appointments with a physiotherapist were common, as were other physical activities such as cycling, walking and swimming (studies I, III). Activities undertaken in a group were motivating, and had the added benefit of social interaction with other persons (study I). Barriers to engaging in physical activities included lack of motivation, but also physical difficulties i.e. pain or severely impaired balance for some, which made training difficult (studies I, III).

Common activities of everyday life such as dressing, eating and being able to perform physical tasks are all affected by PD in one way or another. PwPD engaged in a number of self-care strategies which adapted how they carried out these activities in order to remain independent in everyday life (studies I, III). Many self-care strategies involved food and medication, and were an attempt to ensure that these did not interfere with one another, otherwise they could be less effective leading to reduced symptom control (study III). A strategy for remembering when to take medication involved activating the alarm function on their smartphone, so that it rang to remind them. Strategies for swallowing medication more safely included taking pills with yoghurt instead of water, to avoid the risk of swallowing badly. Participants were aware of the risk of obstipation as a result of PD, so they addressed this consuming laxative foods, and drinking more water and coffee (study III). As there is a risk of orthostatic hypotension some PwPD had their own blood pressure monitors to check blood pressure regularly at home. Aids and techniques were frequently used for managing tasks which were challenging due to motor difficulties such as turning in bed or putting on socks (study III).

The NPS promotes a psychological self-care strategy of keeping a positive mind-set, not letting PD control their lives, and maintaining a belief that a good future is possible. Participants found this to be very helpful (study I,

II) but it was not always easy to achieve at times when the disease was more evident in their everyday lives (study III). However both a generic (EQ5-D) and PD specific questionnaire (PDQ-8) indicated significant improvements in self-assessed health status in PwPD who had attended the NPS programme (study II). In summary, the strategies and activities PwPD developed as a result of the NPS, in terms of managing life with PD supported them in finding a new path in life, strengthened their feelings of regaining control letting PD dictate their lives. These changes were not replicated in a matched control group after 7 weeks of standard care, which did not involve participation in the NPS programme (study II). This led to the conclusion that the NPS programme had mediated improved scores, resulting in greater knowledge of self-management techniques and adopting constructive attitudes in terms of handling everyday life with PD (study II).

### **8.1.3 The companions**

Adjusting to and managing PD is a process, which involves more than the person affected by the condition. The ability to self-manage and handle PD is influenced by interactions with other persons in their social context, such as family, friends and HCP, and also how these persons react (studies I, III). These persons can be seen as “companions” on the path towards self-management, and can either promote or hinder the development of these skills in PwPD (studies I, III). Participants had experienced both supportive and stigmatising attitudes and reactions from other persons in response to PD (study I). Feeling supported by family and friends is comforting, and eases the psychological strain of disease for both PwPD and CP (study I). Study I found that support from family and friends was even more important in enabling PwPD to engage in positive self-management than it was in comparison to a general model explaining self-management in persons with long-term conditions (study I).

Persons with close relationships to PwPD, like CP or other family members, also needed to be able to accept and handle the situation if they were to support the person affected by PD in their everyday life (studies I, III). Having support helped make the adjustment easier for the person affected by PD (studies I, III). The person closest to the PwPD, in many cases a spouse, often steps into the role of CP. CPs viewed managing the impact of PD on everyday life as a shared mission, and not just the concern of the person affected with PD (studies I, III). This approach was described beneficial for well-being and satisfaction with life for them both (study I). The support given by CP to PwPD was evident in many areas of everyday life, including participating in visits with healthcare services, providing motivation and support in physical exercise and following the medical regimen (study III). CP expressed a wish to learn strategies and methods for supporting their partner and for promoting healthy behaviour and well-being (study I).

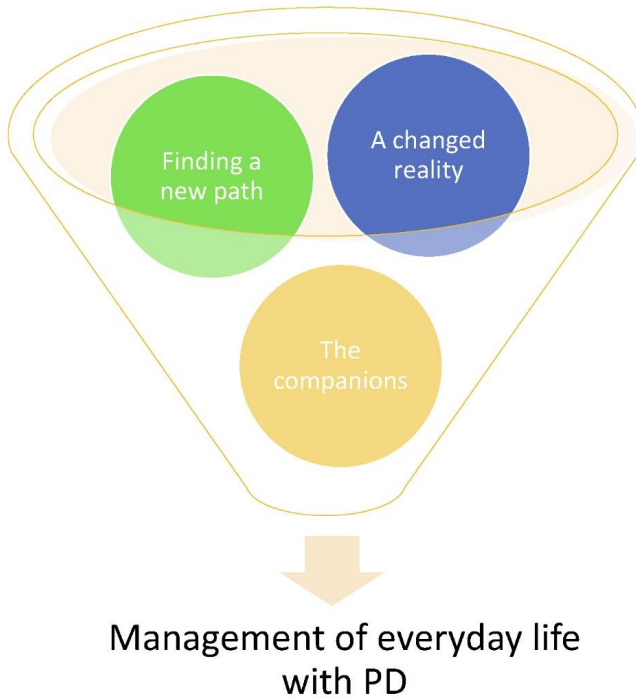
The amount of support needed and provided by a CP gradually increases as the disease progresses, as does the emotional impact of dealing with advancing disease in a loved one. CPs expressed a wish to discuss their role with others in the same situation, in order to support each other and give advice on how to handle situations in life brought about by PD (study I). This interaction with others can serve as support for CPs to manage their situation and help them feel less isolated (study I).

The NPS self-management programme is designed as a dyadic intervention for supporting both PwPD and CP. The participants considered the dyadic design to be beneficial (study I). They felt that receiving the same information and knowledge would lead to a joint understanding of PD and its related symptoms, and that it would serve as common ground for PwPD and CP to manage their life together more effectively (studies I, II). The NPS group format also provided an opportunity to meet with others in the same situation. This was valued highly by both PwPD and CP, and served as a source of emotional support as well as sharing practical advice (study I). Meeting others in the same situation gave them hope for the future, promoted positive thinking and made them feel less isolated and alone (study I). For participants who had already lived with PD as a part of their lives for many years, this social interaction was the most appreciated aspect of the NPS intervention (study I). Although study II, using self-reported questionnaires to evaluate the effects of the NPS programme, did not show any statistical proof of improvements or benefits for CP, the qualitative studies exploring the CP experience (study I) as well as the NPS program evaluation in study II indicated benefits for the CP.

Even though close family, friends and particularly CP are the most important in terms of managing the symptoms of PD on a daily basis, interactions with, and support from HCP also promote positive self-management (study III). PwPD and CP often turn to HCP for medical information and advice about PD and treatments. HCP, on the other hand, encourage PwPD and CP to explain symptoms and experiences of life with PD in their own word in order to gain a deeper understanding of symptoms and their impact (study III). PwPD and CP felt reassured when sufficient time was allocated in clinical appointments for them to tell about life with PD, and it made them feel that their story is important (study III). This trust, mutual understanding and exchange of information can develop and promote joint collaboration and decision making in clinical care (study III).

Interventions for supporting and teaching self-management strategies to PwPD and CP can include educational programs such as the NPS (studies I, II). The outcomes of interventions like these can have positive effects for the participants in terms of improving their ability handle everyday life (studies I, II), but can also be of great value for the outcomes of healthcare encounters (study III). Knowledge and practice of techniques for self-management and

self-observation can enhance the ability of PwPD and CP to communicate symptoms, health status and needs to HCP, thereby improving mutual understanding of the situation and the outcomes of clinical care (study III).



**Figure 6:**

Model of the overall results of thesis. Three major themes developed through thematic analysis of studies I-III. The themes are viewed as building blocks involved in the process towards management of everyday life with PD.



## 9. DISCUSSION

### 9.1 Discussion of the results

This thesis focuses on self-management of PD in everyday life for PwPD and CP. The results deepen knowledge of the process towards self-management, as well as factors which support or hinder it. The studies also describe the experiences and effects of the NPS programme including its usefulness to both participants and healthcare when it is offered as a part of clinical care.

#### **9.1.1 The process of accepting, managing and adjusting to PD in everyday life**

The qualitative studies included in this thesis (I, III) provided rich information on how PwPD and CP experienced life with PD, and the strategies they used to handle the impact of disease on their everyday life. Being diagnosed with PD was described as life changing, to the point of affecting the personal identity of PwPD (A changed reality). The new role of being “someone with a disease” and “a patient in need of care” was not in line with the way they perceived themselves. This sudden change in identity, and the dissonance brought by the disease, have been described as “illness-identity” in several studies related to persons with long-term conditions (Helgeson & Zajdel, 2017; Charmaz, 1995; Oris et al., 2018; Maffoni et al., 2019). Furthermore, in close relationships, shared identity and roles need to be redefined (Roger & Medved, 2010; Mosely et al., 2017). PwPD will be able to function better both physically and psychologically if they develop the ability to integrate the new conditions brought on by the disease and ultimately incorporate them into their personal identity (Campbell et al., 2003; Morea et al., 2008; Oris et al., 2018). This thesis identified that PwPD experienced changes in their identity and sense of self at time of diagnosis (A changed reality). Results also confirmed the importance of incorporating and accepting the new situation, in order to be able to continue with a new outlook on life (Finding a new path). The challenges of accepting the changed situation in life for PwPD have also been identified in previous studies (Sjödahl-Hammarlund et al., 2018; Maffoni et al., 2019).

PwPD not only noted changes in the psychological perception of themselves, but also the changes in other, more tangible personality traits. For example, participants mentioned being less tolerant of stressful situations, less flexible and less able to shift focus. They also noted that they were more likely to be emotional due to the pathophysiological impact of the disease (A changed reality). This has been found in other studies on PwPD and may be



connected to the biological changes in the brain brought about by the pathophysiology of the disease (Sjödahl-Hammarlund et al., 2018; Kudlicka et al., 2011).

As PD is a progressive disease, any worsening of symptoms can throw PwPD into a minor crisis, where they feel a loss of control and difficulties managing the new situation (A changed reality). This unpredictability and uncertainty in the progress of the disease and its symptoms, and the impact on life ahead, were considered some of the hardest aspects of dealing with PD (A changed reality). The unpredictability of symptoms and how they will affect everyday life as well as the uncertainty in terms of fear of the future have also been reported as major concerns of both PwPD and CP in previous studies (Haahr et al., 2011; Sjödahl-Hammarlund et al., 2018; McLaughlin et al., 2011; Habermann & Shin, 2017). The unpredictability and rapid change of symptoms, partly due to fluctuating responses to drugs, is unique to PD and raises special concerns in terms of managing of everyday situations compared to other long-term conditions. Daily and rapidly occurring changes in PD symptoms, as well as medication intake and its effects, are major sources of uncertainty. Not being able to trust their body or handle everyday situations due the fluctuating symptoms and effect of medication is a major challenge for PwPD and CP (Ravenek et al., 2017; Thordardottir et al., 2014).

The support of family and friends is crucial for persons with long-term conditions in terms of managing both the psychological and instrumental aspects of disease (Helgeson & Zajdel, 2017; Grey et al., 2015). The results of this thesis highlight that this is also true for PwPD, where participants considered support and interaction with other persons close to them to be vital (The companions). In fact, several other studies suggest that social support is one of the most influential factors in managing and living well with PD (Lim et al., 2019; Ambrosio et al., 2019). The results of this thesis also seem to support this. Comparison with a general model of self-management highlighted that family and friends were of major importance to PwPD and CP in terms of accepting disease (Grey et al., 2015), and it was suggested as a factor to be added as an activating resource for PwPD (The companions).

PwPD often have a person close to them who function as their main CP, and this is often a spouse (The companions). The concept of being a CP incorporates a view that managing the impact of disease in everyday life is a shared task and responsibility, and not just the concern of the person affected (Bennett et al., 2017). A CP needs to be able to accept PD as part of a shared life. This approach was reflected continuously throughout the studies (The companions) as there were copious examples of the involvement and support given by CP to their spouse. They had to come to terms with the fact that life with PD would impact both of them, not just only the person with the condi-

tion (Theed et al., 2017; Roger & Medved, 2010). Accepting this, recognising themselves in the role of CP can be challenging (Berger et al., 2019; Tan et al., 2012). CP are forced to reconsider their personal identity, as well as the identity of them both as a couple as a result of the new conditions brought on by disease (Roger & Medved, 2010; Mosely et al., 2017).

### **9.1.2 PDNS nursing support for PwPD and CP**

Living with PD is not easy. For both PwPD and CP, the knowledge that they are faced with a long-term, progressing and incurable disease is a burden, as are the physical and mental symptoms they have to confront. PwPD and CP considered support vital not only from family, friends and peers but also from HCP in terms of managing with the disease and the treatments involved (The companions).

A previous study identified that several important features and competencies are needed to provide good nursing support for PwPD and CP (Hellqvist & Berterö, 2015). PDNS often function as the main contact and link to healthcare services. A PDNS assessment of PwPD in terms of symptoms and healthcare needs initiates referral and collaboration with the other members of the MDT (Pedersen et al., 2017; Hellqvist & Berterö, 2015). Easy access to PDNS services was considered very important, and continuity of contact with the same PDNS over an extended period of time was considered to develop feelings of trust and ease worries about the future for PwPD and CP (Hellqvist & Berterö, 2015; Vlaanderen et al., 2019; van der Eijk et al., 2011). This is also identified in this thesis, where intrapersonal meetings and easy access to care were highlighted as important for the quality of care. They were seen to promote mutual feelings of trust as a basis for forming the therapeutic relationship required to provide high-quality care (The companions).

Providing emotional support and reassurance is considered one of the most important aspects of PDNS work throughout the entire disease trajectory. PwPD and CP felt cared for when PDNS took a personal approach, showed a genuine interest in the persons and their lives, and addressed them by names (Hellqvist & Berterö, 2015). Emotional support could involve listening to the concerns and worries expressed by PwPD and CP (The companions), and providing hope that a good life is possible even with PD (Finding a new path, The companions). Helping PwPD and CP set new goals in life and promoting a positive outlook were considered important aspects of emotional support (Finding a new path, The companions). Emotional support and the opportunity to speak about the future in clinical encounters with HPC have been identified as major needs and wishes of PwPD and CP (Vlaanderen et al., 2019; Van der Eijk et al. 2011; Kleiner-Fisman et al., 2013).

Emotional support from PDNS should be targeted towards instilling courage in PwPD and CP, and boosting their feelings of self-efficacy. As several studies have pointed out, alongside social support, self-efficacy seems to be the most influential factor in self-management and satisfaction with life for both PwPD and CP (Rosqvist et al., 2017; Ambrosio et al., 2019; Chenoweth et al., 2008).

PwPD and CP tend to turn to HCP for advice on how to handle symptoms and to learn more about the disease and medication (Schwartz et al., 2019; Vlaanderen et al. 2019). To help strengthen PwPD and CP self-efficacy to manage PD effectively in everyday life, PDNS support includes providing medical information about PD (Lennaerts et al., 2017; Parkinson's UK, 2016). In-depth factual knowledge about PD and treatment, as well as extensive experience in meeting and supporting PwPD and CP are considered vital for PDNS in terms of providing the support needed (Hellqvist & Berterö, 2015). PwPD and CP considered that turning to healthcare for medical information and advice was an important self-management strategy. Moreover, PwPD and CP felt that advice and knowledge provided by HCP were reliable (Finding a new path, The companions). Better knowledge of the symptoms and progression of the disease and of how treatments works, can reduce feelings of uncertainty and loss of control, and can strengthen the self-efficacy of both PwPD and CP to handle PD in everyday life (Chenoweth et al., 2008; Navarta-Sanchez et al., 2017; Lee et al., 2019).

### **9.1.3 Self-management interventions in clinical care to support PwPD and CP**

With appropriate self-management support, PwPD are rarely in need of inpatient care. PwPD and CP manage the disease by themselves at home, as part of everyday life. Accordingly, support and interventions provided by healthcare professionals take place almost entirely in outpatient care. The vital provision of medical information and education by PDNS has been discussed above. SMI is an approach which offers support in management of disease in everyday life and includes an educational element.

SMIs are educational interventions, which specifically aim to enhance the ability of participants to manage disease themselves. Techniques in SMIs often include goal-setting, self-monitoring of symptoms, problem-solving and action planning. SMIs potentially support PwPD and CP in managing everyday life with PD, boosting their self-efficacy and enhancing feelings of satisfaction with life (Finding a new path).

The studies included in this thesis considered different aspects and outcomes of the NPS self-management programme. The NPS is considered to be an SMI involving self-monitoring techniques and strategies to manage symptoms of PD in everyday life. It is provided in a small group format.

Participation in the NPS was seen as beneficial by participants (Finding a new path). Learning and practicing cognitive techniques like self-monitoring through the NPS helped participants to improve how they communicated their symptoms and needs in clinical consultations. Results show that PwPD and CP incorporated these strategies effectively into their lives after participating in the NPS (Finding a new path). This can lead to active involvement and shared decision-making in clinical care encounters (The companions). Persons who are actively engaged in their own care have been shown to be more satisfied with the care provided and more likely to adhere to medical advice and treatment plans (Schwartz et al., 2019; Eyselshoven et al., 2017; Van der Eijk et al., 2013).

To adopt and practise strategies of self-management, persons need the cognitive abilities involved in setting goals and deciding on strategies for achieving them. They need to be able to monitor the progression of the disease and adjust plans to changing circumstances (Burgess & Alderman, 2004). The fact that PD involves changes in cognitive function can sometimes make it hard for PwPD to achieve these aspects. This must be acknowledged, and self-monitoring techniques should therefore be introduced to CP as well, to allow them to support PwPD. In other words, dyadic approaches should be considered. Given the increased risk of cognitive difficulties, SMIs like the NPS, should possibly be offered to PwPD and CP in the early or middle stages of the disease. Most of the participants in the studies were in the mild or moderate Hoehn & Yahr stages. Although cognitive function is an important factor in self-management ability, other aspects are equally important to a successful outcome, such as personality, emotions, motivation, and awareness (Stuss & Alexander, 2000). The results of this thesis showed that an active engagement in life (Finding a new path) and positive outlook on life (Finding a new path) were used as strategies by participants, and were considered helpful.

As previous research has pointed out, PwPD and CP consider the support of friends and family one of the most important factors for satisfaction with life (Pappa et al., 2017; Lim et al., 2019; Ambrosio et al., 2018). The NPS is delivered as a dyadic intervention to support both PwPD and CP. This approach was valued by both CP and PwPD, who noted the benefits of a better joint understanding of PD and their current situation. It gave them the opportunity to continue talking about the disease and their joint efforts to handle life on a daily basis (The companions). A review of SMI has highlighted the need for more dyadic interventions for PwPD and CP, as it revealed that this approach had not been commonly adopted (Kessler & Liddy, 2017). This is surprising, as the importance of CP support for PwPD is well known. Meeting others in the same situation has also been highlighted as valuable for persons with long-term conditions in general not just PwPD and their CP (Kessler & Liddy, 2017; Beaudet et al., 2015; Pappa et al., 2017).

The NPS programme provides an opportunity to meet others living with PD, and also enhances social support through the dyadic approach (Finding a new path, The companions).

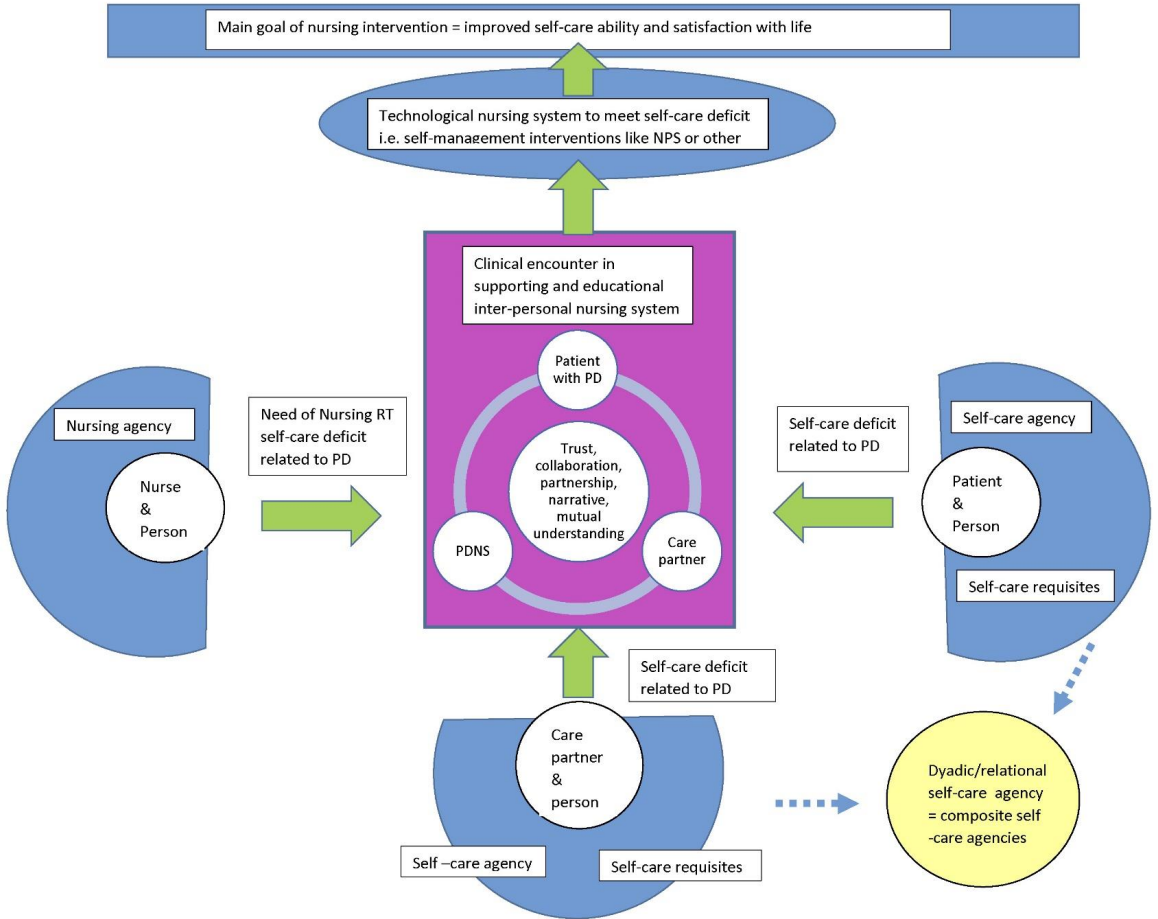
Another factor influencing persons' abilities to handle life with PD is whether they themselves believe that they can manage the situation (Lim et al., 2019; Chenoweth et al., 2008). This is referred to as self-efficacy. Self-efficacy can be stimulated by previous experience of managing successfully, but also through positive role models. Participants in the NPS described how they saw positive role models when they met other participants who were still living good and fulfilling lives after living with the disease for many years (The companions). Participants in the NPS also tended to make comparisons with their own life, suggesting that PD was not so bad, and was not, after all, a fatal disease. These narratives of "there's always someone who's worse off" were used to ease the strain in their own life-situation (A changed reality). These kinds of upward and downward social comparison have also been recognised in PwPD and other populations with long-term conditions as an emotional strategy to boost hope and feel better about their own situation (Sjödahl- Hammarlund et al., 2018).

In conclusion, SMIs for PwPD and CP seem to result in the same positive outcomes as have been demonstrated in other groups of persons with long-term conditions, and should be offered in clinical care to support handling of PD in a positive way in everyday life. PwPD themselves have highlighted that support in self-management, and practical advice and strategies for managing symptoms in everyday life, constitute unmet needs in terms of their care (Kleiner-Fisman et al., 2013; Vlaanderen et al., 2019). The NPS was found to be useful and was appreciated by both PwPD and CP. It is therefore suitable to be used in clinical care. Although this type of intervention will not suit everyone's needs in terms of self-management, or fit with all approaches, it should be offered by PDNS as part of their support to PwPD and CP. However other forms and types support for PwPD and CP to handle disease should also be available and included in PDNS work. Interventions focusing more on social interactions and peer support might be more suitable for CP and PwPD in more advanced stages, who have already lived with the condition for many years, or for those with cognitive difficulties.

## 9.2 Applying the theoretical framework

PwPD and CP consider the support of HCP important and valuable in their efforts to find strategies for maintaining a satisfaction in life also with PD. A PDNS is often the main contact for PwPD and CP, and makes nursing support easily available and accessible to them. The PDNS approach not only considers the medical issues but tries to see to the “whole picture” in terms of supporting and improving management and life satisfaction for PwPD and CP. The overall mission for PDNS working in outpatient care is to support self-management of PD in both PwPD and CP throughout the disease trajectory. Adjusting nursing support and advice to meet the needs of the unique persons and in their personal context and entire life situation is key (Hellqvist & Berterö, 2015).

To explore further how the results of this thesis can be of use for PDNS working in clinical practice, the results are now discussed in relation to the theoretical nursing framework of Dorothea Orem and the philosophical and theoretical assumptions of PCC. A proposed model is presented below, which represents PDNS support within an outpatient care setting. This can serve as a guide for nurses working in the field in terms of applying the results in clinical practice.



**Figure 7:**  
 A model of PDNS support given to PwPD and CP in outpatient care, applied within the framework of Orem’s SCDNT.

### **9.2.1. Overall description of the model**

This model primarily describes the encounter between three unique persons. The healthcare setting also involves an encounter between three roles specific to this setting: the PDNS, the person with PD and the care partner. These roles represent only one dimension of the complex persons involved in the encounter, but are present and evident within the healthcare context. These three persons are represented by the three white circles in the model, both in their situation-specific roles and as persons. The encounters between PwPD, CP and PDNS have a specific aim and goal, which is to help PwPD and CP strengthen their ability to carry out self-care in order to meet the demands brought on by PD, and to maintain their satisfaction in life. The overall goal can be seen in the box at the top of the model. As PwPD and CP manage everyday life together, helping each other manage, their joint ability to handle everyday life is represented by the yellow circle in the lower right-hand corner. In the above model, the abilities required by PwPD and CP in terms of undertaking self-care (self-care agency), and the abilities required by PDNS to perform nursing care (nursing agency) are represented as aspects of the personal assets brought into the meeting in the blue semi-circles surrounding the persons.

According to Orem, the main goal of all nursing actions is to help patients manage their own lives, including the demands brought on by disease. These actions promote self-care, independence and health. Particularly in the first years following diagnosis, PwPD and CP require support in finding strategies to improve self-management (Finding a new path).

The purple box in the middle of the model represents the actual meeting. All the interpersonal interactions take place within this space. A fruitful meeting between PwPD, CP and PDNS can lead to mutual understanding, partnership and trust.

### **9.2.2 Self-care agency in PwPD and CP**

According to Orem, self-care agency involves the skills that persons possess in terms of deciding to undertake self-care activities and knowing how to go about them. This ability can vary between persons with PD, due to conditioning factors, which promote or prevent their capabilities such as age, resources in the environment, co-morbidities and previous experiences in managing difficult situations. The activities required to keep health and well-being are affected by PD, as disease involves new demands. These new demands are known as self-care requisites in Orem's terminology. The self-care requisites brought on by PD, are personal factors unique to every PwPD and CP, represented in the blue semi-circles in the above model.



Self-management of PD, as well as other aspects of self-care including other aspects in life, take place within the context of family and friends (The companions, Finding a new path). Many PwPD and CP considered managing PD to be a shared responsibility and their joint self-care ability would therefore be crucial and influence how they manage the impact of disease in their everyday life (The companions). They can support and help each other to find balance in self-management of PD and self-care together. In the model, this joint or composite self-care agency is represented by the yellow circle in the lower right-hand corner. The known trajectory of PD means that CP are encouraged to become involved from the time of diagnosis, and PDNS often meets both PwPD and CP during clinical encounters (The companions). PDNS know that, as symptoms progress, this will lead to future need of requiring support for PwPD to manage self-care in everyday life. Several studies have indicated that social support is one of the most influential factors in enabling both PwPD and CP to self-manage and cope with the strains of progressing disease in terms of sustained mutuality and satisfaction with life (Berger et al., 2019; Lim et al., 2019; Ambrosio et al., 2019).

Where PwPD have the support of a CP in the various aspects of care, the need for nursing home placement is significantly delayed, even in the later stages of the disease (Haberman & Shin, 2017). With this in mind, PDNS should pay extra attention to PwPD who have no CP or network for social support. As symptoms increase with the progression of the disease, CP will experience more strain (Theed et al., 2017). Symptoms such as cognitive decline and frequent falls will particularly contribute to strain and burden on CP (Karlstedt et al., 2017; Schrag et al., 2006). Therefore, as noted by PwPD and CP, it is vital for the PDNS support to include both (The companions).

### **9.2.3 Nursing agency**

The ability to provide nursing support is referred to by Orem to as nursing agency. According to Orem, this ability is learned ability of the nurse and develops over time. A previous study which explored PDNS work as experienced by PwPD and CP resulted in a description of the dimensions of the service and support provided (Hellqvist & Berterö, 2015). The results of the study can be considered a description of PDNS nursing agency in Orem's terminology (Hellqvist & Berterö, 2015). Several factors condition and influence the ability of PDNS provide nursing support. Crucial for the quality of nursing care are the willingness of PDNS to engage in nursing, skills in relationship building and communication, and the ability to provide comfort and hope for the future (The companions). Basic personal factors like age,

gender and experience in the profession also condition for the nurse's ability to provide nursing care according to Orem.

The results of this thesis show that PwPD and CP considered it important for PDNS to have expert knowledge about PD in terms of pathophysiology, symptomatology, progression of the disease, and any new research and medication which might be available (The companions, Finding a new path) this is called the common-sense nursing knowledge by Orem. Although this professional and factual knowledge is considered vital to outcomes, PwPD and CP also expressed that it was not enough. In order to provide good nursing care, extensive experience of meeting persons with PD was also required for the nurse to be able to evaluate symptoms and health status, and feel confident in giving advice and recommendations following this evaluation (Hellqvist & Berterö, 2015). This knowledge derived from experience is also recognised by Orem and referred to as antecedent nursing knowledge.

#### **9.2.4 Prerequisites for the clinical encounter**

The impact of PD on everyday life of PwPD and CP means they tend to turn to healthcare for support and advice (Finding a new path, The companions). PwPD and CP have a specific reason for entering into an encounter with the PDNS. Using Orem's terminology, that is because the self-care demands brought on by the health-related self-care requisites of PD have exceeded their self-care agency. This imbalance between demands and self-care agency is called the self-care deficit. The self-care deficits due to PD can vary according to the individual symptoms, and stage of the disease, and can include physical as well as psychological and relational deficits (A changed reality, The companions).

According to Orem, self-care deficits related to disease are the main concern and target of nursing support. Self-care deficits are represented in the model by green arrows. These points to the clinical meeting as the motivator for PwPD and CP to enter into an encounter with the PDNS. A self-care deficit or the knowledge of a future self-care deficit is also the only legitimate reason for the PDNS to engage in the situation and provide nursing support according to Orem.

A PDNS must be able to decide on the most suitable way to support PwPD and CP in their current situation according to the needs assessed in a clinical interaction. These nursing actions are called nursing systems in Orem's terminology and are represented by the blue ellipse in the upper part of the model. In outpatient care, these nursing actions are often carried out in order to provide emotional support in dealing with difficult feelings or situations or providing medical information and advice within what Orem calls an intrapersonal educative and supporting nursing system (Finding a

new path, The companions). A major element of this support consists of educational interventions at several different levels, ranging from provision of theoretical knowledge and practical advice, to more complex self-management interventions like the NPS to teach cognitive strategies for promoting changes in behaviour. The educational interventions can be provided as personal interventions, in a dyadic form or in a group format (Finding a new path). Nurses choose the appropriate nursing intervention based on the personal narrative of PwPD and CP, and on the mutual understanding formed through interactions in the therapeutic meeting (Hellqvist & Berterö, 2015).

The overall goal of nursing care and nursing interventions is for persons to regain their self-care agency to meet self-care demands and live a fulfilling and satisfying life, where health and well-being are maintained. When the ultimate goal is achieved, according to Orem, there is no longer a need for nursing actions and nursing care.

### **9.2.5 The relational process of collaboration and partnership to handle impact of PD - Person- centred care in the clinical encounter**

The purple box in the middle of the figure above represents the clinical meeting. All interaction between the persons involved takes place within this space. PCC can be considered both a philosophical and practical concept which guides the interactions in encounters between nurses PwPD and CP. Several aspects of person-centredness were evident in the results of this thesis.

The importance of the personal approach was highlighted, as PwPD and CP wanted support to be tailored to their unique life situation. The ability to meet and listen to every unique person, and their specific wishes and needs in the current situation was key to a good clinical encounter (The companions). Supportive interaction between PDNS, PwPD and CP during clinical encounters has been identified involving the following factors: listening with respect, being interested, providing sufficient time and adopting a personal approach (Hellqvist & Berterö, 2015). By adopting these strategies there was an opportunity for a therapeutic relationship to form. The need for a more personally tailored approach has been described in previous studies regarding PDNS services and support (Lennaerts et al., 2017; Hellqvist & Berterö 2015) but also in a study highlighting the need of considering outcome measures relevant and meaningful to PwPD and CP themselves in evaluating treatment interventions and in research (Benge et al., 2018).

Clinical encounters seem to follow a certain structure, which aims to develop a mutual understanding of the current situation (The companions).

PwPD and CP were encouraged to tell about their experiences of PD symptoms in their own words, and discuss the impact on everyday life. (The companions, *Finding a new path, A changed reality*). Having the opportunity and sufficient time to talk about the impact of PD on their lives was much appreciated by participants, and made them feel cared for and listened to (The companions). How their personal story was received and handled by the PDNS or physician was key. If they listened carefully and showed a genuine interest in the person's life, this in itself could give some relief and promote feelings of being cared for (The companions). This approach also gave participants reassurance that what they had to tell about life was considered important, and that it was an essential aspect of collaboration and care (Hellqvist & Berterö, 2015). Listening is a vital skill in nursing practice, but one which is rarely studied. Active and attentive listening includes an emphatic and non-judgemental mind-set (Shiple, 2010). Listening attentively to patient's narratives is seen as the foundation for comprehending how they view and understand of disease. It is also important in assessing a person's resources and barriers in terms of self-care (McCormack & McCance, 2017; Sharma et al., 2015).

The personal story, the personal narrative, serves as a starting point for discussions and interactions in reaching a mutual understanding of the current situation of a person's life with PD (The companions) Personal stories are considered to be the foundation for mutual understanding, collaboration and shared decision-making between HCP and patients. It is a story that needs to be assessed and reassessed constantly as it develops and changes over time (Sharma et al, 2015; American Geriatrics Society Expert Panel on Person-Centred Care, 2016). The interactions between PwPD, CP and PDNS which take place in the clinical encounter are referred to as the dynamic interpretation space according to Ricoeur's terminology (1992). This is the place where the knowledge of two experts meets: that of the healthcare providers and the persons affected by PD. Allocating sufficient time for this interaction to take place was considered crucial for a fruitful exchange, and a restricted timeframe for clinical appointments was sometimes experienced as a barrier to interaction in this sense (The companions, *Finding a new path*). Through personal stories the persons behind the roles of patients and care partners becomes visible (McCormack & McCance, 2010; Ekman, 2011). The results from this thesis highlight how being seen and valued as a person is very important aspect in how PwPD and CP experience quality of care (The companions). The mutual relationship of trust and cooperation resulting from a fruitful clinical encounter encourages PwPD and CP to be involved in care, and promotes shared decision-making (Buetow et al., 2016; Sharma et al., 2015). PwPD and CP were encouraged to share their stories and thoughts about the situation if they felt that the PDNS or physician also were

committed and willing to interact. This was perceived if they showed an interest in, or made an effort to work out the current problem, or made suggestions on how to manage it (The companions).

In the studies included in the results of this thesis PwPD and CP expressed that they were willing to interact with PDNS and physicians and that they wished to be involved in their own care (Finding a new path, The companions). The willingness of PwPD to be active participants in their care has also been described by Eygelshoven and colleagues (2017). PwPD and CP asked for advice about symptom control and medication, and talked about strategies they had adopted to manage aspects of PD in their lives (Finding a new path). This is in line with a perception that persons are willing to take responsibility for their own lives and health, and are capable of doing so (Ricoeur, 1992). However even if they are capable, all human beings are also vulnerable and in need of support at times. This was evident in these studies, where important aspects of good care were considered to include emotional support, and helping PwPD and CP deal with the emotional impact of the disease (The companions). Nurses working to support PwPD and CP should be able to recognise when they express feelings of anxiety, sorrow and fear of future. They need to be able to give guidance in setting new goals in life, by instilling courage, giving calm advice and comfort, and providing hope for a bright future and a positive outlook on life ahead (Hellqvist & Berterö, 2015).

Relational factors such as respect, empathy, engagement and communication are considered vital aspects of a PCC meeting (McCormack & McCance, 2010) and are also expressed by participants in the results of this thesis. They felt that a sense of trust, confidence and comfort developed gradually in the therapeutic relationship (The companions). Facilitators of a good therapeutic relationship, and mutual understanding and trust, were considered to include easy access to support and advice and meeting with the same care provider several times (The companions). A continuous contact with the same care provider functioning as a primary point of contact with healthcare, have been highlighted as important in achieving PCC for older persons with long-term conditions (American Geriatrics Society Expert Panel on Person-Centred Care, 2016).

The description of a fruitful and encouraging encounter in the healthcare settings in this thesis (The companions) have many similarities with the Person-centred Nursing framework presented by McCormack and McCance (2010). This framework involves five important care processes in the person-centred meetings between nurse and patient. These are describes as exploring and trying to understand and respect patients' values and perceptions of themselves and their environment, working towards shared decision-making, being engaged, being present and receptive, and providing holistic care (McCormack & McCance, 2010). In the overall results of this thesis, these

five components are evident and described by participants in their own words (Finding a new path, The companions, A changed reality). The suggested outcomes of person-centred nursing according to McCormack and McCance are a good care experience, involvement in care, a feeling of well-being and existence of a healthful culture (McCormack & McCance, 2017). These outcomes are applicable both to nurses as well as the persons receiving nursing care. The nurse experiences enhanced satisfaction with work and the persons in need of nursing care feels cared for and listened to (McCormack & McCance, 2017). These can also be expected as outcomes in the PCC meeting between PDNS, PwPD and CP (Buetow et al., 2016).



## 10. METHODOLOGICAL DISCUSSION

### 10.1 Strengths and limitations

The three studies included in this thesis were conducted using several different methods of data collection and analysis involving both quantitative and qualitative approaches. The studies also had a diverse focus, considering the outcomes of NPS self-management programme at both at a personal and organisational level, and investigating self-management support from a nursing perspective. Using different methods and different perspectives strengthens the understanding of a phenomenon as a whole (Polit & Beck, 2014).

To promote diversity, data were collected in an educational setting and also in a healthcare setting. There was also a geographical spread in terms of participants who were from both regional and local hospitals and involved in both neurologic and geriatric care. Variation in settings and characteristics of participants is valuable in highlighting different perspectives of the phenomenon in question in the study (Flick et al., 2004). Participants represented different stages of PD, and time of diagnosis varied considerably from less than one year to more than 20 years of disease. No participants in the studies were in the most severe stage of PD, Hoehn & Yahr stage V. This stage indicates that the person is wheelchair-bound or bedridden unless they receive help. It was therefore considered that they might be too affected by PD to be able or willing to participate in interventions like the NPS. The results of the studies are not applicable to this group of persons with severe PD.

All studies in this thesis investigated the NPS programme and were undertaken in clinical care. There were few restrictions in terms of inclusion criteria. To be eligible to take part in the studies, PwPD only needed to have been diagnosed with PD and to have the cognitive ability to understand and fill in questionnaires. Participants were representative of clinical care, and were not selected by researchers but invited to participate in the NPS by a PDNS or other HCP working at the participating clinic. This is a strength, as the results using this approach are likely to be applicable to clinical care setting and not just relevant in a research environment. This approach is vital in interventions which are intended to be implemented in routine clinical care (Flick et al., 2004). Despite the advantages of this type of sampling for studying clinical care, there is an obvious risk of selection bias. It risks only investigating PwPD and CP who are already interested and motivated in terms of participating in these types of interventions. It also risks including only participants at a certain stage of the disease, or who have had the disease for



a specific length of time, as the general opinion of HCP is that this intervention is more suitable in certain stages of PD than others. Results should be interpreted with this in mind (study I-III).

Study III used dyadic interviews as a method of collecting data. The reasons for this included an opportunity to capture the shared experiences of the dyad. It also meant that the two participants could help each other in the interview, as PD sometimes can affect communication abilities. This was elaborated on in the methods section of this thesis. Although there are several advantages to using a dyadic approach for interviews there are also some concerns. These include the fact that one person in the dyad might take over, making the other passive or reluctant to share a different opinion (Zarhin, 2018). Where dyadic interviews include participants involved in a care partner dyad, one partner may not be comfortable sharing certain information with their partner present (Torgé, 2013).

In study III using interviews and observations, the researcher was present in the room and active in collecting data. The participants were aware that the researcher is also a nurse who specialises in PD. This may have affected interviewees' pre-conceived notions and on how they approached the situation, as well as the content of the interviews. In qualitative methodology, interviews are considered a two-way interaction, involving common negotiation and understanding of the phenomenon in question in the study. Both interviewer and interviewee are involved and important in the interaction. It does not simply involve the interviewee providing information in a one-sided way (Flick et al., 2004). It can be considered ethically sound for the interviewer to introduce him/herself, including mentioning any previous understanding in the situation. This can act as a foundation for trust, and a sense of "knowing who you are meeting" during the interview (Kvale, 1996). The interview takes place in a setting consisting of environmental and social constructs, and should be viewed in this light (Lune & Berg, 2017). During the observations (study III) the researcher was not an active participant in the interaction between the physician, PwPD and CP. On the other hand, it should be recognised that merely being present in the room will have some impact on the interactions of the other persons involved in interaction.

Study I used another type of data collection, involving audio-recordings of group discussions, as a source of qualitative data analysis. The group discussions recorded consisted of a standard session of the NPS programme with participants (both PwPD and CP) and group leaders. The researcher was not present in the room during the session and had no previous relationships to either participants or group leaders. The session was not in any way altered for the purpose of the research, and was a normal session of the NPS programme in clinical care. The advantage of this approach to collecting data is that the absence of the researcher means the latter does not affect the inter-

actions of the group. The audio-recordings can be seen as documenting actual real-world interactions and events during the NPS intervention. Audio-recordings also have a number of disadvantages. The use of auditory data as a single source of information will not reveal all the nuances involved in relational interactions, such as use of non-verbal language and the positioning of participants in the room. The researcher does not have the opportunity to use probing questions or ask participants to explore topics further if they need more explanation or are of special interest in terms of the research question. Even with the obvious drawbacks of this method, the analysis of the transcribed group discussions provided valuable insights into how participants in the NPS experienced the intervention and its value in managing life with disease in the future (study I).

Study II is a quasi-experimental case-control study which evaluates the outcomes of NPS using self-reported questionnaires. Data were collected before and after the NPS programme. Both generic and PD specific questionnaires were used, representing both the proximal effects of self-management education and more distal effects i.e. overall satisfaction with life, health status and fatigue. In order to ascertain more clearly whether the changes found in the questionnaires were due to the NPS programme, a matched control group filled in the questionnaires before and after seven weeks of standard care. A simple form was also distributed to both the intervention group and control group in order to check for “confounders”. The form asked participants whether they had experienced any events in life which had made them feel extraordinarily happy or sad, and if so, to specify the event. PwPD were also asked if there had been any changes in medical treatment since this can affect physical and mental status in both positive and negative ways. Comparing the results with those of a control group, and checking for confounders in other ways, strengthens the design of a quantitative study (Polit & Beck, 2014).

The selection of questionnaires in study II was partly inspired by previous studies evaluating the European PEPP programme (A´Campo et al., 2010a,2010b,2011a,2011b) as the Swedish NPS is developed from the European programme and the researchers wished to see whether the results would be similar. Some of the questionnaires used by A´Campo and colleagues were not available and had not been tested in Swedish and were therefore replaced by other questionnaires. The studies of the European PEPP concluded that the programme is feasible and suitable for most PwPD and CP (A´Campo et al., 2011a; Macht et al, 2007). After participating in the programme, statistically significant effects were demonstrated for both PwPD and CP in terms of less need for help, less bothered by the psychosocial impact of PD and improved mood (A´Campo et al., 2010a, 2010b). PwPD also demonstrated improved health status in a clinical setting.

(A´Campo et al., 2011b). For the most part, the results of the NPS intervention found in study II were similar to those found in the European studies of PEPP, showing that NPS also improved self-reported general and PD specific health status for PwPD after intervention.

One questionnaire was added in study II which had not been used in the previous PEPP studies. The heiQ was added in an attempt to assess the proximal outcomes of self-management education. Other studies using more distal outcome measures to evaluate the effects of educational interventions, such as quality of life or carrying out activities of daily life, often showed minor or no effects, even though participants had expressed the value of these interventions. The heiQ was added in an attempt to clarify this participant perceived value in a more proximal measure. Study II showed the direct effects of NPS on two of the domains of the heiQ demonstrating the impact of the NPS on these proximal outcomes. This supports its usefulness in evaluating in this type of intervention for PwPD.

In study II, no significant changes were found for CP in any of the questionnaires, even though CP expressed a high level of satisfaction with the NPS on the clinical evaluation form for the NPS programme. In addition, the qualitative data in study I show that CP considered attending the NPS to have been valuable. The inability to detect changes in study II could be due to the selection of questionnaires used. The Zarit Burden Inventory is a generic questionnaire for assessing caregiver burden. This questionnaire may not be specific enough to detect changes in the burden to CP of PwPD. A´Campo and colleagues (2010a) used another PD specific instrument to assess burden and found improvements in domains involving psychosocial strain and the need for help. This instrument is unfortunately not available in Swedish, and no other questionnaire specifically targeting PwPD burden for CP is currently known to be available in Swedish, nor any questionnaire, which evaluates the effects of SMI for CP of PwPD. In terms of evaluating SMIs as dyadic interventions, or SMIs targeting CP of PwPD alone, this is an area of major concern.

In research studies, the required sample size varies according to the research question and the methodology used to address it. In qualitative studies, sample sizes are often not decided in advance. Many qualitative studies include between 5 and 30 participants and are dependent on the richness of the data gathered (Kvale, 2009). Qualitative studies usually focus on gaining deeper insights into how a phenomenon is experienced, through persons´ descriptions or through observations of the world (Polit & Beck, 2014). The 25 PwPD and 17 CP included in study I, and the 10 PwPD and three CP in study III were considered sufficient to address the research questions for these studies. In contrast, sample sizes are usually calculated in advance in studies using a quantitative approach, as they seek to observe statistically significant changes in data, and aim to generalise findings to a larger population (Polit

& Beck, 2014). The sample size in study II was sufficient to allow comparison between control and intervention groups in terms of PwPD. However, the study may have been underpowered in terms of the CP group. It was not possible to conduct a proper power-analysis for this group, as there were no outcome measure that could be linked to previous data. Furthermore, there were too few PwPD in the intervention group to analyse outcomes among subgroups, for example different stages of PD. This is a limitation in terms of understanding the value of the NPS programme in the different stages of disease. Qualitative results suggests that the NPS was valued differently by PwPD and CP depending on whether they were new or experienced in terms of living with PD (study I). This is an area in need of further studies, using larger samples.

It has proven difficult to detect and evaluate the more distal effects of SMIs including the potential benefits of these interventions in terms of different outcome measures in healthcare organisation. Traditionally, these effects have been investigated using quantitative measures and questionnaires, and analysed at a group level (Chlund et al; 2016; Kessler & Liddy, 2017; van Hooft et al., 2016). In study III a qualitative approach was tested in order to investigate the outcomes of the NPS, and whether the techniques of self-management included in the programme were being used in clinical care. This was done through participant observations during a clinical care encounter between physician, PwPD and CP who had previously been participants in the NPS. In observing their interactions and analysing the collected data, it became clear that PwPD and CP had adopted the strategies of self-monitoring included in the NPS, and were using them in their everyday lives. They were using these strategies as a way of observing their own behaviour and symptoms, and as a way of communicating healthcare needs and evaluating treatments in the clinical encounter (study III). Observing clinical care in this way is one method of investigating and scientifically establishing the benefits and usefulness of self-management interventions in personal meetings and at a personal level in healthcare. This can add to the limited amount of evidence in terms of the outcomes of SMIs in healthcare. To our knowledge, this approach to evaluation has not been used in studies investigating the effects of SMIs before.

## **10.2 Validity, reliability and trustworthiness**

All studies included in this thesis were checked for quality and rigour and reported using the appropriate Equator guidelines.

### **10.2.1 Generalisability, validity and reliability (study II)**

Validity and reliability are concepts used primarily in studies with a quantitative design, where the general aim is to generalise sample results to a larger population (Kirkwood & Sterne, 2003).

Sample size was calculated in study II to improve validity of the statistical conclusion as a large enough sample improves the ability to detect significant change within a dataset (Kirkwood & Sterne, 2003). In addition, the background characteristics of participants are provided in the study findings for both the intervention and control groups, so that readers can make decisions about the generalisability of findings to similar populations. Data were collected from multiple, geographically diverse sites and included participants in neurological and geriatric settings cared for at both county and university clinics. This diversity makes it more likely that results can be applied across different settings. In an attempt to compare the findings of study II with previous studies in the area of SMIs for PwPD, and particularly the European PEPP programme, similar questionnaires were chosen to assess outcomes. In study II, the concepts of validity and reliability were also considered in relation to the questionnaires used. Reliability is concerned with the stability and accuracy of an instrument. Validity involves an instrument's ability to measure the intended variable (Heale, 2015). A way of enhancing the quality of a quantitative study is consciously choosing the questionnaires. All questionnaires used in study II were available in Swedish and had been tested psychometrically with good results. A control group was included in the study-design to make it even more rigorous, and possible confounders were investigated which might affect the outcomes of the questionnaires (Kirkwood & Sterne, 2003). Choosing a suitable method for analysing data also contributes to the rigour of the study and the credibility of the findings (Polit & Beck, 2014). As data in study II were ordinal and were not normally distributed, non-parametric tests were used (Fowler et al., 2013). Results were compared and reported within as well as between groups.

### **10.2.2 Trustworthiness (studies I and III)**

Throughout the process of developing the qualitative studies, the researcher adopted a flexible and responsive approach as described by Morse and colleagues (2002) using techniques to make the research process more rigorous. These techniques included choosing an appropriate scientific method and form of analysis suitable for answering the research question (methodological coherence), and ensuring an appropriate sample of participants in terms of both size and characteristics. The first analysis of data began while data were still being collected. This provided the researcher with an understanding of what the data contained and what was needed to obtain the required

depth and breadth of data. Thinking theoretically and checking new ideas and assumptions throughout the process, confirming them in the new data collected as well as checking them for confirmation and presence in the body of data already collected. This helped the researcher in developing general theories of what was present in data. The researcher was moving from the micro perspective of data to a macro perspective describing the overarching theoretical understanding of the material studied. These strategies were applied throughout the work of studies I and III to make the qualitative studies more rigorous.

Rigour was also assessed post hoc, when studies were complete, using the five criteria of trustworthiness according to Lincoln and Guba (1985, 1994): credibility, dependability, confirmability, transferability and authenticity. Credibility is the extent to which the results of a qualitative study are believable and reasonable to both the researcher and the reader. To strengthen credibility of findings, investigator triangulation was used in analysis of data of both qualitative studies (study I and III) included in this thesis. Three researchers analysed the transcribed material separately, and then the findings were compared and discussed to reach a consensus. The pre-understanding of the author of the thesis, working as a PDNS in clinical care, enriched the understanding of the area. Researcher triangulation reduced the potential risk over-interpretation, and risk of bias introduced by the researchers previous understandings and experiences. The credibility of the findings was strengthened by methodological variations in the studies, in the sense that the value and outcomes of the NPS were considered from different angles, and with different methods used to collect and analyse data.

Dependability is the extent to which findings seem to be true across time and different conditions. The audit trail was described in detail, including the settings and characteristics of the participants and examples were given from the analysis (studies I, II) to strengthen dependability of the studies. To avoid mixing methods, instructions for each methodology were followed precisely as described in literature. It is vital that procedures and settings are described as detailed as possible so that other researchers can replicate the study if they wish (Polit & Beck, 2014).

Confirmability was tested when the results of the analysis were checked back to the transcriptions of data, to ensure they appeared in the raw data. Moreover the results included citations in the participants' own words to ensure the participants' own voices be heard. This also enhanced the authenticity of the findings.

Transferability involves the extent to which the results shown in these studies are likely to apply to other persons in similar settings. Researchers should provide sufficient information to allow readers to make a critical evaluation when they read the studies. The main goal of qualitative research is not to draw conclusions about how applicable the results are to other groups.

Instead, it aims to broaden understanding of a phenomenon through persons' own experiences and thoughts, in a research setting with few controllable variables (Flick et al, 2004). Nevertheless, comparisons between groups and studies are an undeniable aspect of improving knowledge of the research area. Therefore, all the variables, methods and settings were thoroughly described for studies I and III to provide readers the information needed to assess the audit trail and make a critical evaluation of transferability.

## 11. CLINICAL IMPLICATIONS

The results of this thesis have expanded understanding of the process, which enables PwPD and CP to accept and adjust to PD in everyday life. After the initial shock and emotional reactions following diagnosis, most persons are willing to find ways to manage their new life situation. The findings also further stressed and highlighted the great importance of social connectedness in helping PwPD and CP to manage their new conditions in life. They tend to turn to family, friends, peers and healthcare providers for emotional and practical support, including advice on strategies and techniques to handle situations that occurred in everyday life and were related to PD. These social interactions and the social support were important in maintaining an optimistic outlook on life and the future, and managing the impact of PD in their everyday life.

This thesis provides valuable knowledge, which should enable PDNS working in clinical care to tailor support and services to PwPD and CP. The overall goal of PDNS services is to help PwPD and CP strengthen their self-care abilities in order to manage everyday life with PD, and maintain feelings of control and satisfaction with life. The thesis has highlighted the importance of involving other persons close to PwPD in care and support, such as spouses, family and friends. PDNS need to be attentive to each unique person in every clinical encounter, and tailor support to suit them. A useful approach to this involves adopting a person-centred approach in the encounter, and listening to the personal narratives of PwPD and CP in terms of how they view and experience their life-situation. This approach to the clinical encounter can lead to an improved mutual understanding of the situation and to feelings of trust, collaboration and partnership between PDNS, PwPD and CP.

The knowledge provided in this thesis should guide PDNS in tailoring support not only to the unique person's preferences but also to the person's current phase in this process towards adjustment and adaptation. If PDNS are well informed about the difficult emotional reactions and the feelings of lost identity and control in the period following diagnosis they can provide the appropriate emotional support needed. They can also and reassure PwPD and CP that they are always welcome to contact them for advice, information and support whenever needed. In the following phase, after initial reactions and shock, more education on PD is needed and advice on strategies to manage everyday life. Education and advice are viewed as vital aspects of PDNS support. It is in this phase of finding a new path in life, that SMIs are valued and appropriate as interventions and should be offered in clinical care.



The results of this thesis resulted in improved knowledge of self-management for PwPD and CP, and can be used in improving and adapting nursing services and support to PwPD and CP. The results can be used in developing a Swedish guideline specifying the PDNS professional competencies and work, to further clarify the role and competencies required in the clinical work of the PDNS. If such a guideline was developed, it could also help supervisors and policymakers in healthcare to identify and allocate the resources needed for high-quality PDNS nursing support.

## 12. FUTURE RESEARCH

The results of this thesis provided further knowledge of self-management of PD in everyday life for PwPD and CP, but also reveal several areas for future research. These include:

- Quantitative studies on the outcomes of SMIs using different questionnaires which target the proximal outcomes known to influence PwPD and CP, such as social connectedness, improved self-management abilities and self-efficacy. For dyadic interventions, it would be of interest to use questionnaires which investigate mutuality in the relationship.
- Investigating the need for, and appropriate ways of, providing SMIs to PwPD and CP in the later stages of the disease, where changes in cognition can constitute a barrier for learning and using some of the techniques traditionally used in SMIs.
- Developing and translating specific questionnaires targeted towards the care partners of persons affected by PD. For example, no questionnaire targeting caregiver burden has been tested or made available in Swedish.
- Mapping current practice, including facilitators and barriers for providing SMIs to support PwPD and CP in clinical care. This could also investigate other forms of SMI, perhaps delivered as individual interventions or to CP only, and compare them to the dyadic NPS.
- Further development of qualitative methods for investigating the outcomes of SMIs in healthcare. This could broaden understanding beyond quantitative evaluations, of how these interventions could be of benefit to healthcare for example affecting mutual understanding and shared decision-making.
- To improve understanding of how PDNS support should be tailored and delivered, in order to promote positive self-management strategies and feelings of self-efficacy, for persons to become actively involved in their own care. This might be particularly relevant investigating

how this can be achieved for PwPD without a CP or strong social connections, PwPD and CP with low literacy, and PwPD and CP who are finding it difficult to accept and manage PD.

- Investigating the cost-effectiveness of SMIs as well as PDNS support and care, to clarify whether these are beneficial in a health economical perspective.

## 13. CONCLUSIONS

In conclusion, the results presented in this thesis are the combined results of the three studies included. The results were acquired using qualitative thematic analysis through which three themes describing the process undergone by PwPD and CP in terms of accepting, adjusting and handling PD in everyday life were evident. The first theme “A changed reality” describes the initial reactions, including difficult feelings following a diagnosis of PD. These can involve a sense of lost control, an altered future and changed personal identity following the knowledge of PD. The second theme “Finding a new path” describes the new outlook on life adopted by PwPD and CP as they try to find strategies to handle the new situation. In this thesis data were collected from PwPD and CP who attended or previously had been participants in the NPS programme. The NPS was considered useful and was appreciated by participants. It was found to have positive outcomes on a personal level and in promoting communication in clinical care encounters. The techniques involved such as self-monitoring, were adopted and practised afterwards. The dyadic format used in the NPS and the opportunity to meet peers, added extra value to this intervention. The results are encouraging in terms of the potential use of the NPS alongside other interventions to provide the support required for PwPD and CP to manage life with PD. The third theme, “The companions” highlights the importance of support and social interaction in managing PD in everyday life. The spouse of PwPD often acts as their care partner, and managing PD is seen as a joint concern. They help each other in managing everyday life in the best interests of them both. For PwPD, this CP dyad was considered crucial. This indicates that support provided by healthcare professionals should be tailored to both PwPD and CP, and that special considerations should be given to PwPD who do not have the support of a CP. Other family members and close friends were also a source of support in the process of adjusting, accepting and managing PD in everyday life. Meeting persons in the same situation, and the formal support and care of healthcare professionals were identified as important to handle PD in everyday life throughout the disease trajectory.

PDNS working specifically to support PwPD and their CP will need to tailor support taking into account the pathophysiological disease trajectory, as well as the psychological processes involved in accepting and adjusting to PD. To guide nursing support in the clinical encounter, and tailor it to best fit the unique needs and wishes of each person or CP dyad, Dorothea Orem’s nursing theory may be useful as it aims for independent self-care and can incorporate the intrarelational assumptions of PCC.



# ACKNOWLEDGEMENTS

Engaging in PhD studies and the work resulting in this thesis have been inspirational and exciting. Throughout this long and sometimes rough journey, I have learned a lot and grown as a clinical PD nurse, researcher and person. I am so grateful to have had the opportunity to engage in a topic so close to my clinical work and on ideas sprung out of my own interests in the area. There have been many persons to support me and without whom this thesis could not have been possible. I would like to express my warmest gratitude to all of you.

Först av allt ett stort och varmt tack **till alla ni som lever med Parkinsons sjukdom** de **närstående** som har varit villiga att delta i de olika delstudierna. Tack också till alla **parkinsonspecialiserade sjuksköterskor och annan parkinsonspecialiserad personal** inom hälsoprofessionerna som varit delaktiga i att rekrytera deltagare till studierna samt genomföra Nationella Parkinsonskolan vid era respektive kliniker. Utan er medverkan och engagemang hade avhandlingen aldrig varit möjlig.

To my outstanding supervisors for your accessibility, professional knowledge, practical and intellectual support and input on my work. Thank you for your excellent guidance and patience!

**Carina Berterö**, my main-supervisor. For accepting me as a PhD student and for always believing in me. For sharing your extensive knowledge of qualitative methods. You have always been open to, and supportive of, my thoughts and ideas helping me figure out how to make them fit into a good research design without compromising the clinical perspective and applicability that you know is so important to me. Without you, I would never have had the courage to even start my doctoral studies.

**Peter Hagell**, my co-supervisor. For sharing your invaluable experience within the field of measurement scales, PD specific research and skills in writing scientific manuscripts. For supporting me in the confusing world of statistics and quantitative methods. For your patience in teaching me the principles of SPSS. For your friendship.

**Märta Sund-Levander**, my co-supervisor. For always being available and engaged. For your important thoughts and input on texts and manuscripts. Your always optimistic and supportive approach has helped me survive the bumpy road of PhD studies. I am so glad that you have been a part of our team.

**Nil Dizdar**, my co-supervisor. For introducing me into the fascinating area of movement disorders. For always encouraging me to develop my

clinical as well as scientific skills. For acknowledging the importance of multi-disciplinary care and nursing support for PwPD. For learning me everything I know about PD pathophysiology, symptomatology and medical treatments.

**Christoffer Rundgren** and **Susanna Sundelin** for taking on a great responsibility for the clinical care of PwPD and CP making it possible for me to focus on my PhD work.

**Ing-Mari Knutsson**, colleague and dear friend for all practical arrangements surrounding the provision of the NPS programme at Hälso pedagogiskt Forum, Region Östergötland. Also for your intellectual and emotional support in research and in life.

**All members of the movement disorders section and colleagues working in outpatient clinical care** at the department of Neurology, Linköping university hospital, for your support.

**Patrick Vigren**, head of department of Neurology Linköping University hospital. For acknowledging the importance of nursing research and for providing me the opportunity as a clinical nurse to proceed into the field of academic research.

To **all doctoral students** at the Department of Health, Medicine and Caring sciences for important input and educational seminars. A special thanks to **Jenny Drott** and **Helena Johansson** for your friendship and invaluable support.

**Annelie Dorsell-Svensson** for your enthusiastic work with illustrating the cover of this thesis. Happy colours and capturing the essence of this thesis. It is just perfect!

**Richard Nylander**, for patience and invaluable help with Word layout and formatting, help and troubleshooting.

**Martin Pettersson**, LiU tryck for help and assistance in preparing this thesis for print.

To my friends and colleagues in **Vårdföreningen Movement Disorders (VfMD)** for your support and friendship. **Arja, Maria, Mia, Caroline, Michaela**. And a very special thanks to **Karin Persliden** for always being the greatest of friends, providing me a place to stay and enough coffee to get me through the doctoral courses at KI.

To my awesome friends **Johanna, Anders, Madde, Tommy, Linda, Peter, Pia, Anna-Sara, Anton, Maria, Pelle, Anna, Ola, Diana, Pia, Maria, Jonas, Jenny, Erik, Lena, Lisa** and **Andreas**. Looking forward to spending even more awesome time with you now for laughs, travels and good drinks and dinners!

To the best mother **Sisko** for your love and support in every and any way you can imagine. Thank you for always loving me and encouraging me. For raising me to believe in myself and to follow my dreams.

To my late father **Leif** for your calm and loving support. For giving my neuro-nursing interest direction and meaning. For the insights in what it is like to handle everyday life with PD.

The most brilliant and loved sister **Eva**. Always one step ahead, inspiring me to follow. Her work made me realize that PhD studies was possible also in my profession. To **Niklas** and to **Olivia** for always making me smile!

To my lovely daughters **Majken** and **Vera**. I am so proud and grateful to be your mother. You mean the world to me! Thank you for all the good times spent with you and the horses, forcing me away from the computer for some exercise and peace of mind!

To **Isak** and **Nora** for enriching life and expanding family.

To **Micke** for sharing everything in life with me. You always stand by my side to provide invaluable support in life and in work. You listen and give good advice when things are tough and celebrate and rejoice with me in the good times. Thank you for your love and your patience. I am so grateful to have you in my life.

Thank you all!  
*Carina Hellqvist*





## REFERENCES

- A'Campo, L.E., Spliethoff-Kamminga, N.G., Macht, M., The EduPark Consortium, & Roos, R.A. (2010a). Caregiver education in Parkinson's disease: formative evaluation of a standardized program in seven European countries. *Qual Life Res.*, 19, 55-64. doi:10.1007/s11136-009-9559-y
- A'Campo, L.E., Wekking, E.M., Spliethoff-Kamminga, N.G., Le Cessie, S., & Roos, R.A. (2010b). The benefits of a standardized patient education program for patients with Parkinson's disease and their caregivers. *Parkinsonism & Related Disorders*, 16, 89–95. doi:10.1016/j.parkreldis.2009.07.009
- A'Campo, L.E., Spliethoff-Kamminga, N.G., Stijnen, T., & Roos, R.A. (2011a). Treatment effect modifiers for the patient education programme for Parkinson's Disease. *Int J Clin Pract.*, 66, 77-83. doi:10.1111/j.1742-1241.2011.02791.x.
- A'Campo, L.E., Spliethoff-Kamminga, N.G., & Roos, R.A. (2011b). An evaluation of the patient education programme for Parkinson's disease in clinical practice. *International Journal of Clinical Practice*, 65, 1173–1179. doi:10.1111/j.1742-1241.2011.02765.x
- Ambrosio, L., Portillo, M.C., Rodriguez-Blazquez, C., Rojo, J.M., Martinez-Martin, P., & EC-PC Validation Group. (2019). Influencing factors when living with Parkinson's disease: A cross-sectional study. *J Clin Nurs*. 28(17-18), 3168–3176. doi:10.1111/jocn.14868
- American Geriatrics Society Expert Panel on Person-Centered Care. (2016). Person-Centered Care: A Definition and Essential Elements. *J Am Geriatr Soc.*, 64, 15– 18.
- Andresen, E.M. (2000). Criteria for assessing the tools of disability outcomes research. *Arch Phys Med Rehabil.*, 81(12), 15–20. doi:10.1053/apmr.2000.20619
- Armstrong, M.J., & Okun, M.S. (2020). Diagnosis and Treatment of Parkinson Disease: A Review. *JAMA.*, 323 (6), 548–560. doi:10.1001/jama.2019.22360
- Bandura, A. (1982). "Self-efficacy mechanism in human agency". *American Psychologist*, 37(2),122–147. doi:10.1037/0003-066X.37.2.122
- Bandura, A. (1994). "*Self Efficacy*" in Encyclopedia of Human Behavior. New York Academic Press.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York W.H. Freeman.

- Banfield, B.E. (2011). Nursing Agency: The link between nursing science and nursing practice. *Nurs. Sci. Q.*, 24(1), 42-47. doi: 10.1177/0894318410389060.
- Bashi, N., Fatehi, F., Fallah, M., Walters, D., & Karunanithi, M. (2018). Self-Management Education Through mHealth: Review of Strategies and Structures. *JMIR Mhealth Uhealth.*,6(10), e10771. doi: [10.2196/10771](https://doi.org/10.2196/10771)
- Beaudet, L., Ducharme, F., L'Écuyer, N., Choinard, S., Jodoin, N., & Panisset, M. (2015). Development and evaluation of a dyadic intervention for elderly couples living with moderate stage Parkinson disease. *Applied Nurs Res.*, 28(4), 21-7. doi: [10.1016/j.apnr.2015.02.004](https://doi.org/10.1016/j.apnr.2015.02.004)
- Bédard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden interview: a new short version and screening version. *Gerontologist*, 41(5), 652-657. doi: [10.1093/geront/41.5.652](https://doi.org/10.1093/geront/41.5.652)
- Benge, J. F., Heemsbergen, T., Nelson, R. A., Konesheck, D. O., Konesheck, B., & Aaron, C. S. (2018). Toward patient-centered outcomes for cognitive evaluations: the perspective of those affected by Parkinson's disease. *The Clinical neuropsychologist*, 32(7), 1303–1318. doi:10.1080/13854046.2017.1414884
- Bennett, P. N., Wang, W., Moore, M., & Nagle, C. (2017). Care partner: A concept analysis. *Nursing outlook*, 65(2), 184–194. doi:10.1016/j.outlook.2016.11.005
- Berg, C.A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult lifespan. *Psychol. Bul.*, 133, 920-54. doi: 10.1037/0033-2909.133.6.920
- Berger, S., Chen, T., Eldridge, J., Thomas, C.A., Habermann, B., & Tickle-Degnen, L. (2019). The self-management balancing act of spousal care partners in the case of Parkinson's disease. *Disabil Rehabil.*,41(8)887–895. doi:10.1080/09638288.2017.1413427
- Bhidayasiri, R., Chaudhuri, K.R., LeWitt, P., Martin, A., Boonpang, K., & van Laar, T. (2015). Effective delivery of apomorphine in the management of Parkinson disease: practical considerations for clinicians and Parkinson nurses. *Clin Neuropharmacol.*, 38(3),89-103. doi: 10.1097/WNF.0000000000000082.
- Blok, A. C. (2017). A Middle-Range Explanatory Theory of Self-Management Behavior for Collaborative Research and Practice. *Nurs Forum*, 52,138-146. doi:[10.1111/nuf.12169](https://doi.org/10.1111/nuf.12169)
- Braak, H., Del Tredici, K., Rüb, U., de Vos, R.A., Jansen Steur, E.N., & Braak, E. (2003). Staging of brain pathology related to sporadic Parkinson's disease. *Neurobiol Aging*. 24,2,197–211. doi:10.1016/s0197-4580(02)00065-9
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)

- Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers?. *International journal of qualitative studies on health and well-being*, 9, 26152. doi:10.3402/qhw.v9.26152
- Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2017). Elaboration of the Gothenburg model of Person-centred care. *Health expectations*, 20(3), 407-418. doi: 10.1111/hex.12468
- Brown, R.G., Dittner, A., Findely, L., & Wessely, S.C. (2005). The Parkinson fatigue scale. *Parkinsonism and related disorders*, 11(1), 49-55. doi:10.1016/j.parkreldis.2004.07.007
- Buetow, S.A., Martínez-Martín, P., Hirsch, M.A., & Okun, M.S. (2016). Beyond patient-centered care: person-centred care for Parkinson's disease. *NPJ Parkinsons Dis.*, 2, 16019. doi:10.1038/npjparkd.2016.19
- Burgess, P.W., & Alderman, N. (2004). *Executive dysfunction*. In: Goldstein L.H., McNeil J.E., eds. *Clinical Neuropsychology: A Practical Guide to Assessment and Management for Clinicians*. Chichester John Wiley.
- Burström, K., Sun, S., Gertdham, U., Henriksson, M., Johannesson, M., Levin, L-Å., & Zethraeus, N. (2014). Swedish experience-based value sets for EQ-5D health states. *Qual. Life Res.*, 23, 431-442. doi: 10.1007/s11136-013-0496-4.
- Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488–507. doi: 10.1177/1468794113490718
- Campbell, J. D., Assanand, S., & Paula, A. D. (2003). The structure of the self-concept and its relation to psychological adjustment. *Journal of Personality*, 71, 115–140. doi:10.1111/1467-6494.t01-1-00002.
- Carlborg, C. (2013 a). The new Swedish national Parkinson School can make life simpler and more enjoyable. (in Swedish) *Parkinsonjournalen*, 3, 18-20. <https://www.parkinsonforbundet.se/meny2/Information/Parkinsonjournalen>.
- Carlborg, C. (2013 b). Pilottesting of the Swedish National Parkinson School –“Meeting others equally important as the knowledge itself”. (in Swedish) *Parkinsonjournalen*, 4, 18-20. <https://www.parkinsonforbundet.se/meny2/Information/Parkinsonjournalen>
- Charmaz, K. (1995). The body, identity and self: adapting to impairment. *Sociol Q.*, 36 (4), 657-80. doi: 10.1111/j.1533-8525.1995.tb00459.x
- Chenoweth, L., Gallagher, R., Sheriff, J.N., Donoghue, J., & Stein-Parbury, J. (2008). Factors supporting self-management in Parkinson's disease: implications for nursing practice. *Int J Older People Nurs.*, 3(3), 187–193. doi:10.1111/j.1748-3743.2008.00123.x
- Chlund, M., Bergmann, F., Guthlin, C., Schnoor, H., Larisch, A., & Eggert, K. (2016). Patient education for patients with Parkinson's disease: A randomized controlled trial. *Basal Ganglia*, 6(1), 25-30. doi: 10.1016/j.baga.2015.11.004

- Dickson, D.W., Braak, H., Duda, J.E., Duyckaerts, C., Gasser, T., Halliday, G.M., Hardy, J., Leverntz, J.B., Del Tredici, K., Wszolek, Z.W., & Litvan, I. (2009). Neuropathological assessment of Parkinson's disease: refining the diagnostic criteria *Lancet Neurol.*,8(12),1150–1157. doi:10.1016/S1474-4422(09)70238-8
- Dolan, P. (1995). Modeling Valuations for EuroQol Health States. *Medical Care*, 35(11), 1095-1108. doi:10.1097/00005650-199711000-00002
- Dorsey, E. R., & Bloem, B. R. (2018). The Parkinson Pandemic-A Call to Action. *JAMA neurology*, 75(1), 9–10. doi: 10.1001/jamaneurol.2017.3299
- Eilers, D. (2013). What's in a word--caregiver or care partner? *Nephrology nursing journal: journal of the American Nephrology Nurses' Association*, 40(1), 61–62.
- Ekman, I., Swendberg, K., Taft, C., Lindseth, A., Norberg, A., Bring, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I-L., Kjellgren, K., Lidén, E., Öhlen, J., Olsson, L-E., Rosén, H., Rydmark, M., & Stibrandt Sunnerhagen, K. (2011). Person-centred care-ready for prime time. *European Journal of Cardiovascular Nursing*. 10(4), 248-251. doi: [10.1016/j.ejcnurse.2011.06.008](https://doi.org/10.1016/j.ejcnurse.2011.06.008)
- Ekman i red. (2014). Personcentrering inom hälso- och sjukvård. Från filosofi till praktik. Liber, Stockholm
- Eller, L. S., Lev, E. L., Yuan, C., & Watkins, A. V. (2018). Describing Self-Care Self-Efficacy: Definition, Measurement, Outcomes, and Implications. *Int J Nurs Terminol Knowledge*, 29: 38-48. doi:10.1111/2047-3095.1214
- Ellis, T., & Rochester, L. (2018). Mobilizing Parkinson's Disease: The Future of Exercise. *Journal of Parkinson's disease*, 8(s1), S95–S100. doi:10.3233/JPD-181489
- EuroQol Group. (1990). Euro Qol- a new facility for the measurement of health-related quality of life. *Health Policy*, 16 (3), 199-208. doi:10.1016/0168-8510(90)90421-9
- Eygelshoven, S., van den Hout, A., Tucha, L., Fuermaier, A.B.M., Bangma, D.F., Thome, J., Lobbestael, J., Tucha, O., & Koerts, J. (2017). Are non-demented patients with Parkinson's disease able to decide about their own treatment?. *Parkinsonism Relat Disord.* ,38,48–53. doi:10.1016/j.parkreldis.2017.02.021
- Faul, F., Erdfelder, E., Lang, A-G., & Buchner, A. (2007). G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39(2), 175-191. doi: [10.3758/bf03193146](https://doi.org/10.3758/bf03193146)
- Fereshtenejad, S-M., & Lökk, J. (2014). Active aging for individuals with Parkinson's Disease: Definitions, Literature review, and Models. *Parkinsons Dis.* 2014:739718. doi:10.1155/2014/739718

- Flick, U., von Kardoff, E. & Steinke, I. red. (2004). *A companion to Qualitative research*. London, Sage Publications.
- Fowler, J., Jarvis, P., & Chevannes, M. (2013). *Practical Statistics for Nursing and Health Care*. John Wiley & Sons.
- Fram, S. M. (2013). The Constant Comparative Analysis Method Outside of Grounded Theory. *The Qualitative Report*, 1(18), 1-25. Retrieved from <https://nsuworks.nova.edu/tqr/vol18/iss1/1>
- Fugl-Meyer, A.R., Melin, R., & Fugl-Meyer, K.S. (2002). Life satisfaction in 18- to 64-year-old Swedes: in relation to gender, age, partner and immigrant status. *J Rehabil Med.*, 34 (5), 239–46. doi:[10.1080/165019702760279242](https://doi.org/10.1080/165019702760279242)
- GBD 2016 Parkinson’s Disease Collaborators. (2018). Global, regional, and national burden of Parkinson’s disease 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurology*, 17 (11), 939-953. doi:[10.1016/S1474-4422\(18\)302953](https://doi.org/10.1016/S1474-4422(18)302953)
- General Data Protection Regulation (GDPR) (EU) 2016/679. (2016). <https://eur-lex.europa.eu/eli/reg/2016/679/oj>
- Glaser, B.G. (1965). The constant comparative method of Qualitative Analysis. *Social Problems*, 12, 436-445. doi: [10.2307/798843](https://doi.org/10.2307/798843)
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in methodology of grounded theory*. Mill Valley, CA: Sociological Press
- Goetz, C.G., Poewe, W., Rascol, O., Sampaio, C., Stebbins, G.T., Counsell, C., Gildi, N., Holloway, R.G., Moore, C.G., Wenning, G.K., Yahr, M.D., & Seidl, L. (2004). Movement Disorder Society Task Force report on the Hoehn and Yahr staging scale: status and recommendations. *Mov Disord.*, 19(9), 1020–1028. doi:[10.1002/mds.20213](https://doi.org/10.1002/mds.20213)
- Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self-and family management of chronic conditons. *Nursing Outlook*, 54(5), 278-286. doi: [10.1016/j.outlook.2006.06.004](https://doi.org/10.1016/j.outlook.2006.06.004)
- Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. (2015). A revised self-and family management framework. *Nursing Outlook*, 63(2), 162-170. doi: [10.1016/j.outlook.2014.10.003](https://doi.org/10.1016/j.outlook.2014.10.003)
- Guba, E.G., & Lincoln, Y.S. (1994). *Handbook of qualitative research*. Thousand Oaks: Sage, 1994.
- Gustafsson, H., Nordström, P., Strähle, S., & Nordström, A. (2015). Parkinson’s Disease: a population-based investigation of life satisfaction and employment. *J Rehabil Med.*, 47(1), 5-51. doi: [10.2340/16501977-1884](https://doi.org/10.2340/16501977-1884)
- Haahr, A., Kirkevold, M., Hall, E.O., & Østergaard, K. (2011). Living with advanced Parkinson’s disease: a constant struggle with unpredictability. *Journal of Advanced Nursing*, 67: 408-417. doi:[10.1111/j.1365-2648.2010.05459.x](https://doi.org/10.1111/j.1365-2648.2010.05459.x)

- Habermann, B., & Shin, J.Y. (2017). Preferences and concerns for care needs in advanced Parkinson's disease: a qualitative study of couples. *J Clin Nurs*, 26,1650-1656. doi:[10.1111/jocn.13565](https://doi.org/10.1111/jocn.13565)
- Hagell, P. (2007). Nursing and multidisciplinary interventions for Parkinson's Disease: What is the evidence? *Parkinsonism and related Disorders*. 13, 501-508. doi: [10.1016/S1353-8020\(08\)70057-9](https://doi.org/10.1016/S1353-8020(08)70057-9)
- Hagell, P., Rosblom, T., & Pålhagen, S. (2012). A Swedish version of the 16- item Parkinson Fatigue scale (PFS-16). *Acta Neurologica Scandinavica*, 125 (4), 288-292. doi:[10.1111/j.1600-0404.2011.01560.x](https://doi.org/10.1111/j.1600-0404.2011.01560.x)
- Hagell, P., Alvariza, A., Westergren, A., & Årestedt, K. (2017). Assessment of Burden among Family Caregivers with Parkinson's Disease using the Zarit Burden Interview. *J Pain Symptom Manage.*,53(2), 272-279. doi: [10.1016/j.jpainsymman.2016.09.007](https://doi.org/10.1016/j.jpainsymman.2016.09.007).
- Handley, M., Bunn, F., Lynch, J., & Goodman, C. (2019). Using non-participant observation to uncover mechanisms: Insights from a realist evaluation. *Evaluation*. 1-14. doi:[10.1177/1356389019869036](https://doi.org/10.1177/1356389019869036)
- Hassan, A., Wu, S.S., Schmidt, P., Malaty, I.A., Dai, Y.F., Miyasaki, J.M., & Okun, S. (2012). What are the issues facing Parkinson's disease patients at ten years of disease and beyond? Data from the NPF-QII study. *Parkinsonism Relat Disord.* ,18 (3), 10–14. doi:[10.1016/j.parkreldis.2012.06.014](https://doi.org/10.1016/j.parkreldis.2012.06.014)
- Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence-based nursing*, 18(3), 66–67. doi: [10.1136/eb-2015-102129](https://doi.org/10.1136/eb-2015-102129)
- Helgeson, V., & Zajdel, M. (2017). Adjusting to Chronic Health Conditions. *Annu. Rev. Psychol.*, 68, 545-71. doi: [10.1146/annurev-psych-010416-044014](https://doi.org/10.1146/annurev-psych-010416-044014)
- Hellqvist, C., & Berterö, C. (2015). Support supplied by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses. *Applied nursing research : ANR*, 28(2), 86–91. doi:[10.1016/j.apnr.2014.12.008](https://doi.org/10.1016/j.apnr.2014.12.008)
- Hoehn, M.M., & Yahr, M.D. (1967). Parkinsonism: onset, progression and mortality. *Neurology*, 17(5),427–42. dpo:[10.1212/wnl.17.5.427](https://doi.org/10.1212/wnl.17.5.427)
- Håkansson, C., Dahlin-Ivanoff, S., & Sonn, U. (2006). Achieving balance in everyday life. *Journal of Occupational Science*, 13, 74–82. doi:[10.1080/14427591.2006.9686572](https://doi.org/10.1080/14427591.2006.9686572)
- Håkansson Eklund, J.H., Holmström, I., Kumlin, T., Kaminsky, E., Skoglund, K., Högländer, J., Sundler, A.J., Condén, E., & Summer Meranius, M. (2019). Same same or different? A review of reviews of person-centred and patient-centered care. *Patient Education and counselling*. 102(1), 3-11. doi:[10.1016/j.pec.2018.08.029](https://doi.org/10.1016/j.pec.2018.08.029)

- Jenkinson, C., Fitzpatrick, R., Peto, V., Greenhall, R., & Hyman, N. (1997). The PDQ-8: development and validation of a short-form Parkinson's disease Questionnaire. *Psychol Health*, 12(6), 805-814. doi: [10.1080/08870449708406741](https://doi.org/10.1080/08870449708406741)
- Jonkman, N.H., Schuurmans, M.J., Jaarsma, T., Shortridge-Baggett, L.M., Hoes, A.W., & Trappenburg, J.C.A. (2016). Self-mangement interventions: Proposal and validation of a new operational definition. *Jnl. Clin Epid.*, 80, 34-42. doi: [10.1016/j.jclinepi.2016.08.001](https://doi.org/10.1016/j.jclinepi.2016.08.001)
- Judkins-Cohn, T. M., Kielwasser-Withrow, K., Owen, M., & Ward, J. (2014). Ethical principles of informed consent: exploring nurses' dual role of care provider and researcher. *Journal of continuing education in nursing*, 45(1), 35–42. doi: [10.3928/00220124-20131223-03](https://doi.org/10.3928/00220124-20131223-03)
- Kadastik-Eerme, L., Rosenthal, M., Muldmaa, M., & Taba, P. (2015). Health-related quality of life i Parkinson's disease: a cross-sectional study focusing on non-motor symtoms. *Health Qual. Life outcomes.*, 20,13:83. doi: [10.1186/s12955-015-0281-x](https://doi.org/10.1186/s12955-015-0281-x)
- Kalia, L.V., & Lang, A.E. (2015). Parkinson's disease. *Lancet*, 386(9996),896–912. doi: [10.1016/S0140-6736\(14\)61393-3](https://doi.org/10.1016/S0140-6736(14)61393-3)
- Kang, M. Y., & Ellis-Hill, C. (2015). How do people live life successfully with Parkinson's disease? *Journal of clinical nursing*, 24(15-16), 2314–2322. doi: [10.1111/jocn.12819](https://doi.org/10.1111/jocn.12819)
- Karlstedt, M., Fereshtehnejad, S.M., Aarsland, D., & Lökk, J. (2017). Determinants of Dyadic Relationship and Its Psychosocial Impact in Patients with Parkinson's Disease and Their Spouses. *Parkinsons Dis.* 2017,4697052. doi: [10.1155/2017/4697052](https://doi.org/10.1155/2017/4697052)
- Kessler, D., & Liddy, C. (2017). Self-management support programs for persons with Parkinson's Disease: An integrative review. *Patient education and counseling*, 100(10), 1787-95. doi: [10.1016/j.pec.2017.04.011](https://doi.org/10.1016/j.pec.2017.04.011)
- Kirkwood, B.R., & Sterne, J.A.C. (2003). *Essential Medical Statistics*, John Wiley & Sons.
- Kleiner-Fisman, G., Gryfe, P., & Naglie, G. (2013). A Patient-Based Needs Assessment for Living Well with Parkinson Disease: Implementation via Nominal Group Technique. *Parkinson's disease*, 2013, 974964. doi: [10.1155/2013/974964](https://doi.org/10.1155/2013/974964).
- Kristensson Uggla, B. (2011). *Homo Capax texter av Paul Ricoeur om etik och filosofisk antropologi I urval av Bengt Kristensson Uggla*. Daidalos.
- Kristensson Uggla, B. (2014). Personfilosofi-filosofiska utgångspunkter för personcentrering inom hälso-och sjukvård. In I. Ekman (Eds.) *Personcentrerinig inom hälso-och sjukvård. Från filosofi till praktik*. (pp 21-62). Liber.



- Kudlicka, A., Clare, L., & Hindle, J. V. (2011). Executive functions in Parkinson's disease: systematic review and meta-analysis. *Movement disorders : official journal of the Movement Disorder Society*, 26(13), 2305–2315. doi:10.1002/mds.23868
- Kumlien, C., Miller, M., Fagerström, C., & Hagell, P. (2018). Evaluation of Self-Management Program Outcomes: Adaption and testing of a Swedish Version of the Health Education Impact Questionnaire (heiQ). *J. Applied Meas.*, 19(3), 303-319. PMID: 30169337
- Kvale, S. (1996). *InterViews. An introduction to Qualitative research interviewing*. Sage publications.
- Kvale, S. (2009). *Interviews: learning the crafts of qualitative research*. Sage publications.
- Law on research ethics concerning humans (in Swedish; Lag om etikprövning av forskning som avser människor) (SFS 2003:460). [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2003460-om-etikprovning-av-forskning-som\\_sfs-2003-460](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2003460-om-etikprovning-av-forskning-som_sfs-2003-460)
- Lee, G. B., Woo, H., Lee, S. Y., Cheon, S. M., & Kim, J. W. (2019). The burden of care and the understanding of disease in Parkinson's disease. *PloS one*, 14(5), e0217581. doi:10.1371/journal.pone.0217581
- Lennaerts, H., Groot, M., Rood, B., Gilissen, K., Tulp, H., van Wensen, E., Munneke, M., van Laar, T., & Bloem, B. R. (2017). A Guideline for Parkinson's Disease Nurse Specialists, with Recommendations for Clinical Practice. *Journal of Parkinson's disease*, 7(4), 749–754. doi: 10.3233/JPD-171195
- Levine, C., Faden, R., Grady, C., Hammerschmidt, D., Eckenwiler, L., Sugarman, J., & Consortium to Examine Clinical Research Ethics. (2004). The limitations of "vulnerability" as a protection for human research participants. *The American journal of bioethics : AJOB*, 4(3), 44–49. doi: 10.1080/15265160490497083
- Lim K.E., Kim S.R., Sung Y.H., Oh S.Y., Kim M.S. & Chung S.J. (2019). Factors influencing self-management in Parkinson's disease: A cross-sectional study. *Geriatr Nurs*. 2019; 19, 30532-4. doi:10.1016/j.geri-nurse.2019.10.005
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Thousand Oaks, CA: Sage.
- Lorig, K. R., & Holman, H.R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26,(1).1–7. doi: 10.1207/S15324796ABM2601\_01
- Lune, H., & Berg, B.L. (2017). *Qualitative research Methods for the social sciences. 9<sup>th</sup> edition*. Pearson education Limited.

- Luo, N., Tan, L., Zhao, Y., Lau, P-N. , Au, W-L., & Li, S.C. (2009). Determination of the Longitudinal Validity and Minimally Important Difference of the 8 – item Parkinson’s Disease Questionnaire (PDQ-8). *Movement Disorders*, 24(2),183-187. doi:10.1002/mds.22240
- Macht, M., Gerlich, C., Ellgring, H., Schradi, M., Rusiñol, A. B., Crespo, M., Prats, A., Viemerö, V., Lankinen, A., Bitti, P. E., Candini, L., Spliethoff-Kamminga, N., de Vreugd, J., Simons, G., Pasqualini, M. S., Thompson, S. B., Taba, P., Krikmann, U., & Kanarik, E. (2007). Patient education in Parkinson's disease: Formative evaluation of a standardized programme in seven European countries. *Patient education and counseling*, 65(2), 245–252. doi:10.1016/j.pec.2006.08.005
- MacMahon, D. G. (1999). Parkinson's disease nurse specialists: an important role in disease management. *Neurology*, 52(7 Suppl 3), 21–25. PMID: 10227607
- Maffoni, M., Pierobon, A., Frazzitta, G., Callegari, S., & Giardini, A. (2019). Living with Parkinson's-past, present and future: a qualitative study of the subjective perspective. *Br J Nurs.* ,28(12),764–771. doi:10.12968/bjon.2019.28.12.764
- Mahler, L. A., Ramig, L. O., & Fox, C. (2015). Evidence-based treatment of voice and speech disorders in Parkinson disease. *Current opinion in otolaryngology & head and neck surgery*, 23(3), 209–215. doi:10.1097/MOO.000000000000015
- Mansouri, A., Taslimi, S., Badhiwala, J. H., Witiw, C. D., Nassiri, F., Odekerken, V., De Bie, R., Kalia, S. K., Hodaie, M., Munhoz, R. P., Fasano, A., & Lozano, A. M. (2018). Deep brain stimulation for Parkinson's disease: meta-analysis of results of randomized trials at varying lengths of follow-up. *Journal of neurosurgery*, 128(4), 1199–1213. doi:10.3171/2016.11.JNS16715
- Martire, L. M., & Helgeson, V. S. (2017). Close relationships and the management of chronic illness: Associations and interventions. *The American psychologist*, 72(6), 601–612. doi:10.1037/amp0000066
- Matarese, M., Lommi, M., DeMarinis, M. G., & Riegel, B. (2018). A Systematic Review and Integration of Concept Analyses of Self-Care and Related Concepts. *Journal of Nursing Scholarship*, 50, 296-305. doi:10.1111/jnu.12385
- McCormack, B., & McCance, T. (2010) *Person-centred Nursing: Theory and practice*. Wiley Blackwell.
- McCormack, B., & McCance, B. (2017). *Person-centred Practice in Nursing and healthcare. Theory and practice*. Wiley Blackwell.
- McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2011). Living and coping with Parkinson’s disease: Perceptions of informal carers. *Palliative Medicine*, 25(2), 177–182. doi:10.1177/0269216310385604

- Milbourn, B.T., McNamara, B.A., & Buchanan, A.J. (2014). Understanding the episodic everyday of disrupted lives: scoping the occupational therapy literature. *Can J Occup Ther.*, 81,3,144–153. doi:10.1177/0008417414533315
- Morea, J. M., Friend, R., & Bennett, R. M. (2008). Conceptualizing and measuring illness self-concept: A comparison with self-esteem and optimism in predicting fibromyalgia adjustment. *Research in Nursing & Health*, 31, 563–575. doi: [10.1002/nur.20294](https://doi.org/10.1002/nur.20294).
- Morgan, H. M., Entwistle, V. A., Cribb, A. , Christmas, S. , Owens, J. , Skea, Z. C., & Watt, I. S. (2017). We need to talk about purpose: a critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expect.*, 20,243-259. doi:[10.1111/hex.12453](https://doi.org/10.1111/hex.12453)
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, 13–22. doi: [10.1177/160940690200100202](https://doi.org/10.1177/160940690200100202)
- Mosely, P.E., Moodie, R., & Dissanayaka, N. (2017). Caregiver Burden in Parkinson Disease: A critical review of recent literature. *J.Geriatri Psychiatry Neurol.*, 30,235-252. doi: [10.1177/0891988717720302](https://doi.org/10.1177/0891988717720302)
- Murphy, R., Tubridy, N., Kevelighan, H., & O'Riordan, S. (2013). Parkinson's disease: how is employment affected?. *Irish journal of medical science*, 182(3), 415–419. doi:10.1007/s11845-013-0902-5
- Nag, N., & Jelinek, G. (2019). A Narrative Review of Lifestyle Factors Associated with Parkinson's Disease Risk and Progression. *Neurodegener Dis.*, 19,51-59. doi: [10.1159/000502292](https://doi.org/10.1159/000502292)
- Navarta-Sánchez, M. V., Caparrós, N., Riverol Fernández, M., Díaz De Cerio Ayesa, S., Ursúa Sesma, M. E., & Portillo, M. C. (2017). Core elements to understand and improve coping with Parkinson's disease in patients and family carers: A focus group study. *Journal of advanced nursing*, 73(11), 2609–2621. doi:10.1111/jan.13335
- Nilsson, M.H., Iwarsson, S., Thordardottir, B., & Haak, M. (2015). Barriers and Facilitators for Participation in People with Parkinson's Disease. *J Parkinsons Dis.*, 5(4),983–992. doi:10.3233/JPD-150631
- Nilsson, M., Bladh, S., & Hagell, P. (2013). Fatigue in Parkinson's Disease: Measurement Properties of a Generic and a Condition-Specific Rating Scale. *Journal of Pain and Symptom Management*, 46, 737-746. doi:[10.1016/j.jpainsymman.2012.11.004](https://doi.org/10.1016/j.jpainsymman.2012.11.004)
- Orem, D., Taylor, S., & Mc Laughlin Renpenning, K. (2001). *Nursing Concepts of practice 6<sup>th</sup> ed.* Mosby.
- Orem, D. (1991). *Nursing: concepts of practice.4th ed.* Mosby.

- Oris, L., Luyckx, K., Rassart, J., Goubert, L., Goossens, E., Apers, S., Arat, S., Vandenberghe, J., Westhovens, R., & Moons, P. (2018). Illness Identity in Adults with a Chronic Illness. *Journal of clinical psychology in medical settings*, 25(4), 429–440. doi: 10.1007/s10880-018-9552-0
- Osborne, R.H., Elsworth, G.R., & Withfield, K. (2007). The Health Education Impact Questionnaire (HeiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient education and Counseling*, 66 (2), 192-201. doi: [10.1016/j.pec.2006.12.002](https://doi.org/10.1016/j.pec.2006.12.002)
- Paillard, T., Rolland, Y., & de Souto Barreto, P. (2015). Protective Effects of Physical Exercise in Alzheimer's Disease and Parkinson's Disease: A Narrative Review. *J Clin Neurol.* ,11,3, 212-219. doi : [10.3988/jcn.2015.11.3.212](https://doi.org/10.3988/jcn.2015.11.3.212)
- Pappa, K., Doty, T., Taff, S., Kneipmann, K., & Foster, E. (2017). Self-management program participation and social support in Parkinson's disease: Mixed methods evaluation. *Phys Occup Ther Geriatr.*, 35(2), 81-89. doi: [10.1080/02703181.2017.1288673](https://doi.org/10.1080/02703181.2017.1288673)
- Park, E. O., & Schumacher, K. L. (2014). The state of the science of family caregiver-care receiver mutuality: a systematic review. *Nursing inquiry*, 21(2), 140–152. doi: 10.1111/nin.12032
- Parkinson, J. (1817). *An Essay of the Shaking Palsy*. Whittingham and Rowland.
- Parkinsons UK. (2016). Competencies: A competency framework for nurses working in Parkinson's disease management. Retrieved 200205 at : <https://www.rcn.org.uk/professional-development/publications/pub-005584>
- Pedersen, S. W., Suedmeyer, M., Liu, L. W., Domagk, D., Forbes, A., Bergmann, L., Onuk, K., Yegin, A., & van Laar, T. (2017). The role and structure of the multidisciplinary team in the management of advanced Parkinson's disease with a focus on the use of levodopa-carbidopa intestinal gel. *Journal of multidisciplinary healthcare*, 10, 13–27. doi:10.2147/JMDH.S111369
- Perepezko, K., Hinkle, J. T., Shepard, M. D., Fischer, N., Broen, M., Leentjens, A., Gallo, J. J., & Pontone, G. M. (2019). Social role functioning in Parkinson's disease: A mixed-methods systematic review. *International journal of geriatric psychiatry*, 34(8), 1128–1138. doi: [10.1002/gps.5137](https://doi.org/10.1002/gps.5137)
- Petrie, A., & Sabin, C. (2013). *Medical statistics at a glance. 3rd edition*. Wiley -Blackwell.
- Polit, D.F., & Beck, C.T. (2014). *Essentials of nursing research 8<sup>th</sup> edition. Appraising evidence for nursing practice*. Wolters Kluwer Lippincott Williams & Wilkins.

- Polak, L., & Green, J. (2016). Using joint interviews to add analytic value. *Qualitative research*, 26(12), 1638-48. doi: 10.1177/1049732315580103
- Postuma, R. B., Berg, D., Stern, M., Poewe, W., Olanow, C. W., Oertel, W., Obeso, J., Marek, K., Litvan, I., Lang, A. E., Halliday, G., Goetz, C. G., Gasser, T., Dubois, B., Chan, P., Bloem, B. R., Adler, C. H., & Deuschl, G. (2015). MDS clinical diagnostic criteria for Parkinson's disease. *Movement disorders : official journal of the Movement Disorder Society*, 30(12), 1591-1601. doi:10.1002/mds.26424
- Radder, D.L.M., Sturkenboom, I.H., van Nimwegen, M., Keus, S.H., Bloem, B.R., & de Vries, N.M. (2017). Physical therapy and occupational therapy in Parkinson's disease. *Int J Neurosci.*,127(10),930-943. doi:10.1080/00207454.2016.1275617
- Ramaswamy, B., Jones, J., & Carroll, C. (2018). Exercise for people with Parkinson's: a practical approach. *Practical Neurology* , 18:399-406. doi: 10.1136/practneurol-2018-001930
- Ravenek, M., Rudman, D. L., Jenkins, M. E., & Spaulding, S. (2017). Understanding uncertainty in young-onset Parkinson disease. *Chronic illness*, 13(4), 288-298. doi:10.1177/1742395317694699
- Rees, S., & Williams, A. (2009). Promoting and supporting self-management for adults living in the community with physical chronic illness: A systematic review of the meaningfulness of the patient-practitioner encounter. *JBi Libr Syst rev.*,7(13), 492-582. doi: [10.11124/01938924-200907130-00001](https://doi.org/10.11124/01938924-200907130-00001)
- Resnik, D. B. (2019). Are Payments to Human Research Subjects Ethically Suspect?. *Journal of clinical research best practices*, 15(6), 2374. PMID: PMC7059779
- Reynolds, H., Wilson-Barnett, J., & Richardson, G. (2000). Evaluation of the role of the Parkinson's disease nurse specialist. *International journal of nursing studies*, 37(4), 337-349. doi:10.1016/s0020-7489(00)00013-4.
- Richard, A.A., & Shea, K. (2011). Delineation of self-care and associated concepts. *Journal of Nursing Scholarship*,43,255-264. doi:10.1111/j.1547-5069.2011.01404.x
- Ricoeur, P. (1992). *Oneself as another*. Translation by Kathleen Blame. University of Chicago press.
- Roger, K.S., & Medved, M.I. (2010). Living with Parkinson's disease-managing identity together. *Int J Qual Stud Health Well-being.*,5,2,10.3402/qhw.v5i2.5129. doi:10.3402/qhw.v5i2.5129
- Rosqvist, K., Hagell, P., Odin, P., Ekström, H., Iwarsson, S., & Nilsson, M. H. (2017). Factors associated with life satisfaction in Parkinson's disease. *Acta neurologica Scandinavica*, 136(1), 64-71. doi:10.1111/ane.12695

- Schapira, A.H.V., Chaudhuri, K.R., & Jenner, P. (2017). Non-motor features of Parkinson Disease. *Nat Rev Neurosci.*, 18,435-450. doi: [10.1038/nrn.2017.62](https://doi.org/10.1038/nrn.2017.62).
- Schipper, K., Dauwese, L., Hendriks, A., Leedekerken, J. W., & Abma, T. A. (2014). Living with Parkinson's disease: priorities for research suggested by patients. *Parkinsonism & related disorders*, 20(8), 862–866. doi: [10.1016/j.parkreldis.2014.04.025](https://doi.org/10.1016/j.parkreldis.2014.04.025)
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism Relat Disord.*,12(1):35–41. doi:10.1016/j.parkreldis.2005.06.011
- Schwartz, R., Trivedi, R., Gray, C., Lorenz, K.A., & Zulman, D. (2019). Neurologist Strategies for Optimizing the Parkinson's Disease Clinical Encounter. *J Geriatr Psychiatry Neurol.* ,32,5,246–256. doi:10.1177/0891988719845509
- Sharma, T., Bamford, M., & Dodman, D. (2015). Person-centred care: an overview of reviews, *Contemporary Nurse*, 51(2-3), 107-120. doi: [10.1080/10376178.2016.1150192](https://doi.org/10.1080/10376178.2016.1150192)
- Shin, J. Y., & Habermann, B. (2017). Nursing Research in Parkinson's Disease From 2006 to 2015. *Clinical nursing research*, 26(2), 142–156. doi:10.1177/1054773816634912
- Shin, J. Y., & Hendrix, C. C. (2013). Management of patients with Parkinson disease. *The Nurse practitioner*, 38(10), 34–44. doi:10.1097/01.NPR.0000434090.96229.5c
- Shipley, S. D. (2010). Listening: a concept analysis. *Nursing forum*, 45(2), 125–134. doi:10.1111/j.1744-6198.2010.00174.x
- Sjödahl-Hammarlund, C., Westergren, A., Åström, I., Edberg, A. K., & Hagell, P. (2018). The Impact of Living with Parkinson's Disease: Balancing within a Web of Needs and Demands. *Parkinson's disease*, 2018, 4598651. doi:10.1155/2018/4598651
- Smith Pasqualini, M., & Simons, G. (2006). *Patient Education for People with Parkinson's Disease and their carers*. John Wiley & sons.
- Stenberg, U., Haaland-Øverby, M., Fredriksen, K., Westmann, K.F., & Kvisvik, T. (2016). A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness. *Patient Education and Counseling*, 99, 1759-71. doi: [10.1016/j.pec.2016.07.027](https://doi.org/10.1016/j.pec.2016.07.027).
- Stuss, D. T., & Alexander, M. P. (2000). Executive functions and the frontal lobes: a conceptual view. *Psychological research*, 63(3-4), 289–298. doi:10.1007/s004269900007.

- Swedish Movement disorders society. (2019). Ritlinjer för utredning och behandling av Parkinsons sjukdom. Version 8. [ in Swedish ]Retrieved 200210 at [https://www.swemodis.se/images/Dokument/Swemodis%20Riktlinjer%20for%20utredning%20och%20behandling%20av%20Parkinsons%20sjukdom%20version\\_8\\_A4.pdf](https://www.swemodis.se/images/Dokument/Swemodis%20Riktlinjer%20for%20utredning%20och%20behandling%20av%20Parkinsons%20sjukdom%20version_8_A4.pdf)
- Swedish national board on health and welfare. Socialstyrelsen. (2016). *Nationella riktlinjer för vård vid multiple skleros och Parkinsons sjukdom* (in Swedish). Edita Bobergs AB.
- Tamariz, L., Palacio, A., Robert, M., & Marcus, E. N. (2013). Improving the informed consent process for research subjects with low literacy: a systematic review. *Journal of general internal medicine*, 28(1), 121–126. doi:10.1007/s11606-012-2133-2
- Tan, S. B., Williams, A. F., & Morris, M. E. (2012). Experiences of caregivers of people with Parkinson's disease in Singapore: a qualitative analysis. *Journal of clinical nursing*, 21(15-16), 2235–2246. doi:10.1111/j.1365-2702.2012.04146.x
- Tanji, H., Anderson, K. E., Gruber-Baldini, A. L., Fishman, P. S., Reich, S. G., Weiner, W. J., & Shulman, L. M. (2008). Mutuality of the marital relationship in Parkinson's disease. *Movement disorders : official journal of the Movement Disorder Society*, 23(13), 1843–1849. doi: 10.1002/mds.22089
- Theed, R., Eccles, F., & Simpson, J. (2017). Experiences of caring for a family member with Parkinson's disease: a meta-synthesis. *Aging & Mental Health*, 21(10), 1007-1016. doi: [10.1080/13607863.2016.1247414](https://doi.org/10.1080/13607863.2016.1247414)
- Thordardottir, B., Nilsson, M., Iwarsson, S., & Haak, M. (2014). "You plan, but you never know"--participation among people with different levels of severity of Parkinson's disease. *Disabil Rehabil.*,36(26), 2216–2224. doi:10.3109/09638288.2014.898807
- Torgé, C. J. (2013). Using conjoint interviews with couples that have been living with disabilities and illnesses for a long time – implications and insights. *Qualitative Studies*, 4(2), 100-113. doi:10.7146/qs.v4i2.
- Tysnes, O.B., & Storstein, A. (2017). Epidemiology of Parkinson's disease. *J Neural Transm.*,124(8),901–905. doi:10.1007/s00702-017-1686-y
- US Department of health and human services. (1979) *The Belmont Report*.
- van der Eijk, M., Faber, MJ., Aarts, JW., Kremer, JA., Munneke, M., & Bloem, BR. (2013). Using Online Health Communities to Deliver Patient-Centered Care to People With Chronic Conditions. *J Med Internet Res.*,15(6),e115. doi: [10.2196/jmir.2476](https://doi.org/10.2196/jmir.2476)
- van der Eijk, M., Faber, M.J., Al Shamma, S., Munneke, M., & Bloem, BR. (2011). Moving towards patient-centered healthcare for patients with Parkinson's disease. *Parkinsonism Relat Disord.* ,17(5):360–364. doi:10.1016/j.parkreldis.2011.02.012

- van Hooft, S.M., Been-Dahmen, J.M.J., Ista, E., Van Staa, A., & Boeijeh, R. (2016). A realist review: What do nurse- led self- management interventions achieve for outpatients with a chronic condition? *Journal of Advanced Nursing*, 73 ,1247–1532. doi:[10.1111/jan.13189](https://doi.org/10.1111/jan.13189)
- Vlaanderen, F. P., Rompen, L., Munneke, M., Stoffer, M., Bloem, B. R., & Faber, M. J. (2019). The Voice of the Parkinson Customer. *Journal of Parkinson's disease*, 9(1), 197–201. doi:[10.3233/JPD-181431](https://doi.org/10.3233/JPD-181431)
- Walshe, C., Ewing, G., & Griffiths, J. (2011). Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings. *Palliative Medicine*, 26(8), 1048-54. doi: [10.1177/0269216311432897](https://doi.org/10.1177/0269216311432897)
- Warner, G., Packer, T. L., Kervin, E., Sibbald, K., & Audulv, Å. (2019). A systematic review examining whether community-based self-management programs for older adults with chronic conditions actively engage participants and teach them patient-oriented self-management strategies. *Patient education and counseling*, 102(12), 2162–2182. doi: [10.1016/j.pec.2019.07](https://doi.org/10.1016/j.pec.2019.07).
- Weil, RS., Costantini, AA., & Schrag, AE. (2018). Mild Cognitive Impairment in Parkinson's Disease-What Is It? *Curr Neurol Neurosci Rep.*,1(4),17. doi:[10.1007/s11910-018-0823-9](https://doi.org/10.1007/s11910-018-0823-9)
- Wilde, H.M., & Garvin, S. (2007). A concept analysis of self-monitoring. *Jnl of Adv Nursing*, 57,339-350. doi:[10.1111/j.1365-2648.2006.04089.x](https://doi.org/10.1111/j.1365-2648.2006.04089.x)
- Wilkinson, A., & Whitehead, L. (2009). Evolution of the concept of self-care and implications for nurses: A literature review. *International Journal of Nursing Studies*, 46 , 1143–1147. doi:[10.1016/j.ijnurstu.2008.12.01](https://doi.org/10.1016/j.ijnurstu.2008.12.01)
- World Health Organization. (2015). *World report on ageing and health*. World Health Organization. <https://apps.who.int/iris/handle/10665/186463>
- World Medical Association, WMA Declaration of Helsinki. (2013). Ethical Principles for Medical Research Involving Human subjects. <http://www.wma.net/en/30publications/10policies/b3/>
- Xu, Q., Park, Y., Huang, X., Hollenbeck, A., Blair, A., Schatzkin, A., & Chen, H. (2010). Physical activities and future risk of Parkinson disease. *Neurology*, 75(4), 341–348. doi:[10.1212/WNL.0b013e3181ea1597](https://doi.org/10.1212/WNL.0b013e3181ea1597)
- Yang, F., Trolle Lagerros, Y., Bellocco, R., Adami, H. O., Fang, F., Pedersen, N. L., & Wirdefeldt, K. (2015). Physical activity and risk of Parkinson's disease in the Swedish National March Cohort. *Brain : a journal of neurology*, 138(Pt 2), 269–275. doi: [10.1093/brain/awu323](https://doi.org/10.1093/brain/awu323)
- Young-Mason, J. (2015). The fine art of caring: people with Parkinson disease and their care partners. *Clinical nurse specialist CNS*, 29(2), 121–122. doi:[10.1097/NUR.0000000000000111](https://doi.org/10.1097/NUR.0000000000000111)



- Zarhin, D. (2018). Conducting Joint Interviews With Couples: Ethical and Methodological Challenges. *Qualitative health research*, 28(5), 844–854. doi:10.1177/1049732317749196
- Zarit, S. H., & Zarit, J. M. (1987). *Instructions for the Burden Interview*. Technical Document, University Park, Pennsylvania State University.

# Papers

The papers associated with this thesis have been removed for copyright reasons. For more details about these see:

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-165314>

## **FACULTY OF MEDICINE AND HEALTH SCIENCES**

Linköping University Medical Dissertations No. 1730, 2020  
Division of Nursing Sciences and Reproductive Health  
Department of Health, Medicine and Caring Sciences

Linköping University  
SE-581 83 Linköping, Sweden

[www.liu.se](http://www.liu.se)



**li.u** LINKÖPING  
UNIVERSITY