

**THE EMBODIED EXPERIENCE OF LIVING  
WITH PARKINSON'S DISEASE**

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## Abstract

### **The Embodied experience of living with Parkinson's disease**

People with Parkinson's disease (PD) face many continuous limitations in daily life because of their illness. To illuminate the lived experience of PD and to evaluate ways to give individuals who suffer from PD comprehensive opportunities to come to terms with the impact that the illness has on daily living, two intervention programs and one longitudinal study were carried out.

The overall aims of this thesis were to investigate daily living conditions and the role of environmental and personal strategies for PD-afflicted persons and to illuminate lived illness experience as narrated by persons who suffer from PD – to gain understanding for meeting persons afflicted with PD. The first intervention study (**I**) was design as a five-week outpatient course with two weekly two-hour sessions; each session consisted of one hour of dialogue and one hour of physical performance. The next intervention (**II**, **III**) was carried out for three consecutive years as a week-long stay in a Swedish mountain area. One study (**II**) evaluated the effect of the intervention on PD-afflicted persons' mobility patterns, and the other study (**III**) described environmental influences on lived illness experience as narrated by these persons. In the longitudinal study (**IV**), a woman within the complicated stage of PD was interviewed continuously over a five-year period about her lived illness experiences.

In study (**I**) questionnaires (SIP, UPDRS) and an opto-electronic instrument (PLM) were used to evaluate effects from the intervention. In study (**II**), the PLM was used to evaluate effects from the intervention on mobility patterns in the participants.

In the first intervention, 43 persons with PD participated. The mean age was 75 and mean PD duration was 6 years (**I**). In the second intervention, 12 persons with PD participated, of which three participated three times and three persons participated two times; the mean age was 68 and mean PD duration was 8.5 years (**II**, **III**). When the longitudinal study started, the female participant was 72 and had received the PD diagnosis 15 years earlier (**IV**).

Statistical methods (**I**, **II**) and phenomenological methods were used for data analysis (**III**, **IV**).

In study **I** improvements in the participants' psychosocial dysfunction, sleep patterns, and in daily activities lasted 12 weeks, as did improved mobility patterns. In study **II**, results in mobility patterns showed immediate and long-lasting improvements in movement speed and integration of movements. Study **III** illuminated the importance of the environment for experiences of involvement, experiences of limitations, and trust in own abilities. Experiences during the intervention had long-lasting influence on daily living. Study **IV** illuminated the lived experience of the complicated stage of PD as a striving for involvement within experiences of changing habitual skillfulness that was influenced by environmental and emotional experiences. In creating new forms of expression, new worlds were discovered. These experiences changed the lived meaning of time and space.

*Keywords:* Parkinson's disease, illness experience, embodied experience, mobility, care, environment, intervention, longitudinal study, phenomenology.

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## ORIGINAL PAPERS

This doctoral thesis is based on the following original papers, which are referred to in the text by their Roman numerals:

- I. Sunvisson, H., Ekman, S-L., Hagberg, H. & Lökk, J. (2001). An education programme for individuals with Parkinson's disease. *Scandinavian Journal of Caring Science*; **15**(4), 311-317.
- II. Sunvisson, H., Lökk, J., Ericson, K., Winblad, B. & Ekman, S-L. (1997). Changes in motor performance in persons with Parkinson's disease after exercise in a mountain area. *Journal of Neuroscience Nursing*; **29**(4); 255-260
- III. Sunvisson, H. & Ekman, S-L. (2001). Environmental influences on the experiences of people with Parkinson's disease. *Nursing Inquire*; **8**(1), 41-50.
- IV. Sunvisson, H. Living through the complicated stage of Parkinson's disease. Striving for involvement within experiences of changing habitual skilfulness and a changing horizon (Manus).

## **ABBREVIATIONS AND DEFINITIONS**

ADL	Activity of daily living
H&Y	Hoehn & Yahr staging scale
MBM	Mentation, behavior, and mood
ME	Motor examination
MT	Movement time
UPDRS	Unified Parkinson's disease rating scale
PD	Parkinson's disease
PLM	Postural-locomotor-manual test
SI	Simultaneity index
SIP	Sickness impact profile

## **INTRODUCTION**

When I began working as a nurse on a neurological rehabilitation ward I was surprised by the rapid changes in mobility of my patients with Parkinson's disease (PD). These changes were sometimes due to their medication, sometimes not. Because this was in the mid-1980-s, no nursing care literature was written that focused on patients with PD. To compensate for my lack of knowledge I asked my patients to tell me what it was like to live with these alterations in mobility. They described the impact that PD had on their lives and explained how they used many tricks for becoming mobile in moments of immobility. They told me how greatly physical surroundings and situations affected their mobility. To use my new knowledge (and to learn more) I received permission from the head of the ward to arrange meetings with the PD patients on the ward to discuss ways of coping with the sickness. We discussed what it was like to live with this sickness, ways of meeting their needs, and how to come to terms with different kinds of problems. What I learnt from these meetings was that living with PD involves all dimensions of life. It does not concern just the body or the psyche – it concerned the entire living human. I also learned that people with PD are extremely sensitive to environmental influences. In the literature I read about PD, I found no reference to what my patients were talking about. This became the starting point for my research, which is tied together by these questions:

- What is it like to live with PD, i.e., what is the lived illness experience when suffering from PD?
- Why are PD sufferers so sensitive to environmental influences?
- What kind of knowledge is needed to fulfill the needs described by my patients?

# **BACKGROUND**

## **Perspectives on Parkinson's disease**

Shared values and a common scientific language are the compelling conditions for building and developing theories (Kuhn, 1981/1962). The scientific perspective governs members in a discipline regarding knowledge that is required for what is given and how this knowledge is perceived and understood. Scientific theories influence what questions that are asked and in which way the questions are formulated. This in turn influences the answers and interpretation of these answers. In all scientific societies, phenomena are understood by forming concepts (Meleis, 1997, p. 93).

How PD is described (or understood or explained) depends on perspective of the person's paradigm. This perspective also influences the way of understanding symptoms and illness expressions. The intention of this background study is to scrutinize how well neurological and nursing bodies of knowledge respond to and illuminate my questions.

## ***Neurological perspective on Parkinson's disease***

Since James Parkinson first described symptoms related to "the shaking palsy" as he named this disorder (Tyler, 1987) in 1817 the neurological research on the disease has developed in a profound way. In the paradigm of neuroscience, the human body is mainly understood as a biological body. The paradigm's purpose is to find causal connections to explain illness expressions. Within this paradigm, research on PD has provided important knowledge about the human brain in general and a deeper understanding of physiological structures regarding PD development. This research has contributed to the development of a battery of drugs intended for relieving PD-related symptoms.

Identification of dopamine as a neurotransmitter and the discovery (Carlsson et al., 1959) that depletion of dopamine in animal trials resulted in Parkinson-like symptoms were important breakthrough for researching the course of the disease and for developing drug therapies.

The clinical picture of PD displays a wide range of symptoms, of which the motor symptoms are found to correlate with a dopamine deficiency, and other symptoms less so, which alternatively suggests an indirect correlation (Jankovic, 1987). PD is usually described with four cardinal symptoms (Hagell, 2002). One of these cardinal symptoms is bradykinesia (clinical expressions are micrographia, loss of associated movements and impaired smooth pursuit, difficulty turning in bed, shuffling and short-step gait, festination, and freezing). Rigidity, as an increased resistance to passive stretch, and a low-frequent tremor in rest are two other cardinal symptoms. The last one is postural instability: a decrease in balance associated with propulsion and retropulsion (Jankovic, 1987). Other findings related to motor characteristics are among others hypomimia, speech disturbance, hypophonia, dysphagia, and respiratory difficulties (Sawle, 1999). Non-motor characteristics of PD include, for example, orthostasis, seborrhea, obstipation, impaired thermal regulation, and sexual dysfunction (Jankovic, 1987). Sleep disturbances are common, sometimes related to drug therapy (Larsen, 2003; Homann et al., 2003). Other related symptoms are increased sensitivity for stress, bradyphrenia, and cognitive deficiencies - with or without dementia - such as visuospatial impairment (Lee, 1994, Maeshima et al., 1997). Depression is also commonly related to PD, but is not related to disease severity or to disease duration (Brandstädter & Oertel, 2003). Concerning these many symptoms, it is striking how individual the picture of PD is (Jankovic, 1987). It is of interest to note that bradykinesia, like all symptoms in PD, is affected by the emotional state of the patient. With a sudden surge of emotional energy, the immobile patient may catch a ball or make other fast movements (Hallett & Khoshbin, 1980, Sacks, 1991).

Because the disease is also progressive, this demands continuous, individual adaptation of the medication schedule to visible sign of symptoms (Widner, 2003). Dopamine-deficiency treatment with l-dopa is the most prevalent and usually results an initial dramatic effect, especially for bradykinesia and rigidity symptoms (Hassin-Baer & Giladi 2002). Many other dopaminergic drugs are also available for individually scheduled drug therapy. Within a few years of medical therapy, most patients develop complications. Among these are motor fluctuations - often unpredictable to medical schedule - and dyskinesia, i.e. dystonic and abnormal involuntary dance-like movements (Ahlskog & Muentner 2001) and/or some type of dystonia, which sometime

is painful (Quinn 1998). Psychiatric side effects such as delusions, hallucinations and nightmares may also appear (Onofrj et al., 2002). If increasing in severity, these side effects challenge opportunities for optimal medical therapy (Sawle 1999). It is obvious that despite modern treatment methods, the impact of the disease increases as it progresses (Karlsen et al., 2000), as also confirmed by many studies that focus on the impact of the illness on different areas in life for the afflicted persons (Hagell, 2002). For PD sufferers, the neuroscience research is tremendously important. The skillfulness of the clinical practitioner who is consulted to scrutinize illness expressions to find the most pertinent valuable treatment is also of decisive importance for maintaining the delicate balance between symptom relief and side-effects (ibid.).

Though more investigation is needed, research has shown that PD sufferers are sensitive to environmental influences, for example:

- rhythmic auditory stimulation that increases cadence and stride length (Thaut et al., 1996), and
- external sensory triggers (i.e., a clue on the floor in front of the feet of the PD patient) that improve postural adjustment associated with step initiation (Burleigh-Jacobs et al., 1997).

### ***Perspectives in nursing studies research about Parkinson's disease***

The main body of nursing knowledge concerning PD starts from the neurological way of viewing PD-related symptoms. Previously mentioned PD-related symptoms are described in these papers: (Fritzsimmmons & Bunting, 1993; Lusic, 1997; MacMahon & Thomas, 1998; Noble, 2000; Scott, 2002). Advice is given for how each of these symptoms relate to specific kinds of impact on daily life and for how nurses can help PD-suffers cope. In this symptom-focused nursing literature, patient education on symptoms, medication regimens, and side effects is seen as important for patients' abilities to maintain independent life styles (MacMahon & Thomas, 1998; Noble, 2000; Scott, 2002). Also important is encouraging patients to get involved with local patient groups (Noble, 2000, Scott, 2002).

Other nursing research studies about PD start from the lived illness experience, which is sensitive to patients' perspective. Marr (1991) found that the struggle to live with the impact of PD started even before the PD diagnosis with many "uncertainties" that influenced daily life. Though reactions varied on diagnosis, being diagnosed was experienced valuable for legitimizing bodily experiences and for socially constructing new identities for better or for worse (Marr, 1991; Haberman, 1996; Caap-Ahlgren et al., 2002). During progression of the disease alteration in physical functioning and stamina was a reason for social withdrawing (Marr, 1991). And so was the discomfort felt when visible sign of the sickness attracted others' attention (Haberman 1999; Caap-Ahlgren et al., 2002). Their own bodies became visible as the smoothly functioning body ceases to be. Movements required conscious effort to execute, rising the need for finding new ways to perform activities (Haberman, 1999).

Many demands had to be dealt with: emotional responses, a changing body and changing identity, daily and long-term unpredictability, and different limitation, such as learning to ask for and accept help from others (Haberman, 1996, 1999). Medication methods were based on self-understanding; some of the narrators over-medicated; other under-medicated themselves to enable living and being to continue mainly as before (Haberman, 1996). Different strategies were outlined for coming to terms with daily problems. One way was learning how the medicine worked and then taking medicine in doses that enabled them to cope with daily issues and side-effects (ibid.). When the sense of smell had deteriorated, eating familiar dishes was a way for imagining the taste. Further methods included delegating tiring and stressful issues in order to keep other, more valuable issues intact for a sense of normality and independence. Feeling involved with issues and specific persons gave a sense of capability and togetherness (Andersson & Sidenvall, 2001). Ways of dealing with the illness influenced experiences of health (Marr, 1991). Planning for the future was found to be only essentially worked out for coping with unpredictability in disease progression and maintaining a sense of hope (Marr, 1991; Haberman, 1996; Widerfors, 2000). The narrators in Haberman's study (1996) expressed a need for obtaining knowledge about the sickness in terms of self-care and how to cope with day-to-day illness demands. Knowledge, in medical terms, was gained from health care providers while knowledge about how to deal with illness was gained practically and from others who had PD. This practical knowledge

was widely requested in contacts with health care providers, but seldom given (Marr, 1991; Haberman, 1999).

In a literature review Hayes (2002) found that the most important issues for people with PD were available treatment for providing the best individual solution, maintaining independence and continuing with their present life style. This later issue also concerned a desire for being understood regarding what it could be like to become dependent “rather than responding to patients as ‘diseased bodies’ or types of cases” (ibid. p. 5). The last important issue was to obtain knowledge on how PD affects the brain to be able to understand how the amount of information they had been given related to their own symptoms. With this in mind, it is obvious that the symptom-focused nursing does meet many of the needs that PD sufferers have pointed out.

Wallhagen & Brod (1997) reinforce this statement; they found that perceived control of symptoms on a daily basis was significant associated with patient well-being. However, this symptom-focused nursing approach, which mainly orientated towards the “diseased body” accounts less for the patient’s lived experience. According to Benner & Wrubel (1989) a phenomenological caring approach is grounded in an understanding of how an illness is lived, arguing that “understanding the meaning of the illness can facilitate treatment and cure” (ibid. p. 9). Though there are good intention imbedded in these nursing papers, the symptom-focused nursing offers poor examples of ways of understanding what it would be like to live these symptoms.

The patient-perspective-sensitive research extends the understanding of what it can be like living with this disorder. Advising how to meet needs of the patients, Marr (1991) argues that a focus on the capabilities of the afflicted persons rather than on their deficits would facilitate the individuals’ perception of health. Haberman (1999) implies that the framework of medicine is of limited value if an open dialogue on the patient’s lived experiences is not considered when medical regimen is designed. Patient’s bodily experiences and meaning associated with these experiences must be accounted. If not, then the medication regime is jeopardized, she explains (ibid.).

In summary, with professionals’ expertise, the challenge for nurses in the symptom-focused approach is to educate the patient about the disease, medical regimes and coping mechanisms for maintaining independent lives. This conclusion constitutes a

point of departure in support of patients and is grounded in the nurses' understanding of PD. In symptom-focused nursing, patients, with whom care is negotiated, are presented as passive receivers of help – despite their knowledge from living with PD (Fritzsimmmons & Bunting, 1993; Lusic, 1997; MacMahon & Thomas, 1998; Noble, 2000; Scott, 2002).

The individual-focused nursing research showed patients' need for discussing symptoms in reference to their living body and for finding a comprehensive understanding of illness experiences as they were lived. For the narrators in these studies, symptoms were not experienced as single entities; they were experienced as interference that challenged their way of life and encounters with the world. The individual-focused nursing approach provided knowledge that is required for anticipating patient's short (daily) and more long-term needs. From this individual-focused perspective it is also obvious that there was no general way to adapt. This is in line with Benner & Wrubel (1989) who argue that coping patterns are always situated and contextual. Viewed in this way it could be said that this research in a broad sense concerned with environmental influences or co-determinations.

### **Environment as a central domain of nursing science**

This individual-focused way of illuminating lived experiences provides a path to follow for scrutinising environmental influences. What, then, is environment? Meleis (1997) implies that environment, as a concept, is central to the domain of nursing. Even though it is one of the main concepts inherent in nursing science, it is poorly illuminated (Dahlberg et al., 2003). According to Meleis (1997) there is a need for the development of several types of theories related to the concept of environment (c.f. Andrews, 2002). In nursing science environment has been given different meanings. For Nightingale (1859/1989), being the first author of nursing science to highlight the importance of environment, this concept predominantly concerned sanitation as a health problem. Warmth, light, ventilation and cleanliness were important issues that contribute to patient healing and optimal health (ibid.). In the nursing philosophy outlined by Benner and Wrubel (1989) the term environment is replaced with the term situation as conveying a peopled environment with social definition and meaningfulness (ibid. pp 80-86). Within a frame of a phenomenological understanding of situation they argue

“To be situated implies that one has a past, present, and future and that all of these aspects of temporality ... influences the current situation” (ibid., p. 80). This means that individuals have their own understanding of the situation in the engaged interaction, and that “personal interpretation of the situation is bounded by the way the individual is *in* it” (ibid. p. 84, italic in original). But first, the body is an immediate environment of the lived body. The subject-body is also situated in the most concrete meaning, implying having a place to stand, a place where to be (ibid.).

With the worldly belonging of the subject-body, the way of living is possessed by a certain preferred style; of ways to behave, relate and look upon life (Benner and Wrubel, 1989). In its corporeality the body-subject inhabits the place-world in its directness towards the world as experienced. The perceived act connects man with the world and actions are intentional as well as experienced and lived on both conscious and unconscious levels (Casey, 1999). With its power of intentionality, the body is lived, and as such not a thing in the world but a way in which the world comes to be (Leder, 1998).

### ***Environment as lived places***

For a deeper understanding of environment Casey (2001), investigating the ontological meaning of *place* and how it ties to the human’s lived experience, takes his stand in human as *habitus*. Habitus becomes in his interpretation both habitude and also, in an improvised ability, open for innovation<sup>1</sup>. Understood in this way habitus becomes the mediating link between, for example, consciousness and body, nature and culture, self and others; elements that continuously becomes entwined, uniting us with the world we live. Self is thus constituted by a core of habits that both embodies and constitutes what is experienced. World as place is then sensed and perceived as well as experienced and actively lived. Even if performance mirrors social and cultural patterns, it still is as habitus human in his acting extends towards the place for inhabit it and become one with it (ibid.). But the body not only reaches out for the place-world, it also lodges traces from other places being known. Impression from a place remains present long time after being left. This lodged impression revives when this sensation attunes with

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<sup>1</sup> Casey refers this statement to Bourdieu, P. *Outline of a theory of practice*. Translated by R. Nice. Cambridge, U.K.: Cambridge University Press, 1977

present experiences. As a "thirdspace" place is at the same time social, historical and spatial (Soja, 1996) linking together man, place and time in an experience that rises from attention in the situation being involved in<sup>2</sup>.

### ***The placeness of the body***

Through a living relation with oneself, others, and the world, human beings assign meaning to experiences. In this living relation, things (including self and others) matter. Letting things matter is an ontological condition of human beings and is challenged by life (Benktsson, 1985; Benner, 2001). When experiencing illness, the habituated living in a homelike world disrupts. In the experience of illness the "I" become forced to confront the fact that this "I" am a body and that this "I" am in the world as a body. The way of understand life, meanings, and concerns breaks down, and the habitual body experiences "desituatedness" (Benner & Wrubel, 1989). Or expressed another way, the intentional arc that projects past, future, and human settings; believes and concerns into a unity of senses, 'goes limp' (Merleau-Ponty, 1962, pp. 136). The embodied way of understanding life and the lived body's access to the world thereby becomes challenged by illness experiences (Ibid.). It is the searching for the self's being as a lived body in the world that then motivates contact with health care professionals. The desire to find the lived body's access to the world when not able to realise this wish on own terms is the driving force behind consultation for care and treatment (Sveen, 1997). Illness experiences are then the experience of a changed habitual body (Murphy, 1987; c.f. Haberman, 1996; Caap- Ahlgren et al., 2002). Because the lived body bestows meaning, experiencing new signification may tend to take possession of new possibilities, and allows one to be transformed by new meanings, and as such, they become a part of one self in the realm of the lived world (Benner & Wrubel, 1989). This means that habitual structures are not to be thought of as causal, but motivational (Bullington, 1999). Understanding and making sense of lived experiences is a search for possibilities within a changed world (Toombs, 2001, c.f. Haberman, 1999; Andersson & Sidenvall, 2001). As the lived body is meshed with the world, places become lived in an altered way also in case of illness or disability or by delusions (Toombs, 2001, c.f.

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<sup>2</sup> "The world is not what I think, but what I live; I am open to the world, I have no doubt that I am in communication with it, but I do not possess it, it is inexhaustible." (Merleau-Ponty, 1962, xvi-xvii).

Sacks, 1973, pp. 343 - 344). Some specific condition or experience might also harbor new meaning to the experience of time altering the way time is lived<sup>3</sup> (Benner & Wrubel, 1989, p. 217). From this broadly sketched way of understanding person, place and time, the increased sensitivity for stress (Ellgring et al., 1993) and visuospatial deficit (Maeshima et al., 1997) related to PD might be understood in new ways if the illumination of lived experience within the frame of phenomenology continue (c.f. Merleau-Ponty, 1962, pp. 98 –147). This might assume the challenge from the patients' expectations on health care professionals (Benner & Wrubel, 1989, Dahlberg et al., 2003).

## **RATIONALE FOR THE STUDY**

Arising from the pre-understanding shaped in the meetings with PD-afflicted persons which were a contrast to dominating neuroscience knowledge with its focus on the *diseased body*, the intention was to probe into how perception of environmental influences interacted with the experience of illness by use of interventions. In this definition, environment is to be considered in a broad sense, i.e., it envelops peopled places (Casey, 2001). Because PD is a chronic, progressive disorder, life circumstances are continuously changing (Marr, 1991, Haberman, 1996, 1999). So it seemed important to gain understanding of the lived experience when the progression of the symptoms becomes more complex and when unpredictable responses challenge balance in the medical drug regimen (c.f. Jankovic, 2000).

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<sup>3</sup> The changed relation to future the narrators expressed in studies by Marr (1991), Habermann (1996) and Widerfors (2000) can also be seen as a change in lived temporality.

## **AIMS**

The overall aims of this thesis were to investigate daily living conditions and the role of environmental and personal strategies for PD-afflicted persons, and to illuminate lived illness experience as narrated by persons suffering from PD to gain understanding for meeting persons afflicted with PD.

Specific purposes of the studies were to:

Evaluate if an intervention program would influence the participants' psychosocial situation and ability to manage daily life activities and their mobility pattern **(I)**

Find out whether daily walks in the Swedish Mountains during one week would affect the motor performance of persons with PD **(II)**

Illuminate PD-afflicted individuals' lived illness experiences and influences from the environment on ability to manage daily life **(III)**

Explore how one person experienced the years as living through the complicated stage of PD **(IV)**

# METHODS

## Study designs and settings

Two interventions and one longitudinal study were conducted. The first study was conducted as a five-week-long outward intervention project that involved voluntary participants who were afflicted with PD and lived in Stockholm country (**I**). The aim of this study guided the choice of a quantitative measuring method. Chosen instruments measured generic sickness impact on daily life, specific impairment and activity limitations related to PD, and motor performance. Before the intervention began, one week after the end of the intervention and three months later, a selected combination of these instruments was used. The intervention and the tests were implemented through a hospital in Stockholm as an outpatient project.

The other intervention project was conducted in the mountains of northern Sweden. It lasted for one week and was implemented for three consecutive years in the late summer (**II**, **III**). With the quantitative approach of research questions, chosen instruments measured motor performance and specific impairments related to PD. Before the intervention started, a few days after the end of the intervention, and three months later, a selected combination of these instruments was used.

Results from the first year of intervention in the mountain showed an extraordinary improvement in motor performance that was hard to understand. In the second part of the intervention, the participants were interviewed about their experiences regarding environmental influences three months after returning home from the week in the mountains. In this study, a phenomenological method was used (**III**).

Results from study **III** led to the longitudinal study that covered recurrent interview sessions during five years and was carried out mainly in the home of the participant to explore the lived experience of the complicated stage of PD; here a phenomenological method was also used (**IV**).

## ***Interventions***

Intervention means to intervene - to interfere and imposes an action that intends to change, prevent, or create something (*Swedish Academic Dictionary*, 1986). The interventions in this thesis were designed for creating possibilities for persons afflicted with PD to become aware of how daily life interferes with both illness experiences and environmental influences so that each of person from his or her own condition and interest could come to terms with illness-related difficulties in life.

### Study I

The first intervention was designed as a five-week-long outpatient educational program with two 2-hour meetings each week. The program contained one theoretical and one practical part. The topics of the theoretical part were physical and psychological symptoms from PD, the dialectic connection between body and mind, drug treatments and side effects from these drugs, awareness of possible influences of social life and environment on illness experience, and self care. Participants were asked to perform self-measuring estimations that were discussed at the following meetings. The practical parts were directed towards co-ordination, balance, rhythm, stretching, relaxation and awareness of body language. Special needs were met through education, for example, training in how to get up from a lying position on the floor, how to get into and out of a chair and so on. The hypothesis with the educational program was that a combination of practical performance and theoretical knowledge closely related to discussions about influences from the environment, social concerns, and other matters might improve their psychosocial situation and lead to less illness impact on daily living.

The *Structure of Connection*, developed by Gunnar Kylén (1986), was used as the framework for the discussions. It was used as a tool for giving the participants an understanding for illness influences on areas of importance. The structure of connection describes the interplay between psychology, biology, sociology, and physiology. According to Kylén (ibid.), from a psychological aspect, a human being is seen as acting and experiencing existence, biologically as a living body, sociologically as a communicating creature in relation to others and institutions. The physical aspect concerns persons in relation to environment and physical surroundings. These four domains are proposed to influence each other in a dynamic interplay, with each change

influencing the human being and leading to ongoing changes. With a focus on aspects of the structure of the discussions around different topics, and with reflections from the participants around their own experiences, they were expected to attain knowledge regarding their own limitations and resources, leading to a condition of less illness impact on daily living.

The educational program was held seven times with four to nine participants. Because we wanted the participants to exchange experiences with each other, we let the estimated severity of their PD determine the type of course for which they would receive an invitation. The program, held by one nurse and one physiotherapist, was carried out as a polyclinic patient course within an urban area.

### Studies II - III

- The intervention lasted for seven days and was conducted three consecutive years at late summer time. It was carried out in a mountainous heath-like area in northern Sweden, characterized by low, bog-covered, rolling hills with groups of spruces and small birch trees. The daily schedule was (except for a day trip by bus to a place of interest):
- 8 AM: 20 minutes of moderate morning exercise, thereafter breakfast.
- 10 AM-2 PM: walking together in the surroundings.
- 2 PM-5 PM: free time.
- 5 PM: dinner, followed by an hour of discussion on some topic of interest. Then tea time, and the day ended with about two hours of entertainment.

The participants were lodged in a mountain boarding house with other guests. Though not walking together with these guests, the evening entertainment was enjoyed together. The daily walks lasted for about four hours and covered a distance of between 3– 6 km. There were frequent short breaks and a longer one for eating a packed lunch. The leaders of the groups were two nurses (of which one was the author) and one physiotherapist. Though none did, the participants were informed that they could discontinue their walk at any time and return to the lodge with one of the leaders.

## ***Longitudinal study***

### **Study IV**

The longitudinal study was carried out mostly within the home of the involved woman. The meetings were arranged from one time to another, mostly depending on the health condition of the woman. During the five years the study lasted, the meetings with the woman were mainly once a month for two hours. In total, 12 hours were recorded on the initiative of the involved woman.

### **Participants**

The participants in the two interventions were recruited through the board of the Parkinson Disease Association (**I, II**). Some also participated on the recommendation of a neurologist (**I**).

Inclusion criteria were:

- A PD diagnosis but not over stage four of the Hoehn and Yahr Staging Scale (Hoehn & Yahr, 1967) (**I, II, III**)
- Documented effects of l-dopa treatment (**I**).

In the last study, the participating woman initiated the study; so she selected herself (**IV**).

### ***Participants in study I***

A total of 45 persons participated (**I**), but two of them were excluded because they did not have PD but Parkinson's-like diseases. These two persons participated in the theoretical parts, and they participated in individual educational discussions and individual training that were designed for their specific problems. The remaining 43 participants (16 female and 27 male participants) were between ages 53 – 85 (mean age 75). They had been diagnosed with PD from 1 to 16 years earlier (mean diagnosis time 6 years). Thirty-three of them were retired, four were on sick leave, and six were still employed.

### ***Participants in studies II–III***

The persons in this intervention (**II**, **III**) were between ages 60 – 77 and were diagnosed with PD from 2 to 16 years before their first participation; all were retired. Some had walked in the mountains before, but for some, it was the first time (see Table 1 for an overview of participation). During the three years of the study, a total of 12 persons with PD participated (5 female and 7 male). Of these 12 persons, 3 participated all three years, 3 participated for two years, and the remaining 6 participated for one of the three years. One of these persons, participating a second time, declined to be tested and interviewed the second year. So there were a total of 20 tests performed in study **II**. In study **III**, eleven persons were interviewed; 5 were interviewed twice.

*Table 1. Participants during three years in studies II and III (n = 12).*

Persons	<b>I</b>	<b>II</b>	<b>III</b>	<b>IV</b>	<b>V**</b>	<b>VI</b>	<b>VII</b>	<b>VIII</b>	<b>IX</b>	<b>X</b>	<b>XI</b>	<b>XII</b>
Years with PD*	10	5	13	2	12	4	4	16	11	7	11	8
Age*	72	70	70	77	77	60	60	65	65	65	69	67
Years of participation	1,2,3	1,2	1,2,3	1,2,3	1,2**	2,3	3	3	3	3	3	3

\*Data from first participation.

\*\*Person V refused participation in the test and interview the second year.

### ***Participant in study IV***

The woman participating in this study (**IV**) was 72 years old when the longitudinal study began and had been diagnosed with PD 15 years earlier. She was living in her own home. For two years of the study, she received home service aid, and during the last year, she moved into a nursing home.

## **The quantitative studies, I and II**

### ***Data collection and analyses for the quantitative studies***

#### Evaluation instruments and procedure for evaluation

These instruments were used:

- Sickness impact profile (SIP) (**I**)
- Postural-locomotor-manual test (PLM) (**I, II**)
- Selected parts of the unified Parkinson's disease rating scale (UPDRS) (**I, II**)

#### *Sickness impact profile*

The *SIP* is a self-reporting questionnaire that examines sickness-dependent influences on daily life and is considered tantamount to a sense of well-being (Sullivan, 1989, Langius & Björvell, 1993). The instrument consists of 136 statements that are ticked (checked) if the respondent agrees that the statement is due to his/her sickness. These statements are grouped into 12 sub-scales focused on walking, mobility, body care and movement, social interaction, communication, alertness behavior, emotional behavior, sleep and rest, eating, home management, recreation and pastimes, and work. The sub-scales walking, mobility, body care and movement, can be quoted together as a physical domain, and the sub-scales communication, alertness behavior, emotional behavior and social interaction as a psychosocial domain. The sub-scales sleep and rest, eating, home management, recreation and pastimes, and work are regarded as autonomous scales. A percentage score (0-100) is obtained for the total SIP for the physical and the psychosocial domains and for the 12 sub-scales. The higher the scores, the poorer the person's perceived health-related functional status. Because most participants were retired, the work sub-scale was not used. The participants filled in the form before the start of the course and three months after its end. Those who found it difficult to fill in the form were offered help.

### *Postural-locomotor-manual test*

The *PLM* test is design to measure mobility patterns, i.e., speed and co-ordination in motor performance, with focus on PD sufferers who usually have decreased ability for simultaneous motor performance and demonstrate slowness of movements (Steg et al., 1989). In performing the test, the person must pick up an object from the floor, walk with it for a distance of 1.5 m, place it on a shelf at shoulder height, then immediately take it down and walk backward with it to the starting position. The *P* means the phase of straightening up the body after bending down to pick up the object, the *L* stands for locomotion, i.e., walking, and the *M* for the arm swing. The movement time (MT) is defined as the time from the moment the object is lifted from the floor until it is placed on the shelf, while the rest of the time is determined. As an indicator for the level of co-ordination of movements, namely, P, L, and M, a simultaneity index (SI) is calculated on the sum of P, L, and M divided with MT. If the P, L, and M phases are well-integrated and overlapping each other, there will be a high SI index; if not, the SI index will be low.

Before starting the measurement, six reflecting markers were placed on the head, shoulder, elbow, hip, and knee of the person's most PD afflicted side and the foot of the opposite side. A seventh marker was placed on the test object. Reflections of the markers in the optoelectronic camera were rendered two-dimensionally in a special computer program. Each participant was instructed by a physician (II) or by the author (I) to practice the exercise until they felt familiar with the way in which it should be performed. Then they did the test three consecutive times, the two last trials as fast as possible, and the best of these trails was used for evaluation.

### *Unified Parkinson's disease rating scale*

The *UPDRS* questionnaire contains five domains composed to cover areas of importance for estimating the impact of PD (Fahn et al., 1987). The *UPDRS* consists of four scales with a total of 42 items, and a scale for an overall impact estimation of PD is added to the instrument. The four scales are mentation, behavior, and mood (MBM), activities of daily living (ADL), motor examination (ME) and complication of therapy. The added scale is a modification of the Hoehn & Yahr Staging Scale (H&Y; Hoehn & Yahr, 1967). This selection of sub-scales from the *UPDRS* was made:

- Section ADL was only used in the first intervention (I).
- MBM was only used in the second intervention (II).
- Sections ME and H&Y were used in both interventions (I, II).

The selected UPDRS scales rank severity from no visible signs of disease/functional loss (0 points) to severe disease/functional loss (4 points). In both interventions the same physician interviewed the participants about ADL and examined mobility for the ME scores; stages in the H&Y were based on the physician's overall judgment of visible signs of PD in combination with the ME scores. The physician also asked the mountain participants about their medical schedules and if they had other diseases of significance to their participation (I). This information was also important for the leader to have during the intervention.

#### Test schedule

In the first intervention (I), the participants were tested before the course started (week 0), a few days after the course ended (week 5) and three months thereafter (week 17). At the first and third test occasions, all instruments were used; at the second test occasion, only the PLM and selected parts of the UPDRS were used.

In the second intervention (II), the participants were tested with the PLM, selected parts of the UPDRS before the intervention, and with the PLM a few days after its end and three months after for the first and third years and six months after for the second year.

#### Data analysis

Guidelines were followed for converting scores in the SIP to percentages (Sullivan, 1989) (I). The PLM computer-assisted optoelectronic measuring system automatically sorted collected data in the Mac Reflex software program, and the WingZ processing program was used for analyzing sorted data (I, II). Results from the UPDRS were not converted.

For the interventions, results before the intervention were compared with results after the interventions to find statistical correlation following the statistical methods that were used. Analysis in the SPSS statistical program was calculated with a two-tailed student's t-test for a null hypothesis for identical mean values (I), and the analysis in the

Excel statistical program was calculated with a two-tailed student's t-test of 95% confidence interval (II).

### **The qualitative studies III - IV**

#### ***Phenomenological Approach***

Scientific phenomenological methods were used in the qualitative studies (III, IV). The purpose of these methods is to illuminate essences and the meaning structure of a phenomenon as lived and experienced by subjects. Because these methods have their origin within a phenomenological philosophy, it is necessary to mention some issues of importance within the phenomenological approach.

Edmund Husserl (1859-1938), a German mathematician and philosopher who is regarded as the founder of modern phenomenology (Bengtsson, 1988), intended to develop a method for the stringent, scientific scrutinizing of the givenness of a phenomenon for a consciousness without questioning its origin or existence (Husserl, 1989/1907).

Husserl (1989/1907) implies that man's experience of the world as subjective and culturally meaningful reconnects the experienced phenomenon to the subject's experiencing. He thus connects the perceptual act to a subject, understanding intentionality to be a fundamental concept in phenomenology (ibid.). Hence, phenomenology emphasizes the meaning bestowing activity of consciousness, and the individual is seen as the determiner of the meaning of his/her world. Consequently, the phenomenological field concerns the world as *meant* or *intended*, and the phenomenological task is to investigate how man experiences and constitutes the world *as a world*. To scrutinize the experienced givenness of an object the scrutinizer works within an attitude of phenomenological reduction, thus bracketing his/her attitude of the natural world (ibid.). This reduction is not to be understood as a minimising but as becoming present to the givenness of a phenomenon and thereby being able to vary it in such an extent that the essence of it appears and can be grasped in its original meaning (Husserl, 1992/1977).

### *Data collection and analyses for the qualitative studies*

Data for the qualitative studies were collected as concretely experienced narratives (**III**, **IV**).

#### Data collection in study **III**

In the mountain intervention (**III**), the author interviewed persons who participated during the second and the third years—about three months after returning home from the mountain stay. They were asked to give concrete lived experiences according to the phenomenon of study related to three stages:

- Daily life
- Environmental influences during the mountain stay
- How the mountain stay experiences may have influenced daily life after returning home

During the interviews, the interviewer asked clarifying questions. The interviewee decided where the interview should be carried out. All but two were done in their homes. All interviews were recorded. Eleven persons were interviewed, but because five of them participated both years, the total number of interviews was 16. The recorded interviews lasted 45 - 80 minutes and were verbatim transcribed.

### Data collection in study IV

In the longitudinal study (IV) the participant was interviewed on her own terms when she wanted her narration being recorded. Over coffee, we started to talk about how things had been since our last meeting. If the woman then indicated that she had something she wanted to be recorded, then the recorder was turned on. During her narration questions were asked for clarification or for a more detailed picture of some section not found being described in a comprehensive way for the interviewer (the author). When the meeting place was other than in her home, the author made notes about issues of interest during the meeting or after. These notes were used as a reminder about some issue of interest for later development. Recording sessions were continuously transcribed verbatim and given to the woman at the next meeting.

### ***Data analyses***

The methods used in studies III and IV inherent in this thesis are *The Descriptive Phenomenological Psychological Method* developed by Amadeo Giorgi (Giorgi, 1985; Giorgi & Giorgi, 2003) and *The Empirical Phenomenological Psychological Method* developed by Gunnar Karlsson (1995). These two methods refer to the phenomenology of Husserl. But as this is a philosophy of meaning on an ontological level, Husserl's philosophy is modified to become a useful tool for illuminating selected phenomena relevant for the researched field of profession (Giorgi, 1985; Karlsson, 1995). Although Giorgi and Karlsson are psychologists, their methods are also useful for researchers from other disciplines (Giorgi, 2000; Karlsson, 1999, p. 330)<sup>4</sup>

### Data analysis in study III

The method developed by Giorgi (1985) was used in study III and the data analysis process proceeded in following way.

By explicitly identifying and bracketing (holding back) my own scientific knowledge of relevance for the studied phenomenon, an attempt was made to work within an attitude

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<sup>4</sup> Example on the methods used in the nursing discipline, see Palo-Bengtsson & Ekman (2002) and Söderhamn (1998).

of scientific phenomenological reduction. During the entire analysis process, this bracketing of knowledge was questioned to reveal a presence for the phenomenon under study. From a nursing perspective, with focus on the phenomenon being studied, the analysis process then began with an open reading of the verbatim-transcribed interviews to get a sense of the whole text. Thereafter, in a more thorough reading, the text was divided into smaller meaning units guided by awareness of shifts in the meaning of the text due to the phenomenon studied. In the next step, each meaning unit was reflected over with the method of imaginative variation to reveal its meaning and to sensitively transform the meaning unit with the attempt to highlight its inherent meaning due to the studied phenomenon. When all meaning units were transformed, insights contained in the transformations were condensed and synthesized into a structure supposed to illuminate the constitution of environmental influences on lived illness experiences.

#### Data analysis in study IV

The empirical phenomenological psychological method developed by Gunnar Karlsson (1995) was used in study IV in the following way.

Relating to Karlsson's (ibid.) criterion for ability to work within the attitude of scientific phenomenological reduction, my own theoretical knowledge of PD was made explicitly for not being used when studying the phenomenon. Following this method, the text was first carefully read through several times in its entirety to get an understanding of the participant's emotional feelings in her narrated experiences. Thereafter, entering into the scientific phenomenological reduction, subordinating the emotional understanding, the text was reread and divided into meaning units when a discerned shift in meaning was experienced according to the phenomenon being studied. Then I focused on finding the imbued meaning about the lived experience in the meaning units due to the phenomenon under study and transformed each of them into a descriptive language that highlighted its meaning. To better comprehend the large amount of data, each of the five years was observed as separate protocols. Hence, the transformed meaning units from each year were synthesized into five situated structures. From this point, I started over again by scrutinizing the meaning units and the transformations of them in the light of an understanding from all protocols for discovering the solidity of the situated structures. In the last step all eidetic constituents in the situated structures were

condensed into a general structure, taking all steps, including the raw data, into consideration.

#### *Commonalities of the methods*

Comparing the two methods by referring to Giorgi (Giorgi & Giorgi, 2003) and to Karlsson (1995) the following commonalities are found.

Using concrete descriptions of experienced events according the research object, the purpose of both methods is to describe essences and meaning-structure of the studied phenomenon by using of imaginative variations within the contextual level of actual meaning. Because the methods aim to scrutinize the lived meaning, understanding intentionality is essential. Sensitive presence for the phenomenon studied is due to the success for adopting the attitude of scientific phenomenological reduction, which is to bracket known theories, and not using hypothetical constructions according the phenomenon under consideration.

#### *Divergences of the methods*

Comparing the two methods by referring to Giorgi (Giorgi & Giorgi, 2003) and Karlsson (1995), the following divergences are found.

The method developed by Giorgi is working within the attitude of scientific phenomenological reduction through all steps, while Karlsson, with his hermeneutic approach, first grasps the subject's experience with an emotional understanding, which is subordinated in the following interpretation of the meaning of the text. Karlsson's argumentation for a partial phenomenological reduction is to find the hermeneutical approach to the method, already present in the first reading of the text, seen as a tensional field between the researcher's pre-understanding of his/her cultural and historical belonging and a necessary presence for the phenomenon being studied.

#### **Ethical considerations**

In this thesis focus was on persons with PD. Though participating voluntary, the people involved participated in interventions they believed would contribute in some way to their state of health. This means that being a volunteer can have several dimensions.

Ethical considerations thus concern the autonomy and integrity of participants (Hermerén, 1986). They all were guaranteed confidentiality and it was emphasized that they could refuse or discontinue participation in tests and/or interviews without any explanation, without being refused the opportunity to complete the intervention. All participants were informed verbally and in writing about the nature of the interventions and all but one (II, III), gave their informed consent to partake. The one who refused to partake in tests and interviews during the second year of the intervention participated in the intervention on the same conditions as the others.

Careful attention was paid on the interviewee's emotional reactions during the interview sections, the educational sessions and the mountain stay. All of the interviewees permitted recordings of their interviews, and they were assured that the data would be stored in a safe place. Guaranteeing confidentiality, they all agreed to the use of quotations from the interviews in such a way that there was no possibility of identification (c.f. Kvale, 1996). Each interview section was carried out in a place chosen by the participant.

The Regional Research Ethical Committee of the Karolinska Institutet, Sockholm, Sweden (diary number 94:15, with additional permission 48/97 and 23/8-01) granted permission to do the studies.

## **SUMMARY OF RESULTS**

### **Study I**

The initial results for the 43 participants in this intervention according the H&Y in the *UPDRS* scale demonstrated a wide range (between 1 – 4; mean of 1.9). This gives a heterogeneous picture of the participants from slightly and unilaterally afflicted to severely disabled, though still able to walk unassisted. Initial results according to H&Y were stable at the two follow-ups, as were the ME results. Results of the ADL scale showed improvements between the initial result and the first follow-up with further improvement when compared with results from the second follow-up. The *PLM* results showed improvements in speed and in integration of movements when comparing base-line data with the first follow-up—a result also stable at second follow-up (see Tables 1 and 2).

*Table 1. PLM results. Differences in simultaneous index between the evaluation sessions.*

	<b>Week 0</b>	<b>Week 5</b>	<b>Week 17</b>
Mean score	1.903	1.989	1.963
Std. dev.	0.169	0.165	0.163
<b>Comparison</b>	<b>Mean diff.</b>	<b>P value</b>	
Week 0 vs. week 5	-0.084	0.0001***	
Week 0 vs. week 17	-0.060	0.0075**	

\*p = 0.05, \*\*p = 0.01, \*\*\*p = 0.001 (Student's *t*-test)

*Table 2. PLM results. Differences in movement time between the three evaluation sessions.*

	<b>Week 0</b>	<b>Week 5</b>	<b>Week 17</b>
Mean score	2.112	1.819	1.757
Std. dev.	0.169	0.165	0.163
<b>Comparison</b>	<b>Mean diff.</b>	<b>P value</b>	
Week 0 vs. week 5	0.290	0.0019**	
Week 0 vs. week 17	0.356	0.0008***	

\*p = 0.05, \*\*p = 0.01, \*\*\*p = 0.001 (Student's *t*-test)

Overall results for *SIP* showed improvement as did results for psychosocial dysfunction, while results for physical dysfunction were unchanged. In the remaining single sub-scales, only results for sleep and rest showed significant improvements. The other sub-scales were stable. The heterogeneous picture of the participants is also seen in the *SIP* results (see Table 3).

*Table 3. Sickness impact profile results. Changes between baseline score and second follow-up.*

	<b>Week 0</b>		<b>Week 17</b>		P-value
	Mean	SD	Mean	SD	
Overall result in <i>SIP</i>	11.99	1.23	1.41	9.52	0.0341*
Physical dysfunction	9.52	11.28	9.58	12.30	0.953 n.s.
Psychosocial dysfunction	11.27	14.86	8.72	13.32	0.0446*
Sleep and rest	22.24	15.86	14.65	15.38	0.0001***
Eating	3.126	9.23	3.098	6.58	0.985 n.s.
Home management	18.90	22.66	16.58	2.87	0.958 n.s.
Recreation, pastimes	16.68	17.15	12.19	15.26	0.083 n.s.

\*p = 0.05, \*\* p = 0.01, \*\*\*p = 0.001 (Student's *t*-test)

These results indicate an improved psychosocial situation for the participants, improved sleep with less resting periods during the day and improved mobility patterns. Even though results according to the ADL scale in the UPDRS showed improvements, these are not verified by results from the SIP instrument. So improvements in managing practical skills are not possible to report. Because all scales are quoted in the overall SIP, the significant result in the overall SIP might be due to the strong significant result in the sleep and rest scale.

## **Study II**

When examined by the physician before the intervention, eight of the twelve participants admitted slight depressive signs, and six of those eight also expressed lowered self-motivation. All participants' levels of disease severity according to the H&Y in the UPDRS scale showed a wide range between 1–4: from slightly and unilaterally afflicted to severely disabled, though still able to walk unassisted. Comparing the first follow-up (four days after the intervention) with the baseline result, improvements were found in the PLM test, which showed increased mobility speed and increased ability to integrate movements. The mobility integrative improvement remained at the second follow-up, while mobility speed was further improved. This follow-up contains results from measurements made three months after (according to the design of the first and the third years) and from measurements made six months after returning home from the mountains (according to the design of the second year). Results from the one-week intervention indicate long-lasting improvement in motor performance and improved physical condition.

## **Study III**

These stages of environmental influence were explored:

1. Environmental influence on daily life
2. Environmental influence in the mountains
3. Influence from the mountain event on daily life

The structure in stage 1 was described as being enslaved by illness experiences and a sense of loss of control and feelings of insecurity. In stage 2, it was described as a

feeling of capability in a sense of shared understanding, and the ability to see possibilities, and in stage 3 as consciously searching for good experiences and a sense of confidence.

1. In ordinary living, they experienced themselves as *being enslaved by illness* because slowness in fragmented action resulted in fumbling performance and reduced their abilities to speed up. Activities also depended on the current degree of stamina. Some participants also experienced reduced ability to shift focus and cope with surprises. Together with easily becoming exhausted, this gave them *a sense of losing control*. Their reduced ability to simultaneously conduct tasks and the shift in stamina gave feelings of insecurity in their abilities to carry out plans. This was also an underlying cause for some participants' experiences of not being understood by others, and for the anxiety they felt in social life and for a future burdensome life. Their awareness of a changed behavior made them focused on their bodies, and this was accentuated when experiencing being questioned by others. This led to *feelings of insecurity*.
2. The mountain stay was experienced as providing a feeling of capability. The *shared understanding* during the mountain stay arose from a feeling of safety among the others and the leaders and gave them the courage to talk about odd and frightening illness experiences. It also arose from the confidence they felt by being among others with similar conditions and sharing similar struggles. The *ability to see possibilities* arose from absence of stress and performance demands. Also increased endurance from shared feelings of fatigue contributed to this ability. Earlier pleasant memories from other walks in the mountains were revived, and the memories influenced the present experience, enabling feelings of satisfaction, belonging, and harmony between self and surroundings. The surroundings and the ground had an influence on their body rhythms, inspiring them to break through previous perceived boundaries.
3. Memories from the mountain stay inspired them in different ways to a *conscious search for good experiences* in similar propitious environments and situations, and to try new ways of coming to terms with difficulties and limitations. The memories also gave a *feeling of confidence* that influenced their daily living and renewed ways of understanding oneself.

Accordingly, with favorable environmental experiences they were able to be directed outwardly, while unfavorable environmental experiences forced inward awareness of the body. This means that the environment influenced the experience of involvement, the experience of limitation of one's own abilities, and the experience of trust in one's own abilities.

#### **Study IV**

The most obvious experience of living through the complicated stage of PD was found to be a striving for involvement within an experience of changing habitual skilfulness and changing horizon. This was given in the following structured way:

Changing habitual skilfulness seen as:

*A fragmented bodily skilfulness, requiring presence and concentration in acting.* This experience forced the involved woman to focus on her body and consciously guide her movements when acting which arose a need to divide motility acts in single sequences render fumbling, slow behavior in doings and change her experience of distance.

*A rigid bodily skilfulness, requiring structuring of activities and a living in a slow rhythm of time.* The person involved experienced increasing difficulties for rapidly changing focus while carrying out activities or making quick decisions. Her rigid bodily skilfulness forced her to carefully structure her day, which changed the way she lived time. Living in a slow rhythm of time also made it difficult to adapt to other's rhythm of time.

*An unreliable bodily skilfulness, requiring a living with doubts for own competence.*

Unexpected bodily reactions sabotaged accomplishment of planned actions. Stressful environment violated actions, sometimes to such extent that the person experienced a sudden loss of connection with her intentions and others.

Condition for involvement seen as:

*Searching for understanding and insight* was a key point for the person involved. She strove to find solutions for regaining balance in her medical schedule and in her life.

With time, these strategies were challenged by experiences of rapid aging in a physical breakdown and of unsolved, unforeseen drug reactions.

The woman's experiences of *changing conditions were influenced by environmental and emotional experiences*. Specific environmental conditions, feelings, and events

interacted with her sense of involvement. When emotionally involved, she experienced herself being within what she was doing without the need for concentration on movement fragments. When not feeling involved, her body called for attention giving her awareness for her way of moving and her appearance. Living the complicated stage of PD, the woman strove to maintain her life values, challenging herself and remaining in par (mutual) with others. With time, she more obvious that she had to estimate how to use her decreasing strength, because activities and engagements were followed by periods of increasing exhaustion. This was her way of *embrace personal challenges and adjust to changed conditions*.

A Changing horizon seen as:

The woman, realizing discrepancies between memories of her vital body and her actual body, searched new way for remain faithful to her understanding of what she believed was her mission in life. In *creating new forms of expression* her life project found new forms. With increasing fragility, the woman lived with a strong consciousness of the finiteness of life, which made her experiences of her narrow world more intensely. Her visions of the future became limited to her life here and now.

In her narrow surroundings, she experienced a new concentration and density that develop into a *discovery of new worlds*. These experiences changed her lived meaning of time and space.

## **METHODOLOGICAL CONSIDERATIONS**

### **Design**

The first study (I) evaluated if the intervention program would influence the participants' psychological situation and ability to manage daily life activities and mobility patterns by comparing measured results before and after the course was carried out. With the evaluation design of the study, the possibility of finding out if and how the participants' understanding of illness impact changed with their participation was neglected. This should have been an important issue because the study was an educational program. The structure of connection as outlined by Kylén (1986) lacks temporal aspects for lived experiences and cultural dimensions of importance for the

understanding and interpretation of events in one own life situation (c.f. Emami et al., 2001). But the structure of connection was found to be a useful tool when discussion how illness influenced different areas of life and to be a guide for finding and developing new strategies in a changing existence.

The second study (II) aimed to discover whether daily walks in the mountains during one week would affect the motor performance of persons with PD. Measured baseline results were compared with two follow-up results. Weakness occurred when methodological design was changed between the years. Within the first and the third years, the second follow-up was after three months, while in the second year it was after six months. This change in design has probably influenced the results. But it is difficult to isolate variables in month-long periods. There are many things people become involved in during such a long period. But comparing results from the second and the third study (II, III) it might be possible to suggest that improvements were due to the intervention. Question also must be raised about the importance of the three leaders' role in the intervention. Because the intervention was design for create a supposed optimal environment, the role of the leader should be seen as a contribution to this design. A less enthusiastic group of leaders would have jeopardized this goal.

## **Considerations concerning the quantitative studies**

### Selection of participants

In the quantitative studies all participants were volunteers and to a lesser degree, selected. Inclusion criterion (I, II) was having been diagnosed with PD but not being past stage four in disease severity according to H&Y (Hoehn & Yahr, 1967) and with documented effect of l-dopa treatment. This minimal selection rendered in heterogeneous groups of participants regarding disease severity. This made analysis of data difficult to interpret. Because of the selection of participants, it is not possible to generalize these results.

### Evaluation instruments

The PLM method was developed as a tool for studying movement disorders and quantitative neurology that focuses on motor program execution and motor program co-

ordination (Steg et al., 1989). The method is also used for evaluating motor performance of PD patients (Johnels et al., 1989, Ingvarsson, 1997). The subject easily performs the test, but its use is mainly limited to research studies because it requires a special location, and the equipment is relatively expensive. The instrument is found to be an objective measurement tool and it has been valid against an ADL scale; thus, it is related to performance in everyday tasks (Matousek, 1995).

The PLM method is found to be useful for measuring small changes in mobility pattern. Instruction and training before registration of movements is crucial for avoiding biases (Kokko et al., 1997). In the present studies, all participants were carefully instructed and trained in performance before registration. Thus there is a problem with the reliability of the results considering the disease-related changes in mobility during the course of the day for PD sufferers. To minimize such biases, all tests were performed mainly at the same time of the mornings. Despite this arrangement, shifts in mobility in one or the other direction were seen in some participants.

The UPDRS is a commonly used instrument in research studies and in clinical practice, and the instrument has been found to be reliable and valid (Lousis et al., 1996). But the validity of the instrument has been questioned because it encompasses a mixture of impairments and activity limitations and because there is an absence of weighted values in the sub-scales, which results in difficulties in evaluating symptoms of importance for ADL performance (Ingvarsson, 1997).

The SIP questionnaire is found to be reliable and valid for measuring impacts from different diagnoses (Sullivan, 1989) also in a study involving PD patients (Longstreth et al., 1992). Results have shown good correlation between H&Y and the physical sub-scales of the SIP, while the psychosocial sub-scales had only weak correlation, which indicates weak correlation between physical symptoms and psychosocial impact (ibid.).

### Data analyses

Although the participants in the first study (I) in each single course were similar in age and at similar levels of disease severity, participant groups from all courses were very heterogeneous. This should be important for the statistical outcome. For more reliable results, these heterogeneous differences among participants in the first study (I) and the

absence of a control group in the consideration data should be analyzed with another statistical method, for example, with a confidence interval.

This was the method used in study **II**. The weakness in the results of study **II** relates to changed evaluation design and a small sample.

## **Considerations concerning the quantitative studies**

### ***Phenomenological analyses***

The common goal of proper evidence validation criteria used in the language of quantitative research does not have the same meaning in qualitative research, so the language is not easily applied to qualitative methods (Kvale, 1996). However, validation criteria suggested by the creators of the phenomenological methods (Giorgi, 1988; Karlsson, 1995) used in studies **III** and **IV** are used to retrospectively reflect upon methodological considerations concerning these studies.

### **Data collection and analysis in study **III****

For Giorgi (1988) validity in a scientific phenomenological sense has been achieved if the essential description of a phenomenon truly captures the intuited essence, that is, the most invariant meaning that can be assigned to a phenomenon for a given context. The entering of the phenomenological reduction must have been successful for the researcher's ability to be freshly present to the phenomenon studied – without being influenced by parenthetical assumptions. Acts of identifying must be considered, and these identifying acts must be consistently performed (ibid.).

Study **III** illuminates environment influences on PD-afflicted individuals' lived illness experiences. Because the method outlined by Giorgi (1985) was used in the study **III**, methodological consideration follows his validation criteria (Giorgi, 1988). To truly capture a phenomenon, data must have certain qualities. First, the informants must have experience with the research question and must be interested in narrating these experiences. Second, the narratives must also be rich in concrete, lived experiences about the research issue (Giorgi, 1985; Kvale, 1996). In this study, the informants were afflicted with PD, and they participated in the intervention. The interviewed persons were all familiar with the interviewer after the time they shared together. It is possible

to believe that these persons trusted the interviewer, and the impression was given that they all wanted to express their lived experiences regarding the research question. If so, data comply with the research aim. Although the interviews were of varying quality, the main part of them was filled with nuances and a richness of concrete, lived experiences. So the data are in align with data criteria for this method.

According Giorgi (1988), success in entering the scientific phenomenological reduction is a pivot point for the study when using his method. This means making knowledge about the phenomenon being studied explicit to oneself. Besides what the participating persons with PD had told me about their increased sensitivity for environmental influences and I had read neuroscientific and nursing literature on PD, I had red about coping strategies, health indexes, and psychological and psychosocial models. This was the knowledge I bracketed. But success in working within the attitude of scientific phenomenological reduction is difficult, as learning phenomenology seems to be a lifelong challenge.

Weakness in this study, according Giorgi's (1988) criteria for validity, is foremost shown in the result where environmental influences are presented in form of "situated structures" within three different placed environments. The suggested constituents relate to these placed environments, and a general structure is not presented in accordance to the method, but more as a philosophical reflection. Considering this weakness in methodological implementation, it can be said the phenomenon studied has been illuminated in a sensitive, nuanced way, and it is also validated with quotations. So the study also can be seen as meaningfully communicate PD-afflicted persons' lived experience of environmental influences, which agrees with Giorgi's (ibid) validation criteria.

#### Data collection and analysis in study IV

Study IV illuminates the lived experience of the complicated stage of PD. In this study, the method developed by Karlsson (1995) was used. Karlsson (ibid.) implies that three criteria have to be met for validity when using his method:

- The degree of success in the implementation of the reduction, which means how successful the researcher is in not imposing his or her own understanding of the explored phenomenon with biases and prejudice.
- Horizontal consistency of interpretations, which means the fitness of the meaning discovered to all protocols.
- Vertical consistency of interpretation, which means that truthfulness can be paid to the researcher's interpretation as the most plausible.

Karlsson (ibid.) implies that reliability understood as a state of truth refers to the relationship between a statement and a corresponding fact. Because the aim of phenomenological research is the search for meaning and not to collect facts for identification of causal connections, he suggests an understanding of reliability in terms of meaningfulness. As such, an interpretation of a text could be more or less meaningful instead of more or less true. A pivotal point is the quality of the data material (ibid). For meeting these criteria, there must be data that describe the phenomenon being studied. In this study, a woman, diagnosed with being in the complicated stage of PD initiated the study, as she believed her lived experiences would contribute to a deepen understanding of first person knowledge of PD. This woman was interviewed for five years, and in line with methodological criteria, the data express a richness of concrete lived experiences.

For meeting criterion for implementation of the reduction, my own theoretical knowledge of the PD was explicitly not used during the study. The long time spent together with the informant influenced my way of thinking, and in the analysis process, careful attention was paid to the delicate balance of not being ruled by these emotional memories and of using these influences as a vehicle for see 'things' give themselves in new and sensitive ways. Although there was a succession of interviews, an artificial division of them was made by year. With this division, the criterion for horizontal consistency of interpretations was not met, because the meaning discovered did not totally fit to all years. However, there was only one person interviewed, and the interpreted meanings were present in most of the protocols. There has also to be a vertical consistency for truthfulness in the researcher's interpretation of the phenomenon. Care was taken to validate interpretations with quotations, aimed to meet

this criterion. The presentation of the phenomenon can be seen as meaningful for a deepened understanding of the lived condition when suffering from the complicated stage PD.

## **DISCUSSION**

Results from two interventions and one longitudinal study inherent in this thesis have illuminated the lived illness experience of persons suffering from PD and determined the role of environmental and personal strategies for their living condition. The first two studies measured impact on the participants from activation (**I, II**) and discussed effects from illness on daily living and ways to cope with illness (**I**). By correlating variables before the intervention with variables after the intervention, results showed that such forms of participation resulted in improved physical fitness and motor performance (**I, II**), less psychosocial sickness impact, and a better sleep with less need for daily rests (**I**). The improved mobility pattern indicates strengthened physical condition as well as an improved mobility integrative capacity. Because these results correlate with results from other studies with similar design in physical training (Kamsma et al., 1995; Müller et al., 1997; Morris, 2000), it is reasonable to believe that both training in suitable surroundings (**I**) and specific designed training (**II**) are valuable for improving mobility patterns in persons with PD. The improved psychosocial function is also verified by results in similar studies (Ellgring et al., 1990; Trend et al., 2002). Improved sleep, with less need for rest during the day, might be a result from the physical training during the intervention (Kamsma et al., 1995), while the improved psychosocial function might be an effect from discussions during the intervention and an effect from the improved sleep and strengthened condition. Because it is known that sleep pattern and mood interferes with psychosocial factors (Brown & Jahanshari, 1995; Trenkwalder, 1998), it is reasonable to suggest the intervention had an indirect effect on mood, while personal social strategies developed (Andersen, 1999). Hence, results in studies **I** and **II** indicate the importance of the PD sick persons' comprehensive understanding of illness experiences and execution of suitable activities for developing personal strategies that open up for possibilities in life. In this sense, these interventions are seen to be useful tools.

### **Altered lived body rhythm**

Results in studies **I** and **II** showed that participants had impaired motor performance compared to aged matched healthy persons (Matousek, 1995) and the participants presented in studies **III** and **IV** experienced changed habitual performance that altered their body rhythms. When activities were performed with fragmentation of conscious guidance of movements, their flow in motility disappeared. The amount of concentration needed for performing these activities consumed a lot of energy. The exertion expended on a single act in executions might be related to the fatigue these participants felt (**III, IV**) and which other PD sufferers commonly complain about (Herlofson & Larsen, 2003). This need for concentration might also be related to the decreased capacity for simultaneous movement (Norberg et al., 1987; Malapani et al., 1994) and slowness in motor performance (Jankovic, 1987). These PD-related symptoms change bodily rhythm. Living rhythm is intimate and personal and mainly an unconscious act, whereas others understand bodily expressions of emotions or intentions from the way in which they are performed (Weiss, 1999). With unpredictable changes in motility and altered body rhythm, their own body images also underwent changes (**III, IV**, c.f. Haberman, 1996; Caap-Ahlgren et al., 2002). Although physical, psychological, cultural and social factors contribute to formation of body images, they also characterize personal phenomenon (Weiss, 1999). Body images are further constructed through constant communication with the body images of others (ibid.). On a pre-reflective level, body image is more felt than articulated, or as Casey implies (1999, p. 53) “more inflected than reflected”. With less of an ability for sensitivity to other people’s body image, intercommunication might express and be given other meanings – one cause of insecurity or distress in social situations (**III, IV**, Caap-Ahlgren et al., 2002).

## **Orienting space**

To deepen understanding of the altered body rhythm in people with PD, it will be discussed as a reasonable condition of an altered way of performance (c.f. **III**, **IV**, Toombs, 2001). In Gallagher's (1986, 1995) scrutiny of Merleau-Ponty's philosophy, Gallagher makes a distinction between body image and body schema<sup>5</sup>, where body schema operates in a tacitly lived space on a preconscious level, while body image is supposed to be the result of an attention, a belief or an attitude (Gallagher, 1995)<sup>6</sup>. The body schema operates in the selection of movements built up by practice and the cultivation of habitual movements in actively meeting environmental challenges. As a system of motor programs, body schema "operate(s)"<sup>7</sup> 'below' the level of self-referential intentionality" (Gallagher, 2001, p. 150), which makes postural and motility attunement to the environment possible without the need for constant body attention. With this suggestion, body schema is neither a pure cortical representation nor the same as body image but reflects an oriented attunement of the body to its environment. According to Gallagher (ibid.) to understand motility, it must be studied as a relation between the body as a whole within a specific environment. Casey (2001) also argues that spatial and temporal living bodies do not work in place but rather inhabit place in an oriented way. This supports Merleau-Ponty's contention that "the possession of the body implies the ability to change levels and to 'understand' space" (1962, p. 251). It is within this pre-reflective "understood" space that the phenomenal body moves. When reaching out a hand to catch something, in this motor intention, not only is the hand moved, but posture is also attuned to the movement in a gearing of the body in an intentional way towards the object (Merleau-Ponty, 1962, c.f. Burleigh-Jacobs et al., 1997). Further, in this reaching out as an intention, the thing reached for shapes the intention and the phenomenal body becomes caught up by things and the world<sup>8</sup>. Merleau-Ponty (1962, p. 317) said: "The object which presents itself to the gaze or the touch arouses a certain motor intention which aims not at the movements of one's own

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<sup>5</sup> Gallagher (1986) means that in *Phenomenon of Perception* the term *shema corporel* is translated to body image, but should be body schema. Compare also the Swedish translation "Kroppens fenomenolog" Daidalos förlag, Göteborg, 1999, p. 72 with the English translation of *Phenomenon of Perception*, p. 98 (1962). See also Weiss (1999).

<sup>6</sup> See Weiss (1999) for a more profound understanding of the concept body image.

<sup>7</sup> Gallagher suggests there might be several body schemas connected as a network (2001).

body, but at the thing itself from which we are, as it were, suspended". The body does not, then, act within a spatiality of *position* but within a spatiality of *situation* (Merleau-Ponty, 1962, p. 100) as an orientation in space is to act within a projection of a pre-reflective horizon of meaning (Merleau-Ponty, 1962, pp. 98-148). For the persons with PD (III, IV; c.f. Haberman, 1996), it seems like there was sometimes a rupture in this oriented space, a disturbance in the projection of the body that the virtual and actual body in some way did not mesh. When not oriented in space, movements had to be constructed and in such a way that they lost their melodious impression and precision. Or, described in another way, when not able to move within oriented space, no pre-reflective horizon was spread out and no access to build up habitual movements was in use for actively meeting the challenges from the environments. When the participants in studies III and IV experienced themselves moving smoothly in a skilled way, these experiences were actively attuned to the moods, tones, emotions, and special condition of events and place. When no such special conditions were experienced to elicit new motor intentions, then motor actions had to be self-consciously constructed, that rendered into slow and fumbling acting (III, IV, c.f. Hallett & Khoshbin, 1980; Sacks, 1991).

The participants with PD also experienced themselves as living with unpredictable motility (III, IV) which, according to previous discussion, is living with ongoing, change-oriented attunement of the body to its environment (c.f. Gallagher, 2001).

This means that their capacity to respond with fluid movements in certain situations fails as their motility gets locked. In these moments, their awareness in the present, as a result from a readjustment of the previous level of awareness, fails because adjusting capabilities for attuning to the present field are impossible to achieve in an oriented way (c.f. Merleau-Ponty, 1962, pp. 248-290).

### **Meeting needs when place and time are lived in certain ways**

Results in studies III and IV give a picture of the illness as lived and experienced. In certain situations these PD-afflicted persons found themselves ruled by their illness, in other situations when feeling involved, illness experiences faded away. The way they

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<sup>8</sup> Why is crumbs on the table more challenging for being swept away for parents than for teenagers?

were in the situation had importance for involvement experiences and for their ability to carry things out.

Events do not exist in space. Instead they are taken up as embodied experiences (Merleau-Ponty, 1962, pp. 254-267). Environmental influences are then the way place and time is lived (Casey, 2001, c.f. **III**, **IV**). An altered way in performance changed the way of inhabiting time and place and access to the world (**III**, **IV**). Understanding the lived body as a way in which the world comes to be (Leder, 1998) means to ask for the individual way of living the situation (Sacks, 1991), for its lived meaning of body rhythm (c.f. Malapani et al., 1994; Jankovic, 1987), of being in an off-stage (c.f. Ahlskog & Muenther 2001), of living with hallucinations (c.f. Onofrj et al., 2002), of feeling fatigue (c.f. Herlofson & Larsen, 2003), of living uncertainty with doubt for own ability (c.f. **IV**, Haberman, 1999, Murphy, 1987), and so forth.

This understanding of the lived body has importance in meeting the needs of the patients (Benner & Wrubel, 1989; Dahlberg et al., 2003). It sets the perspective for what to perceive, ruling the way for interpretation and understanding and cultivating openness and attentiveness in a certain direction; sensitivity for the patient's way of living his/her illness and sensitivity for emotions in the situation (Benner, 2000). One example might shed light on this. Many of us who have met patients with PD might find it hard to understand when a patient reacts on a suggestion with a rigid, rejecting body. Maybe we find this person obstinate, maybe we just let it go, waiting for another time that might fit the patient better. If we can understand this person's way of living place and time, then we might more sensitively make our suggestions. If the lived rhythm of time becomes slow and the possibility to hurry up isn't there (**IV**), this means that we as professionals must adjust to the patient's rhythm of time. If we adjust own body rhythms to the body rhythm of this person, then it might be possible for him/her to open up (or keep open) capabilities for involvement and activity. If not, the impact may be that this person loses his/her orientation in space and time, and we see this locked-in person as "unwilling" to co-operate (c.f. Sacks, 1991).

Having PD is to live with a neurological disorder with initiated use of medical drugs viable. Because the lived body is an "intertwining" intentionality and materiality (Merleau-Ponty, 1968, pp. 130-155), notions of disease should involve both existential

and biological terms that concerns care and treatment (Leder, 1998). In the care for a person suffering from PD, the neurological knowledge about PD then has to be used in such a way that it becomes comprehensive and meaningful for that particular person. For meeting this challenge we have to ask for this particular person's lived experience and self understanding (Benner & Wrubel, 1989; Dahlberg et al., 2003). Whatever the aim of a meeting between a health care professional and a person suffering from PD might be, this ambition must exist.

## CONCLUSION

In this thesis results showed illness affects on daily living, and how the illness experiences interfered with experiences of involvement and balance in demands from self, others and from their placed living (**I, II, III, IV**). These experiences also involved balance in medication (**IV**) and the importance of personal social strategies for decreasing effects from the illness on daily living (**I, III, IV**). If the results from this thesis make sense, they should be followed by clinical implications.

When someone is living with certain place-time sensitivity, like persons suffering from PD, we have to be sensitively open-minded in the meeting with this person. We have to reflect on what influences the place for communication might have, what influences one's own body image might have for this person's experience of stress and involvement. We must be sensitive to the way in which this person inhabits place and become attuned to this person's rhythm of time. Because illness is an embodied experience, we have to understand how this person finds release and involvement by discussing environmental influences and if concerns that matter are given up or are maintained - maybe in new ways. This could be the base from which rehabilitation can start.

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## SVENSK SAMMANFATTNING

När jag började arbeta som sjuksköterska på en neurologisk rehabiliteringsavdelning i mitten av 80-talet fann jag de snabba svängningarna mellan rörlighet och orörlighet hos patienterna med Parkinsons sjukdom (PD) svåra att förstå, och jag ställde många frågor till dem om detta fenomen och hur de upplevde dessa svängningar. Deras berättelser om detta, om hur det var att leva med denna sjukdom och berättelser om deras känslighet för inverkan från den miljö de vistades i ville jag förstå på ett djupare plan. Under hela den tid jag ägnat åt detta avhandlingsarbete har jag burit med mig dessa frågor:

- Hur är det att leva med PD; vad är den levda erfarenheten av denna sjukdom?
- Varför är personer med PD så känsliga för den miljö de vistas i?
- Vilken kunskap behövs för att kunna möta de behov personer med PD har?

### **Bakgrund**

Hur PD beskrivs eller förklaras beror på det perspektiv som berättaren har. Varje disciplin har sin tolkningsgrund för hur olika mänskliga fenomen ska förstås. Det finns ingen förklaring som är helt ”rätt” eller helt ”fel”. Istället kan man förstå förklaringen som mer eller mindre meningsfull för vad den ämnar till. I neurovetenskaplig forskning är den biologiska kroppen i förgrunden, och orsaker till fysiologiska förändringar undersöks för att utveckla metoder att komma tillrätta med dessa och att utveckla olika läkemedel. Den neurovetenskapliga forskningen om PD är djup och omfattande, och har resulterat i utvecklandet av en mängd olika medicinska och kirurgiska metoder, som är av livsavgörande betydelse för patienten. Likaså är vårdpersonalens skicklighet i att tolka sjukdomens uttryck avgörande för initierad vård och behandling.

Inom omvårdnadsforskning har i allt större omfattning forskning inriktats på att belysa den levda erfarenheten av olika sjukdomar, för att fördjupa och utveckla en omvårdnad som utgår från den enskilda individens upplevelser och tolkning av dessa upplevelser. Dock har endast ett fåtal studier gjorts om Parkinsonsjukas upplevelser, och ingen studie har inriktats på hur de upplever miljöns inverkan på sjukdomsupplevelse.

Inom omvårdnadsvetenskap råder överensstämmelse om att den grundar sig på fyra konsensusbegrepp: person, hälsa, miljö och omvårdnads-handlingar. Hos omvårdnadsteoretiker har konsensusbegreppet miljö olika tolkningar, infallsvinklar och djup. För Florence Nightingale var den stora betydelsen av en vårdande miljö att den skulle vara hälsobringande; t.ex. att patienterna hade det rent och varmt, och att de fick en kost som närde dem. Patricia Benner menar att begreppet miljö borde förstås som situation, eftersom situation dels är befolkad av någon eller flera, dels också innebär att besitta en plats. Situation är dessutom upplevd av någon.

### **Avhandlingens syfte**

Det övergripande syftet med denna avhandling är att undersöka miljöns och personliga strategiers betydelse för personer med PD, att beskriva och belysa dessa personers levda erfarenhet, för att få en fördjupad förståelse för deras behov.

Avhandlingen består av fyra vetenskapliga arbeten. Tre av dessa arbeten är interventionsstudier, ett är en longitudinell studie.

Delarbetena har syftat till att:

- Evaluera huruvida interventionsprogrammet för personer med PD hade återverkningar på deras psykosociala situation och förmåga att hantera dagliga livets aktiviteter och på deras rörelsemönster **(I)**
- Undersöka om dagliga vandringar i svensk fjällmiljö under en vecka påverkade rörelsemönster för deltagande personer med PD **(II)**
- Belysa miljöns inverkan på Parkinsonsjuka personers upplevelse av sin sjukdom och miljöns influenser på deras förmåga att hantera dagligt liv **(III)**
- Belysa upplevelsen av att genomleva det komplicerade stadiet av PD **(IV)**

### **Metod**

#### ***Intervention i form av kursverksamhet (I)***

Den första interventionen var utformad som en poliklinisk kurs för personer med PD. Kursen omfattade 20 kurstillfällen; två per vecka och varje möte varade två timmar.

Varje möte hade en teoretisk del och en praktisk del. I den teoretiska delen diskuterades Parkinson-sjukdomens symptomatologi, läkemedelsbehandling och biverkan, och sjukdomsupplevelsens inverkan på socialt umgänge och nätverk, inverkan från den fysiska miljön (boende och närmiljö) och egenvård. I den praktiskt inriktade delen tränade deltagarna kroppskännedom, koordination, balans och avspänning. Även olika sätt att komma tillrätta med specifika svårigheter tränades. En sjukgymnast och en sjuksköterska ledde tillsammans mötena. Sammanlagt genomfördes 7 kurser med 4 – 9 deltagare i varje kurs; totalt deltog 43 personer. Före kursens start, några dagar efter dess slut och 12 veckor därefter undersöktes deltagarnas PD-relaterade problem av en läkare utifrån ett testinstrument, och deras rörelsehastighet och förmåga att samordna sina rörelser mättes med ett opto-elektroniskt instrument. Före kursen och 12 veckor efter dess slut fick deltagarna också besvara en enkät för att utvärdera vilken inverkan kursdeltagandet haft på deras vardag. Insamlad data har analyserats med hjälp av statistiska metoder.

### ***Intervention i form av fjällvandringar (II och III)***

Den valda miljön för denna intervention var ett lättillgängligt område med omväxlande natur i svenska fjällen. Interventionen genomfördes en sensommarvecka under tre på varandra följande år. Deltagarna bodde tillsammans med tre ledare på ett fjällpensionat. Varje morgon startade med ett kort gymnastikpass, och någon timme senare gjordes gemensamma vandringar på 3 – 6 km under 4 timmar med frekventa raster. Kvällarnas underhållning bestod av dans, allsång och olika lekar tillsammans med övriga gäster. En dag varje vecka gjordes en bussutflykt till någon plats av särskilt intresse. Deltagarna i denna intervention var sammanlagt 12 personer. Av dessa deltog 3 personer alla tre åren och 3 personer deltog två gånger.

I arbete **II** redovisas resultat från alla tre åren på deltagarnas rörelseprofil, vilket mättes med ett opto-elektroniskt instrument och har analyserats med hjälp av statistiska metoder.

I arbete **III** intervjuades de deltagare som deltog det andra och det tredje året om miljöns inverkan på deras upplevelse av sin sjukdom och förmåga att hantera sitt dagliga liv. Intervjuerna har analyserats med en fenomenologisk metod.

### ***Longitudinell studie (IV)***

I denna studie deltog en kvinna som var diagnostiserad att vara i det komplicerade skedet av PD. Hon intervjuades fortlöpande under fem års tid om sina upplevelser. Även dessa intervjuer har analyserats med en fenomenologisk metod.

### **Resultat**

Resultat i studie **I** visade att deltagarna efter interventionen fått en lägre inverkan på psykosociala faktorer, en förbättrad sömn med mindre behov av vila under dagen och ett förbättrat rörelsemönster.

Resultat i studie **II** visade att deltagarna efter interventionen fått en bättre samordning av rörelser och en ökad rörelsehastighetsförmåga, både direkt efter interventionen och i uppföljning 3 månader senare.

Resultat i studie **III** visade att miljön påverkade deltagarnas upplevelse av sjukdomens begränsning av, och tilltro till, sina förmågor. I en upplevd ogynnsam miljö var deras uppmärksamhet riktad mot kroppen och rörelser måste mer eller mindre styras mentalt, vilket gav ett långsamt och fumligt rörelsemönster, medan i en gynnsam miljö tonades behovet av att mentalt styra rörelserna ned och kroppen gjorde sig inte påmind. Den upplevda gynnsamma miljön under fjällveckan gav känsla av tillfredställelse med sin tillvaro och en medvetenhet om miljöns inverkan på deras sjukdomsupplevelse, vilket ledde till ett sökande efter liknande sammanhang efter interventionens avslutande.

Resultat i studie **IV** visade att sjukdomen innebar ett fragmenterande av rörelser och att leva i en långsam tidsrytm. Sjukdomens opålitlighet innebar en osäkerhet om egna förmågor. Hur situationen upplevdes påverkade möjligheten att känna sig involverad. Med en tilltagande begränsning av möjligheter, upptäcktes nya värden i den nära miljön, och livsvärden tog sig nya uttryck. Detta innebar en örändrad upplevelse av tid och rum och en förändring av hur tid och rum levdes.

### **Diskussion**

De sammantagna resultaten i de fyra studierna visade att PD har stora återverkningar på det dagliga livet. Med ökad kunskap om sjukdomen, möjlighet att utbyta erfarenheter med andra drabbade och fysisk träning kunde personerna med PD förbättra sitt

rörelsemönster (I, II), uppleva en förbättra psykosocial situation (I), uppnå en högre initiativförmåga och förbättrad tillfredställelse med sin tillvaro (I, III). Resultatet visade också att miljön hade stor inverkan på upplevelse av sjukdomen (III, IV). Upplevelsen av tillfredställelse med tillvaron gav konkreta återverkningar på deras fysiska kapacitet. Detta visar betydelsen av att se människan som en helhet i samspel med sin miljö. Det är sjukvårdens stora utmaning att ge människor drabbade av sjukdom optimal medicinsk behandling *och* att hjälpa dem att återfinna hälsa och välbefinnande även om sjukdomen inte är botbar. Att förstå människan i sitt sammanhang innebär att efterfråga den enskilda personens upplevelse av sin sjukdom och vilken inverkan den har på olika områden i livet. Det är denna förståelse som bör utgöra grunden för vårdhandlingar.