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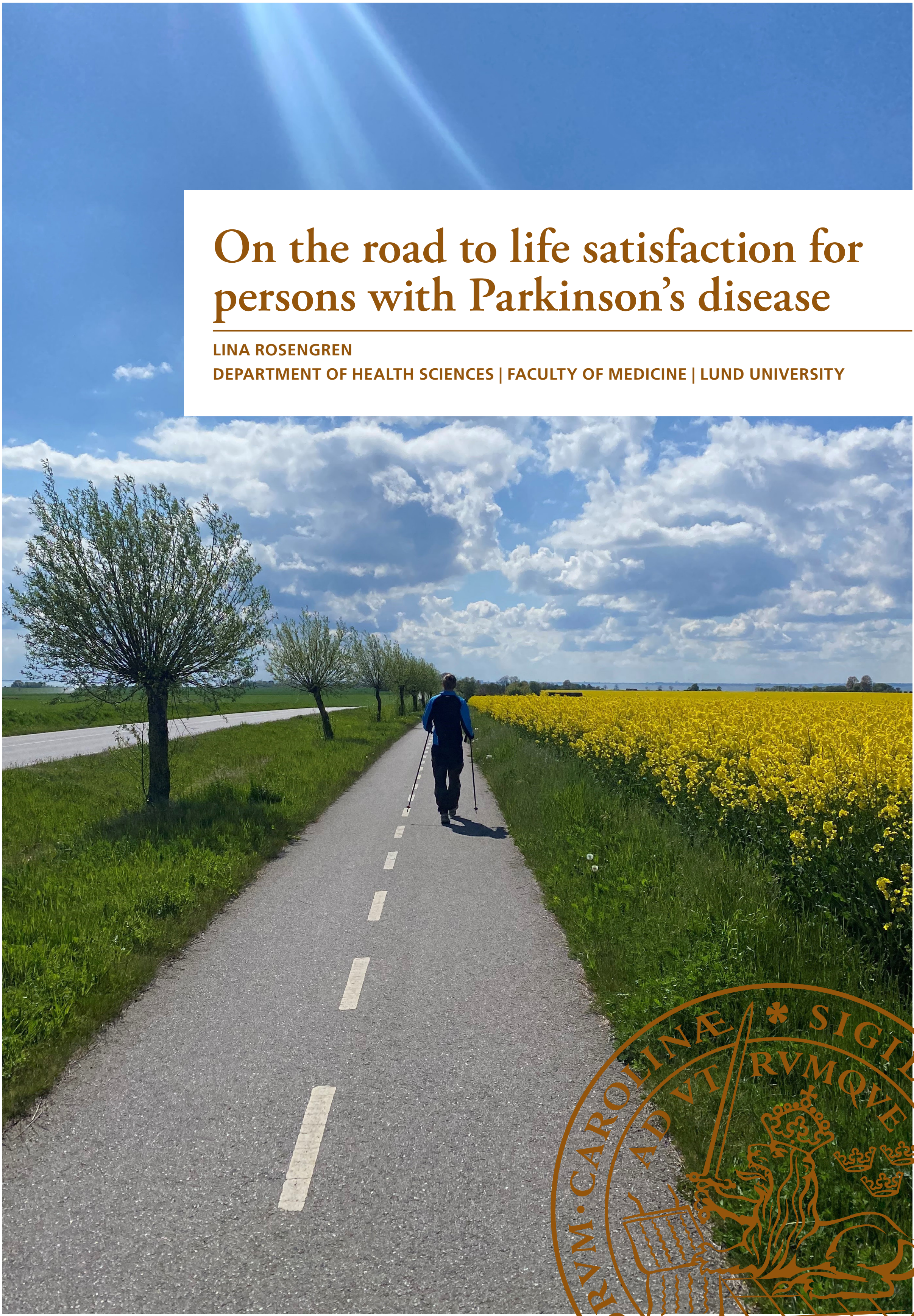
On the road to life satisfaction for persons with Parkinson's disease

LINA ROSENGREN

DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



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Parkinson's disease is a complex, life-long, neurological disorder with an individual progression, often having an irregular pattern. It can be experienced as unpredictable and difficult to manage. An impact on everyday life is inevitable despite the best possible available treatments. The consequences of Parkinson's disease can lead to a decreased level of life satisfaction. Life satisfaction is an overarching goal in modern care management and rehabilitation, but the knowledge about life satisfaction and Parkinson's disease is lacking. This knowledge is needed in order to develop rehabilitation interventions for increasing and maintaining a high level of life satisfaction for persons with Parkinson's disease.

This thesis comprises a methodological pluralism to assess and explore life satisfaction for persons with Parkinson's disease. The results have led to proposals on how persons with Parkinson's disease can achieve and maintain a high level of life satisfaction. It also describes important factors for healthcare professionals to consider when supporting persons with Parkinson's disease in this process, so that they can achieve and maintain a high level of life satisfaction over time.

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On the road to life satisfaction for persons with Parkinson’s disease

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DOCTORAL DISSERTATION

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Abstract:

Parkinson's disease (PD) is one of the most common neurodegenerative disorders. The motor and non-motor symptoms of PD lead to a number of consequences in everyday life for persons with PD (PwPD). PwPD continuously need to adapt to their new life situation and despite medical treatment, the impact of PD on everyday life is inevitable and can lead to a lower level of life satisfaction (LS). LS is an overarching goal for medical rehabilitation and has been suggested as being an ultimate goal for PD care. However, the knowledge that is needed for developing rehabilitation interventions aiming at increasing LS for PwPD is very limited.

The overall aim of this thesis was to increase the knowledge about LS for PwPD. The specific aims were to evaluate the psychometric properties of a rating scale for assessing LS, to describe LS and evaluate associated factors, to gain an in-depth understanding of the meaning of LS and adaptation, and to explore the process of the change and LS when living with PD.

A methodological pluralism was used to gain a broad, holistic and greater understanding of LS. In Study I, a psychometric evaluation of the Satisfaction With Life Scale (SWLS) was performed in a sample of 97 PwPD. The SWLS was then used in Study II to assess LS in 80 PwPD, and associated factors were analysed with hierarchical multi-regression analysis. Thirteen PwPD participated in in-depth interviews in Studies III and IV and the data were analysed with two different qualitative methods (phenomenological hermeneutics and grounded theory) to explore the meaning of LS and adaptation, as well as to describe the process of change and LS when living with PD.

The results showed that the SWLS has a high level of data completeness, scaling assumptions and targeting within the recommended criteria, an acceptable internal consistency and reasonably acceptable test-retest reliability. The mean value of SWLS was just above the midpoint between satisfied and dissatisfied with life. The salutogenic concept Sense of Coherence (SOC) had the strongest association with LS. PwPD describe an ongoing process of change when either adapting through acceptance or struggling in resistance towards the disease and its consequences. Acceptance makes adaptation and a high level of LS possible. The process of change for PwPD consists of four steps where the persons actively work to comprehend, accept, adapt, and balance their life situation, when striving for social belonging, which is a prerequisite for LS.

In conclusion, the SWLS is a psychometrically sound tool to assess LS in PwPD. Persons with mild to moderate PD are generally satisfied with life, but there seems to be a great variation in the level of LS for PwPD. Persons with a strong SOC have a higher level of LS. Adapting to PD is a process of change characterised by either acceptance or resistance. Acceptance makes a high level of LS possible, while resistance constituted a behavioural barrier to both adaptation and LS. By continuously working to comprehend, accept, adapt, and balance the new life situation, PwPD strive for social belonging, which in turn increases their LS. Healthcare professionals can support PwPD to achieve and maintain a high level of LS over time by understanding this process.

Key words Parkinson's disease, Life Satisfaction, Adaptation, Qualitative research, Sense of Coherence,

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Table of Contents

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List of papers

This thesis is based on the following papers, which will be referred to with Roman numerals throughout the thesis.

I. Rosengren L, Jonasson SB, Brogardh C, Lexell J. Psychometric properties of the Satisfaction With Life Scale in Parkinson's disease. *Acta Neurologica Scandinavica*. 2015 Sep;132(3):164-70

II. Rosengren L, Brogardh C, Jacobsson L, Lexell J. Life satisfaction and associated factors in persons with mild to moderate Parkinson’s disease. *NeuroRehabilitation*. 2016; 39(2): 285-294.

III. Rosengren L, Forsberg A, Brogardh C, Lexell J. Life Satisfaction and Adaptation in Persons with Parkinson’s Disease—A Qualitative Study. *International Journal of Environmental Research and Public Health*. 2021, 18, 3308.

IV. Rosengren L, Forsberg A, Brogardh C, Lexell J. Social belonging as the main concern for achieving life satisfaction when adapting to Parkinson’s disease. *International Journal of Environmental Research and Public Health.* 2021, 18, 8653.

Abbreviations

ADL	Activities of Daily Living
DBS	Deep Brain Stimulation
FOF	Fear of Falling
GDS	Geriatric Depression Scale
GT	Grounded Theory
ICC	Intra-class Correlation Coefficient
ICD 10	International Classification of Diseases and Related Health Problems 10th edition
ICF	International Classification of Functioning, Disability and Health
HRQL	Health-related Quality of Life
LS	Life Satisfaction
PD	Parkinson's disease
PwPD	Persons with Parkinson's disease
RNLI	Reintegration to Normal Living Index
SOC	Sense of Coherence
SOC-13	Sense of Coherence 13 item scale
SWB	Subjective Well-being
SWLS	Satisfactions With Life Scale
SDD	Smallest Detectable Difference
SE	Self-efficacy
SEM	Standard Error of Measurement
QoL	Quality of Life

Definitions

Activity	The execution of a task or action by an individual [1].
Activities of Daily Living	A term used to collectively describe fundamental skills required to independently care for oneself, such as eating, bathing, and mobility [2].
Activity limitations	Difficulties an individual may have in executing activities [1].
Coherence	The situation when the parts of something fit together in a natural or reasonable way [3].
Coping	The fact of dealing successfully with problems or difficult situations [3].
Deep Brain Stimulation	Involves a surgical implantation of one or more electrodes into specific areas of the brain, which modulate or disrupt abnormal patterns of neural signals in order to improve motor symptoms of Parkinson's disease [4].
Disability	An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual and that individual's contextual factors [1].
Everyday life	Refers to the practical tasks common to most persons, such as getting dressed, eating, washing, moving around at home and in the community and involves social interactions with other persons [5, 6].
Impairment	Problems in body function or structure such as a significant deviation or loss [1].
Life satisfaction	A subjective and cognitive evaluation of one's current life situation compared to one's own unique set of criteria [7].

MAO-B and COMT	Enzymes involved in dopamine breakdown and metabolism. Inhibitors of these enzymes are used in the treatment of Parkinson's disease [8].
Multicollinearity	A phenomenon in multiple regression, where two or more independent variables are highly correlated to each other. Multicollinearity causes problems when trying to draw inferences about the relative contribution of each predictor variable [9].
On and Off fluctuations	Usually occurs for PwPD when the disease progresses. “On” represents the part of the day when the medication is effective. “Off” represents the part of the day when the symptoms are more severe due to decreased effect of the medication [4].
Participation	Involvement in a life situation [1].
Psychological flexibility	The ability to respond to stimuli in a manner that is functional given a particular context, and that is congruent with personal values [10].
Rehabilitation	A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment [11].
SDD	Calculated as $SEM\ x\ 1.96\ x\ \sqrt{2}$ [12].
Self-efficacy	Refers to an individual's belief in his or her capacity to execute behaviours necessary to produce specific performance attainments [13].
SEM	Calculated as $SD_{baseline}\ x\ \sqrt{1-ICC}$ [14].
Sense of Coherence	A psychological factor related to the preservation of good health regardless of external strains [15].
Subjective Well-being	Comprise how and why persons experience their lives in positive ways, including both cognitive judgements and affective reactions [16].

Preface

My journey along the road for this thesis started many years ago. I remember being a little girl hearing about this frightening disease my grandfather dealt with. At first, Parkinson's disease (PD) scared me with the tremors, stiffness, and impact on daily life. As a young adult, working in home care, I developed an understanding for the complexity of the disease and the fear became a fascination. I started to wonder how some persons* seemed to be so satisfied with their lives despite their obvious disabilities and difficulties in everyday life.

During medical school I realised I wanted to work in cooperation with the patients, with a holistic approach. The life and person behind the diagnosis was my motivation more than the diagnosis itself. When I came across Rehabilitation Medicine, the choice for residency was obvious, and the road was straight and clear. Getting the opportunity to write my master thesis, with my supervisor Professor Jan Lexell, opened the door to research. My wonderings about the ability to have a good life despite a complex neurological disease made me think 'How can I, as a physician, support persons to have a good life situation", which has been a question motivating me throughout this thesis.

Writing a thesis is so much more than just writing. Sometimes it is frustrating, even with a feeling of moving backwards instead of forwards. Despite the frustration, I am grateful it took some time, giving me a possibility to develop and grow as a researcher, clinician, and as a person. I used to see myself as a clinician doing research but now, I see myself as both a clinician and a scientist, and from this day I will not be able to separate these roles. The title of this thesis refers to the road for persons living with PD, but it also symbolises my own journey writing this thesis, where I sometimes almost felt lost before finding the road again.

At the beginning of the road, I was not sure I would get the answer to my question. Now I know how I, as a rehabilitation medicine physician, can support persons with

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* One can discuss what term a person with a disease or impairment should be called. In the healthcare system, the term 'patient' is normally used. This refers to a person who suffers and makes the person passive and subordinated in relation to the healthcare professionals. In rehabilitation medicine, the person with an impairment is highly participating in the management and rehabilitation. The 'patient' is, first of all, a human being living with a disease or an impairment, and we should therefore remember 'the person first', i.e., a person with PD. The noun 'person' has two plurals – people and persons. To keep the individual perspective and person-centred approach I've chosen to use the term 'persons with Parkinson's disease' throughout this thesis.

PD (PwPD) to improve their life situation. I appreciate the opportunity to explore both quantitative and qualitative research in this thesis. Through the qualitative approach, the knowledge is now in my mind, hands, and heart. With this book I have tried my very best to also put it on paper, to share with you.

Now this part of my journey along the road to this thesis has come to an end. I want you to see this thesis as a road map for PwPD, and their clinicians, on the journey for achieving a high level of life satisfaction. Wherever the road brings you, I hope you will enjoy it!

Context of this thesis

This thesis has been written from my perspective as a coming specialist in rehabilitation medicine. I have been carrying out the research in parallel with my clinical work while doing my internship and residency in rehabilitation medicine. There is a great deal of fundamental research on PD, but less on rehabilitation and management while living with the disease. Some studies have explored quality of life. However, being diagnosed with PD means per definition loss of quality of life because of the physical disabilities. I wanted a more subjective focus, letting the person evaluate his/her own life situation, which is more in line with the patient-centred care in rehabilitation medicine. After reading the definitions of life satisfaction (LS) it became an appealing focus for me. In addition, when I started my research there was nothing to find on LS and PD in the literature. I found a huge knowledge gap that I wanted to fill.

The logical start was to study how to assess LS and which factors that are of importance for LS. The further I came in the process, the more I faced the complexity of LS in PwPD. It became evident that I would not gain the understanding I was aiming for by only using quantitative methods. I also received valuable feedback in the halfway review that encouraged me to focus more on a qualitative approach. In addition, qualitative methodology is still a new way of doing research on PD and has just become more common in recent years.

The second part of this thesis has therefore been conducted in a qualitative approach and having the opportunity to cooperate with Professor Anna Forsberg provided a greater depth and width. Being able to work in the Multipark research environment also gave me the opportunity to gain input from scientists in other areas of the PD research field, which also stimulated the process.

More scientists in Sweden and throughout the world have, to my delight, started to focus on LS and PD during the course of this thesis, but still after eight years, the knowledge is very limited. The Swedish National Guidelines for PD were published in 2016, and I was relieved that more people had understood the importance of rehabilitation for PwPD. Unfortunately, when I met persons living with PD, I realized that these guidelines were not always implemented. It thus became important for me that this thesis should contain distinct suggestions and recommendations for healthcare professionals that could easily be applied in their clinical work. This thesis can thus facilitate the implementation of the national guidelines and result in a more equal care and rehabilitation for PwPD, so that they can achieve and maintain a high level of LS over time.

Introduction

Parkinson’s disease

Parkinson’s disease (PD) is one of several conditions in the group of movement disorders. It is a life-long progressive neurological condition and the second most common neurodegenerative disease. The condition is named after the English apothecary and surgeon James Parkinson who was the first one to describe the cardinal symptoms of PD in his publication “An essay on the shaking palsy” in 1817 [17].

Pathophysiology and Epidemiology

The cause of PD has not yet been fully identified despite a large body of research. Most evidence suggests a combination of genetic and environmental factors. Several genes have been described to be related to PD, but most persons developing PD do not have these genetic variations [18]. There are several known environmental risk factors, including exposure to pesticides, head injury, drinking water from a well, consumption of dairy products, substantial emotional stress, and agricultural occupations. Some environmental factors have been described to reduce the risk of developing PD, such as tobacco smoking, coffee drinking, long-term use of anti-inflammatory drugs and intensive physical activity [18-20]. However, the mechanism of these risk factors and potentially protective factors has not been fully explained.

PD is developed through a complex interaction between inherent vulnerability of the nigrostriatal dopaminergic systems, a possible genetic predisposition, and exposure to environmental stressors such as toxins or physical trauma [21], as described above. The complex interaction results in a progressive loss of dopaminergic neurons within the substantia nigra, part of the basal ganglia in the mid-brain. This area is important for coordination and performance of movements; the loss of dopaminergic neurons thus leads to tremors and difficulties with movements, described as the cardinal symptoms of PD [22]. More specifically, the loss of dopaminergic neurons is caused by aggregations of misfolded alpha-synuclein proteins [18]. These misfolded proteins form so called Lewy-bodies within the cell body. Evidence now suggests that chronic neuroinflammation is associated with the pathophysiology of PD and that nigrostriatal dopaminergic neurons are more vulnerable to pro-inflammatory and oxidative mediators than other cell types, which is hypothesized to explain the selective death of dopaminergic neurons [21]. The damaged cells with misfolded proteins are also hypothesized to spread these misfolded proteins to other neurons, leading to the progression of the disease. One hypothesis describes a gradual circuitry degeneration within the nigrostriatal pathway as the disease progresses, gradually producing motor, cognitive and psychiatric symptoms [23].

The prevalence of PD increases with age and PD affects about 1% of the population above 60 years of age. The prevalence in Sweden is estimated at 20 000 individuals, and approximately 2000 persons are diagnosed with PD every year [24]. Approximately 6.1 million persons are estimated to have PD in the world, with a fairly equal distribution between men and women. The global burden of PD has more than doubled in the past generation. As a result of improved medical treatment and a longer life expectancy in the general population the number of PwPD is expected to almost double in the coming decades [25, 26]. This will lead to a greater number of persons living with PD for many years of their lives, which will result in an increased need for healthcare resources for the management and rehabilitation for PwPD.

Clinical manifestations and medical treatment

Clinical symptoms and stages

The PD diagnosis is mainly based on clinical observations and assessments of a neurologist specialising in movement disorders [27]. Dopaminergic imaging and lumbar punction are often performed to rule out other diseases [18]. The diagnosis of PD requires presence of bradykinesia and at least one of the cardinal signs: tremor at rest, rigidity, and postural instability. There are also a number of exclusion criteria and supportive criteria to facilitate the diagnostics. A positive response to medical treatment will further strengthen the diagnosis. Apart from the cardinal signs, there are several other so called motor symptoms in PD, such as walking difficulties with reduced step lengths, gait speed, arm swing, and a stooped posture [28]. Many persons have speech impairments [29], and freezing of gait is also common in later stage of the disease [30]. Although PD is still often considered a motor disorder, almost all PwPD experience multiple non-motor symptoms. These include for example fatigue, loss of smell, cognitive impairment, psychiatric symptoms like anxiety and hallucinations, sleep disorders, pain, autonomic dysfunction (such as constipation and orthostatic hypotension) [31, 32]. Common motor and non-motor symptoms of PD are illustrated in Figure 1.

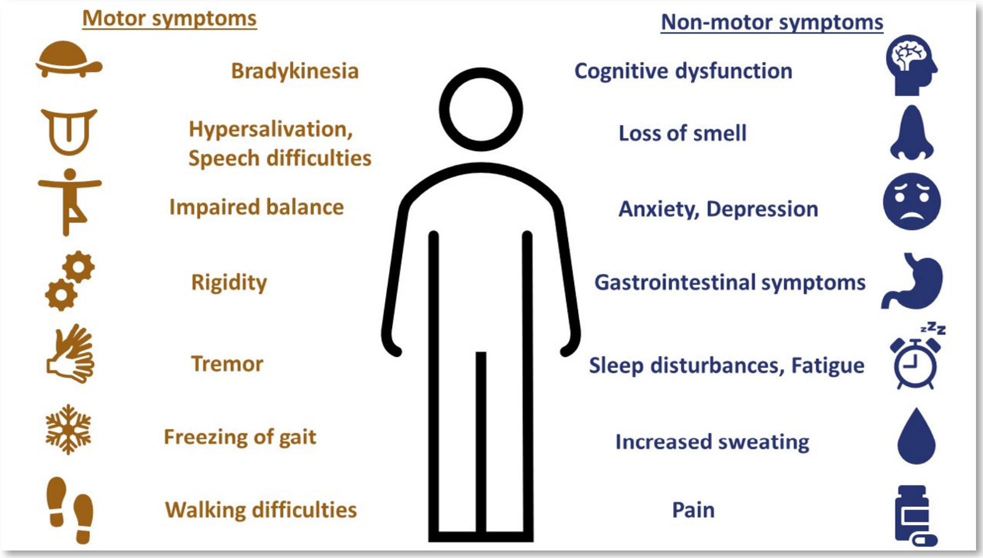


Figure 1. Symptoms of Parkinson's disease
Illustration of common motor symptoms (brown) and non-motor symptoms (blue) of Parkinson's disease.

The progression of PD is highly individual and in order to be able to describe the level of the disease and its progression, several classifications for PD have been presented [33]. The Hoehn et Yahr staging has been used for many years [34]. This system of five stages is based on the clinical motor features of the disease: stage 1-3 covers minimal to moderate disability, whereas stage 4 and 5 describe severe disability. Stages 1-3 are also commonly referred to as "earlier stages" and stage 4-5 as "advanced stages". A preclinical or prodromal phase has also been described where the motor and non-motor symptoms are not severe enough to qualify for a diagnosis [35]. Due to the complexity of the disease, the lack of evaluation of non-motor features in the Hoehn et Yahr staging, and the need of a holistic management, the term "advanced" has been questioned and it has been suggested that the later stages of PD should be referred to as "complex" instead [36]. The several systems and attempts to categorize PD elucidates the complexity of the disease and emphasises the need for research to better understand how each individual is affected by the disease.

Pharmacological and advanced treatments

There is no curative treatment for PD. All treatments are still symptomatic and will not slow down the progression of the disease. The most commonly used treatment is medication with dopaminergic effect, i.e., drugs targeting dopaminergic receptors. The main categories are Levodopa and dopamine agonists. In addition, there are several enzyme inhibitors used to prolong the effect of the dopaminergic drugs, such as MAO-B and COMT inhibitors. The medication results in higher dopaminergic levels and is often effective in the early years of the disease [4, 18].

The effect of the medical treatment starts to fluctuate as the disease progresses and a need for increased doses of medications can lead to side effects, such as involuntary movements, “on and off fluctuations”, hallucinations and reduced impulse control [4, 37]. Finally, in an advanced or complex phase, patients may experience motor complications despite optimized pharmacological therapy [38]. Furthermore, the non-motor symptoms are usually less responsive to medications. Apomorphine, a dopamine agonist, can be used as therapy for persons with motor fluctuations, with potential positive effects on non-motor symptoms [39]. As the disease progresses, oral medication may be insufficient to provide acceptable symptomatic control.

Some persons with severe PD symptoms might benefit from more advanced treatment methods, such as subcutaneous administration with a medical pump (so - called Duodopa pump) to ensure an even flow of medication over the day [40]. Another advanced treatment option is the implantation of a deep brain stimulator (DBS) to block the abnormal activity in the basal ganglia, and thereby reduce the movement difficulties [4]. Attempts to treat neurodegenerative diseases with stem cell transplantation has been performed for the last decades, and several clinical trials are currently ongoing [41].

Non-pharmacological treatments

In addition to the pharmacological treatments, there are several non-pharmacological interventions aiming at improving function and long-term prognosis. Regular physiotherapy and physical activity are an important complement to pharmacological treatment, and can improve balance, gait, functional ability, as well as reducing non-motor symptoms such as sleep disturbances, fatigue, pain, anxiety, and constipation [42, 43]. There is also a growing evidence for neuroprotective effect of physical activity, suggesting that physical activity might slow down the progression of the disease [44]. A disease specific voice treatment (referred to as Lee-Silverman Voice Treatment) has been developed for improving volume and articulation of speech, and is specifically targeting PwPD with speech impairments [29].

Despite a combination of pharmacological, non-pharmacological and, for some persons, advanced treatments, the motor and non-motor symptoms lead to various consequences in daily life for PwPD.

Parkinson’s disease and consequences in daily life

The majority of PwPD are community dwelling for the main parts of their lives, and after 10 years with the diagnosis most of them still live in their own residences [45]. The disease can be perceived as unpredictable and difficult to control, with the individual progression of both motor and non-motor symptoms, often in a fluctuating and complex pattern [46]. The impact on everyday life is inevitable [47] and PwPD will be forced to several changes in everyday life. Everyday life is referred to as the practical tasks common to most persons, such as getting dressed, eating, washing, moving around at home and in the community and also involves social interactions with other persons at home and in the community [5, 6]. This section describes some of the consequences in everyday life for PwPD, however these are just a few examples of consequences one might experience with PD. Interactions and activities that are considered to be included in everyday life, and how these activities are affected by PD, is highly individual.

The bradykinesia, tremor and rigidity lead to slowness and difficulties in conducting activities of daily living (ADL), which is used as an indicator of a person’s functional status [2, 48]. ADL includes activities such as eating, bathing and mobility. This can make daily living more demanding and time consuming.

PwPD might have communication difficulties due to rigidity of facial muscles, causing impaired facial expression and blurred speech. This, in turn, can affect personal relationships with family and friends, as well as impact the interactions at work or in the community. PwPD tend to have fewer close friends and it has been described that PwPD lose friends when they are diagnosed with PD. The motor symptoms such as tremors, dyskinesias, freezing of gait and balance problems can be experienced as embarrassing in social contexts, leading to PwPD avoiding social events. The experienced stigma of several of the symptoms can lead PwPD to hide their symptoms and diagnosis instead of speaking openly about it, leading to further loss of friends [49, 50]. In addition to the decreased social interactions with friends and family, PwPD often retire earlier from work, leading to loss of social interaction at work, and a loss of income. The retirement is often due to an inability to meet the demands at work, as a result of symptoms such as motor function, fatigue or stress sensitivity. Work is an important part of one’s identity for most PwPD, and plays an important role in their everyday life [51]. The inability to work can therefore be a great loss.

The physical disabilities also lead to an increased risk of falling and thus also to the common phenomenon fear of falling (FOF). FOF is associated with reduced physical activity and walking in the community, is a barrier for ambulatory persons to engage in physical exercise and leads to restricted participation in meaningful activities. FOF thus leads to a more sedentary life style and thus further increasing the social isolation [52].

The motor and non-motor symptoms become more prominent, as the disease progresses. Even though most PwPD continue living in their own home, they become subsequently less independent and need support from others to manage everyday life. Aside from the personal ADL described above, this may also include housework, taking care of bills, driving a car, and following the medication regimens etc. [53]. Non-motor symptoms, such as cognitive impairment, sleep disorders and fatigue, can be the first presentation of the prodromal phase [32], but can also be prominent with for example severe fatigue, hallucinations or dementia in the more advanced stages of the disease, and severely affect the life situation [54].

Despite the manner of the disease progression, living with PD incorporates a complex web of changed prerequisites for managing day-to-day demands and social participation [47]. The motor and non-motor symptoms lead to a variety of impairments, activity limitations and participation restrictions. This impacts the persons whole life situation [55-59]. Since there are no curative medical treatments for PD, PwPD need support to manage the consequences of the disease in everyday life. This may be achieved through medical rehabilitation.

Rehabilitation for persons with Parkinson's disease

The Swedish National Board of Health and Welfare has published national guidelines for supporting the county health authorities and the municipalities in the treatment, care and rehabilitation of PwPD, due to the complexity and progression of the disease [24]. The guidelines suggest that PwPD should be offered regular check-ups by a neurologist experienced in PD, at least twice a year. It is further recommended that PwPD should be offered interdisciplinary team rehabilitation.

Rehabilitation is a process defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" [11]. It is aimed to provide persons with disabilities with the tools they need to achieve and maintain self-determination and independency. Rehabilitation is highly person-centred where every intervention and approach should be selected for each individual and based on their specific goals and preferences [6]. Rehabilitation can entail managing symptoms, treatment, physical and psychological consequences, everyday life, and behavioural changes that need to be done when living with an impairment.

Important components of medical rehabilitation are self-management and empowerment [60]. Self-management is conceptualized as a set of tasks and processes that is used by an individual to maintain wellness in the presence of an ongoing illness or impairment [61]. Empowerment has been acknowledged as a way to guide the provider-patient relationship [62], and focus on the individuals' capacity to make decisions about their health behaviour and to take control over aspects of their life related to health [63]. Empowerment incorporate personal control and self-efficacy and occurs when health care professionals support the patient to increase the capacity to make autonomous, informed decision and choosing meaningful realistic goals [64]. Empowerment and self-management are thus important components of the behavioral change in the rehabilitation process.

However, how these rehabilitation interventions should be performed for PwPD, has not been described and the access to interdisciplinary rehabilitation differs in Sweden, often due to a lack of resources. The rehabilitation of PwPD is often based on clinical experiences and not on empirical evidence, which may not be sufficient for supporting PwPD living with the consequences of the disease. When asking PwPD what support they need, it emerges a need for research on living with the disease, as a complement to fundamental research on PD [65].

When designing rehabilitation interventions, they need to be scientifically evaluated, which is accomplished by scientific research. One emphasized outcome measure in rehabilitation research is life satisfaction (LS), which has also been suggested to be an overarching goal in modern management and rehabilitation for persons with life-long disabilities, such as PD [66, 67].

Life satisfaction

LS is a generic term commonly referred to as a person’s subjective contentment with life. It is a cognitive judgement of one’s life situation and is defined as “a global assessment of a person’s quality of life according to his chosen criteria” [16, 68]. LS is a part of the broader concept of subjective well-being (SWB), the cognitive aspect, whereas the other parts refer to the emotional aspect in terms of the individual’s emotional responses, as illustrated in Figure 2 [16, 69].

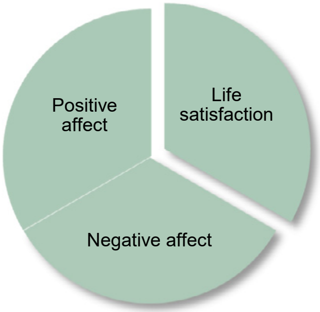


Figure 2. Subjective Well-being
Life satisfactions, as the cognitive part of the wider concept of subjective well-being (SWB). Positive and negative affect refer to the emotional aspects of SWB.

LS embraces what leads persons to evaluate their lives in positive terms and relies on the standards of each individual to determine what is the good life [16]. LS is dependent on a person's adaptation process and reflects the degree to which individuals perceive that their own aspirations and achievements in life are met [70]. A hallmark of LS is its subjectivity. It focuses on the person's own judgment in a research context and not on some criterion that is considered to be important by the researcher [16].

It is worth mentioning that LS is sometimes mistaken for quality of life (QoL), but these concepts should not be considered to be equivalent. QoL has been of paramount importance in the evaluation of the quality and outcome of health care, but there has not been a consensus on the definition or proper measurement of QoL. One of the most commonly used concepts is Health Related Quality of Life (HRQL). There is a small but important distinction between LS and HRQL, where the latter includes objective measurements and focuses more on physical functioning, whereas LS is completely subjective, where psychological assets and skills are of importance [71]. LS allows the person him/herself to evaluate his/her life situation, despite physical impairments. In addition, in a review of the conceptualisation of QoL and the inherent difficulties of this task, the authors suggest that defining QoL in terms of LS is the most appropriate way [72].

LS has been suggested to be an overarching goal in modern management and rehabilitation for persons with life-long disabilities [66, 67], levels of LS can thus be regarded as an indicator of how well rehabilitation interventions provide for the support needed by the individual. In order to use LS for this evaluation, we need to be able to assess LS and understand which factors that might influence LS for PwPD.

Assessing and exploring life satisfaction

In order to use LS as an outcome measure for rehabilitation, we need to be able to evaluate it. Since LS is subjective, it is usually assessed through self-reports [73]. Several tools for assessing LS exist, and one of the most commonly used is the Satisfaction With Life Scale (SWLS) [74]. The SWLS was developed by Diener et al. in 1985 as a brief questionnaire intended to assess an individual's general sense of satisfaction with life as a whole [75]. The questionnaire consists of five items and has demonstrated good psychometric characteristics in several populations [7]. The Swedish version of the SWLS has been used among persons with traumatic brain injury [76], but has not been evaluated for PwPD before.

If one wants to increase or maintain a high level of LS, gaining an understanding of the factors that influence LS is a necessary complement to knowing how to assess LS. One such factor is the salutogenic concept Sense of Coherence (SOC) developed by Antonovsky [15]. SOC is a psychological factor and construct, related to the preservation of good health regardless of external strains [15, 77] and has been found to be an important resource in coping with life-long conditions [77], such as PD. A strong SOC is associated with a high level of LS [76, 78]. SOC comprises the three components comprehensibility, manageability and meaningfulness [15]. This can also be described as: individuals who experience their lives as understandable, feel that they are capable of managing their life situation and experience their lives as meaningful, are more successful in reaching a high level of LS. Thus, there is a need to understand the association between SOC and LS, as well as other factors that might be of importance for LS for PwPD.

In order to be able to plan appropriate person-centered rehabilitation interventions to increase LS, it is essential to understand their inner perspective with regard to their view on PD and consequences for daily life and LS. In order to gain such an understanding, a suitable approach is to apply qualitative methodology [79], since qualitative research deals with experiences, perceptions and meaning, and thereby allows an in-depth understanding from the persons' own perspectives [80].

Life satisfaction for persons with Parkinson's disease

The impact of PD leads to inevitable changes in everyday life and can reduce the persons LS [58]. Since PD is a progressive disorder, one can assume that there is a great need for PwPD to continuously adapt to their situation in order to achieve and maintain a high level of LS. PwPD might be in need for support of rehabilitation when going through this individual process of change.

The subjectivity of LS is well suited for evaluating the whole life situation of a person living with a life-long neurologic disease, such as PD. The motor symptoms required for the diagnosis of PD result in decreased levels of HRQL or other concepts including physical function evaluation. Each person can be given the opportunity to truly evaluate his/her life situation according to his/her unique criteria by using LS measurements, which is essential in patient-centred health care. Improved LS has also been suggested as being the ultimate goal for PD care [55]. LS can thus be considered a suitable way for evaluating the life situation for PwPD. They should also be offered interdisciplinary rehabilitation in accordance with the National Board of Health and Welfare [24], and LS has been proposed as the overarching goal in rehabilitation.

However, the level of knowledge about LS and PD is surprisingly low. At the beginning of this project, there was nothing to find in the literature on LS for PwPD. More scientists have started to explore LS in PwPD during the last couple of years [55, 56, 58, 59, 81]. The existing knowledge about LS in PwPD shows that the illness is related to decreased LS, and LS tends to decrease further as the disease progresses [55, 59]. General self-efficacy, walking difficulties and depressive symptoms have been suggested as being important predictors of LS [55, 59], but only a handful of studies have been performed. As mentioned above, adaptation is important for LS, but to the best of my knowledge, there are no studies on adaptation and LS for PwPD or how PwPD are going through the process of change when living with PD, which might influence their LS. Further knowledge is needed about rehabilitation interventions for PwPD aiming at increasing and maintaining high levels of LS over time.

Rationale

Knowledge about LS and PD was virtually non-existent when starting this project. Nothing could be found in the literature about how to assess LS, which factors that might be of importance for LS in PwPD or the meaning of LS from the perspective of PwPD. This knowledge is needed in order to develop rehabilitation interventions for PwPD aiming to achieve and maintain a high level of LS.

Despite the best possible available treatments, the progression and complexity of PD lead to various consequences in daily life for PwPD and affect the person's LS. LS can be used as an outcome measure for rehabilitation inventions and as an ultimate goal in PD care. In order to design interventions aiming at increasing LS, there is a need for knowledge about how to assess LS, what factors are associated with LS. In addition, knowledge is needed about how the persons themselves experience the meaning of adaptation and LS, and the process of change when living with PD.

LS for PwPD thus needs to be explored with different approaches in order to gain a wide and deep understanding of this phenomenon. The increased knowledge can enable the future development of rehabilitation interventions for achieving and maintaining a high level of LS for PwPD over time.

Aims

The overall aim of this thesis was to increase the knowledge and understanding of LS in PwPD.

The specific aims of this thesis were:

I. To evaluate the psychometric properties (i.e., data completeness, scaling assumptions, targeting and reliability) of the SWLS in a sample of persons with PD.

II. To describe LS in persons with mild to moderate PD and to evaluate the association with gender, age, years since diagnosis, and sense of coherence, perceived participation, and mental and emotional status.

III. To gain an in-depth understanding of the meaning of LS and adaptation in persons with PD.

IV. To investigate the process of the change and LS, and the main concern in this process, when living with PD.

Overview of this thesis

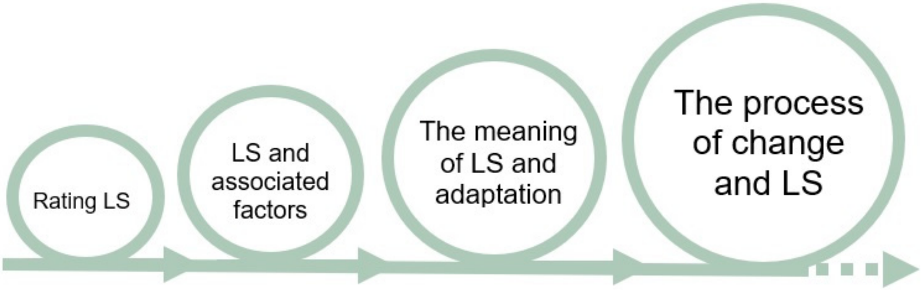


Figure 3. Expanding the knowledge about LS for PwPD
The knowledge about LS has been expanded from a narrow reductionist point of view, to a broad, holistic and greater understanding of LS.

In order to increase the knowledge about LS and PD, the focus on LS has been evolved from a narrow reductionist point of view in terms of a measuring instrument, to a broad, holistic and greater understanding of LS (Figure 3). The empirical studies in this thesis have been guided by a specific research interest to expand the knowledge of LS in PwPD.

The epistemological assumption involves a belief that knowledge about e.g., living with PD can be studied by assessing the behaviour of the patients by using measurement instruments, as well as interviews. The efforts to gain scientific knowledge included evaluating the measurement properties of a commonly used rating scale (Study I) as well as associations between LS and determining factors (Study II) and exploring the lived experience of LS and PD (Studies III and IV). The data collection methods were thus both deductive and inductive, and included questionnaires and interviews. Study I was motivated by the absence of a method for assessing LS in PwPD. In study II, numerical data were collected to allow comparison and enable statistically significant relationships. The measurements and questionnaires were used to evaluate and assess LS and associated factors among PwPD. The results from the two initial studies contributed with knowledge as a foundation for the two following studies that supported the need for an in-depth understanding of adaptation and LS, and when developing the theoretical model in the fourth study.

The thesis is thus comprised of two different methodologies: quantitative (Studies I and II) and qualitative (Studies III and IV). These methodological approaches will hereby be referred to as *Assessing LS* (Studies I and II) and *Exploring LS* (Studies III and IV). The four studies included in this thesis are summarized in Table 1.

Table 1. Overview of the four studies of this thesis.

	Study I	**Study II**	**Study III**	**Study IV**
	Assessing LS		*Exploring LS*	
Brief title	*Rating LS*	*LS and associated factors*	*The meaning of LS and adaptation*	*The process of change and LS*
Aim	To evaluate the psychometric properties of the SWLS in a sample of PwPD.	To describe LS in persons with mild to moderate PD, and to evaluate the association with gender, age, years since diagnosis, and SOC, perceived participation, and mental and emotional status.	To gain an in-depth understanding of the meaning of LS and adaptation in PwPD.	To investigate the process of change and LS, and the main concern in this process when living with PD.
Design	Quantitative Cross-Sectional	Quantitative Cross-sectional	Qualitative Inductive	Qualitative Inductive
Participants	97 participants with mild to moderate PD	80 participants with mild to moderate PD	13 participants with mild to moderate PD	
Data Collection	Postal survey	Postal survey	Semi-structured interviews	
Outcome(s)	SWLS	SWLS, SOC-13, RNLI, GDS-20	Participants' experiences	
Analysis	Data completeness Scaling assumptions Targeting Reliability	Hierarchical multiple regression analyses	Phenomenological hermeneutic	Grounded Theory Constant comparative method

SWLS= Satisfaction With Life Scale; PD= Parkinson's disease; PwPD= Persons With Parkinson's Disease; LS= Life Satisfaction; SOC=Sense Of Coherence; RNLI= Reintegration to Normal Living Index; GDS= Geriatric Depression scale

The methods and results of the four studies are merged in the following chapters and will be presented as *Assessing LS* (Studies I and II) and *Exploring LS* (Studies III and IV). A comprehensive discussion and summarized conclusions follow, as well as a presentation of the summarized clinical implications and future perspectives.

Assessing life satisfaction

An exposition of the methods and results from the two quantitative studies aiming at assessing LS is presented in this chapter under the brief titles *Rating life satisfaction* (Study I) and *Life satisfaction and associated factors* (Study II).

Rating life satisfaction

In order to be able to assess LS we need a rating tool that is reliable, stable and user-friendly. These aspects can be assured by exploring the psychometric properties of a measuring tool or rating scale. The methods and results from the psychometric evaluation in Study I will be described in this section.

Study design

There are some aspects that always need to be considered when using a rating scale for clinical use or in medical research. First of all, one needs to know if the rating scale captures the intended focus, i.e., if it is valid or not. After confirming the validity of the rating scale, it is necessary to determine whether the scale is of high quality, has a small measurement error, and is suitable for the intended population. This can be evaluated by studying the scale's psychometric properties, such as data completeness, scaling assumptions, targeting, and reliability [82]. These properties are sample dependent and always need to be evaluated when using a rating scale in a new sample, such as PwPD. The first study of this thesis was thus a psychometric study of the rating scale SWLS in a sample of persons with mild to moderate PD.

Satisfaction With Life Scale

The SWLS, developed by Diener et al (1985), is intended to assess a person's global judgment of his or her LS. The rating scale consists of five items, assessed with a 7-point Likert scale, see Table 2. The user rates each item with a score from 1 (=strongly disagree) to 7 (=strongly agree). All items are keyed in a positive direction, meaning that the five responses can be added up to a total sum score with a possible range from 5 to 35 points.

Table 2. The five items of the Satisfaction With Life Scale

Item no	Statement
1	In most ways, my life is close to my ideal.
2	The conditions of my life are excellent.
3	I am satisfied with life.
4	So far I have gotten the important things I want in life.
5	If I could live my life over, I would change almost nothing.

The scores can be interpreted with categories describing the person's satisfaction with life; a total point of 20 points representing the neutral point of the scale. Scores from 5 to 9 points indicate that the person is extremely dissatisfied with life, while scoring 30 to 35 points indicate that the person is highly satisfied with life. For a full interpretation of the total sum scores of the SWLS, see Table 3.

The scale was developed for use in the assessment of LS in people with a wide range of ages and health conditions [75]. The scale has shown good convergent validity with other scales and assessment tools of SWB, and has also shown discriminant validity from emotional well-being measures [7]. Several studies have been performed on the psychometric properties in different populations, with a Cronbach's alpha ranging from 0.79-0.89, indicating that the scale has a high internal consistency [7]. Test-retest reliability has been evaluated with coefficient of 0.82 over a two-month interval [74], and 0.54 over a span of 4 years [7]. These studies suggests that LS has a moderate temporal stability but can change over time.

Table 3. Interpretation of the SWLS score*

Total sum scores	Categories
30-35p	Very high score; highly satisfied
25-29p	High score
20-24p	Average score
15-19p	Slightly below average
10-14p	Dissatisfied
5-9p	Extremely dissatisfied

*Categories stratified according to Diener [83].

Participants and data collection

The data collection was carried out through a postal survey, sent on two occasions to explore the test and retest with approximately a two-weeks interval. The participants were recruited from two outpatient clinics in southern Sweden and the data were collected by the second author of the first paper (SBJ). The inclusion criterion was a diagnosis of PD (ICD10: G20.9) for at least one year. Exclusion criteria were clinically confirmed dementia, difficulties in reading and writing Swedish or a cognitive or medical condition that was assumed to constrain giving informed consent or participating in the study.

A PD-specialized nurse at each clinic assisted in screening the medical records for all PD patients that had visited the clinics during the past year (n=275). The inclusion and exclusion criteria were applied and a total of 174 potential participants remained and were invited to take part. A total of 97 participants were finally included in the study; 63 persons had not responded, six communicated that they did not want to participate, five had left the SWLS questionnaire unanswered, and three had not answered the questionnaires themselves.

Table 4. Characteristics of the 97 participants with Parkinson's diseae in Study I

	n*/years
Sex	
Men	56 (58%)
Women	41 (42%)
Age (years)	
Mean (SD)	73 (8)
Range	52-91
Years since diagnosis[a]	
Mean (SD)	7 (6)
Range	1-30
Self-rated disease severity[a]	
Mild	24 (26%)
Moderate	58 (62%)
Severe	11 (12%)
Use of walking-aids	
Indoors[c]	23 (25%)
Outdoors[d]	39 (42%)
Activities of daily living[e]	
No difficulties	23 (26%)
Mild difficulties	47 (53%)
Moderate difficulties	16 (18%)
Severe difficulties	0 (0%)
Extreme difficulties	3 (3%)

*Note that not all participants answered all questions.
[a]n=93, [b]n=96, [c]n=91, [d]n=92, [e]n=89

All the participants received the postal survey containing information about the study, a written informed consent form, background questions with social-demographic and disease-related questions, the SWLS and a pre-stamped envelope to return the questionnaires. The SWLS was administrated twice (for test and retest) with a two-weeks interval. A reminder was sent for the non-responders on the first survey after two weeks, and after one week on the second survey.

Fifty-six percent of the 97 participants were men and 42% women, with a mean age (SD) of 73 (8) years. The mean disease duration in years (SD) since diagnosis was 7 (6), with a range from 1 to 30 years. Basic demographic data and the participants' characteristics show that 88% rated their PD as mild to moderate and 79% had no or mild difficulties in ADL. Patient characteristics in Study I are presented in Table 4. This population thus represents persons in the earlier stages of the disease.

Data analyses and summary of results

The psychometric evaluation was based on four parts: data completeness, scaling assumptions, targeting and reliability (internal consistency reliability and test–retest reliability). A brief explanation of each part of the analysis is presented in Table 5. Data completeness and test-retest reliability was based on the two surveys (T1 and T2), while the scaling assumptions, targeting and internal consistency were based on data from the first survey (T1). The four parts of the analysis are presented separately in this section.

Table 5. Data analyses in study I

A brief summary of the four parts of the data analyse	
Data completeness	Evaluates the extent to which a rating scale has been completed.
Scaling assumptions	Explores the legitimacy of summing item scores for generating a total sum score.
Targeting	Explores whether the rating scale's score distribution adequately represents the true level of SWLS in the sample
Reliability	Evaluates the extent to which the score reflects the actual true score rather than a random error, and the reproducibility of scores.

Data completeness

If many of the respondents choose not to complete or fail to complete a rating scale, it can be an indication that the rating scale is irrelevant or difficult to understand for the respondent [82]. Data completeness was therefore calculated by the percentage of missing items responses and total scores, which are indicators of data quality since a scale score cannot assuredly be estimated if there is a high level of item-level missing data [82, 84]. Of the 97 participants, 89 (92%) had answered all five items of SWLS at T1, seven had left one or more items unanswered, and one response was not interpretable. The response rate of the five items was 92% to 97%.

The response rate at T2 was 93% to 97%, and a total of 83 participants (86%) had given a total score on both T1 and T2 and were thus included in the test-retest reliability analyses.

Scaling assumptions

Scaling assumptions were analysed to explore the legitimacy of summing item scores in order to generate a total sum scale score. There are a series of criteria that should be met for a set of items to be summed to form a total sum scale score [82, 84]. It is stated in these criteria that the items should be approximately parallel to equally contribute to the variance of the total score. This is met when the mean scores, standard deviations (SDs) and distributions of item response option frequency are roughly equivalent. The scores of the SWLS in Study I showed a roughly parallel item mean and SDs for all five items of the SWLS. The items should also measure the same underlying construct, being internally consistent. To meet this criterion, the item-total correlation should exceed 0.4. In the third criteria it is stated that the items should contribute with similar proportions of information on LS. This is met by the corrected item-total correlations exceeding 0.3 [82, 84]. The items in Study I had a corrected item-total correlation between 0.7 and 0.83, and thus met the criteria for internal consistency and the items contribute with similar proportions of information.

Targeting

Targeting is a term referring to whether the rating scale's score distribution adequately represents the true level of SWLS in the sample [82]. This is assessed by exploring the rating scale's score distribution, skewness and floor and ceiling effects. The mean total score should be reasonably close to the scale's midpoint to have a good distribution. In addition, the total scores should range the full span of possible total scores. The data showed that the scale spanned the full range of possible scale scores, from 5 to 35 points, with a mean (SD) score of 24.4 (7.7) points. Skewness was less than 1, which is within the stated criteria range that skewness should be less than +/- 1 [82, 85]. Floor and ceiling effects were evaluated to see whether a too great number of responders were rating the maximum or minimum scores, which could indicate that the scale did not contain a sufficient number of scale levels. This is measured by the percentage of responders scoring the minimum (floor) or maximum (ceiling) possible total score. This should not exceed 15% [86], and the present data showed floor and ceiling effects of 1.1% and 4.5%, respectively. The results thus showed a low floor and ceiling effect within the recommended limits.

Reliability

Reliability is evaluated by measuring the random error associated with the scale's score, in other words, the extent to which the score reflects the actual true score rather than random error, and the reproducibility of scores [82, 84]. Reliability was examined by the internal consistency reliability with Cronbach's alpha [82, 87] at 0.90. A value of 0.75 or more is considered acceptable [88].

Reliability was also examined by exploring the stability of the scale, which was performed by evaluating test-retest reliability. This shows the scale's ability to reproduce a stable score over a time period when the respondent's life situation is unchanged. Evaluating reliability was also performed by measuring the mean difference ($\bar{d}$), and the 95% confidence interval (CI) around $\bar{d}$ was calculated to include 0, which is considered to prove that there were no systematic differences between T1 and T2 [89]. Test-retest reliability was evaluated with a one-way random, single measures intraclass correlation coefficient (ICC) with absolute agreement definition of concordance [89, 90]. The ICC was 0.78 and is close to 0.8, which is considered acceptable [91].

Variability, which was assessed by the standard error of measurement (SEM), was also examined. SEM represents the limit for the smallest change that indicates a real change for a group of individuals, which in Study I was calculated to 3.6 points. Thereafter, the smallest detectable difference (SDD) was calculated. SDD represents the limit for the smallest change for a single individual that can be interpreted as a real change and not within measurement error [12], and was calculated to 10.0 points.

In summary, the results of the psychometric evaluation in Study I showed that the SWLS had a high level of data completeness, scaling assumptions and targeting within the recommended criteria, an acceptable internal consistency and reasonably acceptable test-retest reliability.

Life satisfaction and associated factors

Based on the findings that SLWS is a psychometrically stable instrument for assessing LS, it could then be used for assessing LS and associated factors in order to examine which factors influence LS, and thus may be useful for rehabilitation interventions. The methods and results from Study II will be described in this section.

Study design

Study II was designed as a cross-sectional descriptive study with relationship analyses in order to examine factors that are associated with LS. The previously evaluated SWLS was used to assess LS. Various factors have shown to influence LS in other populations, and therefore some of these were examined to see whether they would be important for LS in PwPD. One of these factors is the previously described SOC, which has shown to be important for LS in persons with traumatic brain injury [76], and could also be of importance for LS for PwPD. Perceived participation, i.e., a person's subjective experience of his or her involvement in life situations [1], is another important factor for LS [92, 93]. A third factor that has been shown to be as important as physical functioning for LS is mental and emotional status [94]. The questionnaires that were used to assess these three factors will be described below.

Assessment tools

The Swedish versions of the following questionnaires were used in Study II.

Satisfaction with Life Scale

The Satisfaction with Life Scale (SWLS) [74], was used to obtain an overall measure of LS. For more information about the SWLS, see a more detailed description in the section *Rating life satisfaction* above.

Sense of Coherence scale

The 13-item Sense of Coherence scale (SOC-13) rates the three dimensions of SOC: comprehensibility, manageability, and meaningfulness [15, 95]. The scale consists of 13 items and is designed as a 7-point Likert scale ranging from 'agreement' to 'disagreement' with applicable phrases at each end such as 'very often' and 'never'. All item scores are combined to a total sum score ranging from 13 to 91 points. There are no cut off values for SOC-13, but a higher score indicates a stronger SOC. The scale has shown acceptable internal consistency with Cronbach's alpha from 0.70 to 0.92 [95].

The Reintegration to Normal Living Index

The Reintegration to Normal Living Index (RNLI) has been suggested as a suitable tool for assessing perceived participation [96, 97]. RNLI comprises 11 declarative statements such as 'I move around in my community as I feel necessary' and the rating tool includes domains such as community, indoor, distance mobility, self-care, recreational and social activities, family role(s), personal relationships, and general coping skills. Each statement is rated by the user on a 4-point scale ranging from 'does not describe my situation' (=1 point) to 'fully describes my situation' (=4 points). The 11 items covering all described domains are added up for a total sum score ranging from 11 to 44 points. A higher score can be interpreted as a higher level of perceived participation [97]. The scale has shown good internal consistency with a Cronbach's alpha from 0.73 to 0.97 [98].

Geriatric Depression Scale

The Geriatric Depression Scale (GDS-20) was used to assess the participants mental and emotional status. GDS-20 was developed to evaluate whether or not a person could suffer from depression [99]. The scale consists of 20 questions to be answered with either 'yes' or 'no', such as 'Do you feel that your life is empty?' and 'Have you dropped many of your activities and interests?'. Each question answered with a 'yes' generates one point, adding up to a total score of 0 to 20 points. The cut off is at 6 points, meaning that a total score of 0 to 5 points indicates that the individual is not depressed, while 6 points or more indicates that a depression should be suspected. GDS is a commonly used screening tool and has shown to be reliable and valid in a Swedish elderly population [99]. GDS has also been suggested as the most efficient depression screening tool for PwPD [100, 101].

Participants and data collection

Persons with mild to moderate PD were recruited from an outpatient clinic in southern Sweden with the following inclusion criteria: a clinically verified PD diagnosis (ICD-10:G20.9) for at least one year, living in ordinary housing and being ambulatory with or without mobility devices. The exclusion criteria were a diagnosis of dementia, cognitive or medical problems of such degree that giving informed consent or completing the questionnaires would not be possible. Having difficulties reading or writing Swedish was also an exclusion criterion. A PD specialised nurse, with detailed knowledge of all PD patients at the clinic, supported in the screening of the local database which at the time comprised 285 persons with PD. A total of 128 persons met the inclusion and exclusion criteria and were thus invited to participate.

The data collection was made through a postal survey, where the potential participants received a letter with information carefully explaining the study, an invitation to participate, a consent form, the questionnaires described above, and one questionnaire with background information such as living situation, vocational status and occupational status. Sixty-five of the 128 potential participants gave their written informed consent to participate in the study, two persons declined and 61 did not respond. The non-responders received a reminder after three weeks, and a further 15 persons consented to participate. A total of 80 persons thus consented to participate in the study.

Table 6. Characteristics of the 80 participants with Parkinson’s diseaes in Study II

	n*/years
Sex	
Men	46 (58%)
Women	34 (43%)
Age (years)	
Mean (SD)	70.1 (10.3)
Range	42-86
Years since diagnosis[a]	
Mean (SD)	7.4 (6.5)
Range	1-26
Marital status[b]	
Single	21 (27%)
Married/cohabiting	58 (73%)
Living situation	
House	34 (43%)
Apartment	46 (58%)
Vocational status	
Working or studying	15 (19%)
Old age pension/disability pension	65 (81%)
Mobility device	
No device	51 (64%)
Indoors	2 (3%)
Outdoors	10 (13%)
Both indoors and outdoors	17 (21%)

*Note that not all participants answered all questions.
[a]n=75, [b]n=79

Forty-six men (58%) and 34 women (42%) participated in the study. They had a mean age of 70.1 years (SD 10.3, range 42-86 years) and a mean time since diagnosis of 7.4 years (SD 6.5, range 1-26). The background information showed that 21 participants (27%) were single and 58 (73%) cohabitated or were married, one did not respond on marital status. The majority (n=65, 81%) of the participants had old age or disability pension, while 15 persons (19%) were working or studying. A large proportion of the participants (n=51, 64%) did not use any mobility device. The participants’ characteristics are also described in Table 6. The mean total sum score of the participants’ ratings of the SWLS was 21.8 points (SD 7.0, range 5-35). The distribution of participants in the six categories of the total sum score is presented in Table 7.

Table 7. Distribution of the the total sum score on the SWLS for the 80 participants with PD.*

Total sum score	Categories	n (%)
30-35p	Very high score; highly satisfied	10 (13)
25-29p	High score	26 (33)
20-24p	Average score	17 (21)
15-19p	Slightly below average	15 (19)
10-14p	Dissatisfied	8 (10)
5-9p	Extremely dissatisfied	4 (5)

*Categories stratified accoring to Diener [83].

Association analysis and results

Bivariate correlations between variables were analyzed using Spearman rank correlation coefficient (Spearman's rho) in order to examine association between LS and the different factors. Data on the GDS were dichotomized as 'non-depressed' (5 points or less) and 'suspected depression' (6 points or more). The three variables SOC-13, RNLI and GDS, as well as years since diagnosis were all significantly correlated to SWLS. Age and gender did not, however, correlate with the SWLS. The strongest significant correlation was between the SWLS and SOC-13 (rho=0.50, $p<0.01$), meaning that a greater value on SOC-13 was related to a greater value on the SWLS. The strongest significant negative correlation was between years since diagnosis and SWLS (rho=-0.42, $p<0.01$), indicating that the longer the participants had lived with PD, the lower they rated their LS, with the SWLS.

Hierarchical multiple regression analyses were used in order to determine how different variables concurrently were associated with LS [9, 102]. The independent factors were background information (gender, age, years since diagnosis) and the total sum score of SOC-13, RNLI and GDS-20 (dichotomized). The dependent variable was LS assessed as the total sum score of the SWLS. The independent variables were added stepwise in the multiple regression analysis in a hierarchical manner (the variables strongest correlated to the SWLS being added first).

The hierarchical multiple regression analyses were performed in several steps (See Table 8), resulting in a final model where all the mentioned variables were included. The SOC-13 (Standardized beta coefficient 0.42**) and years since diagnosis (Standardized beta coefficient -0.33*) were the only significant contributing variables in the final model. These correlations mean that a higher score on SOC-13 was related to a higher score on the SWLS, and the longer the participants had lived with PD, the lower they rated LS with the SWLS. This final model explained 36% (R^2adj = 0.36; $p<0.001$) of the variance of the SWLS score.

Table 8. Results of the hierachical multiple regression analyses for the 80 participants with PD, with the SWLS as the dependet variable.

SWLS						
SOC-13	0.54***	0.49***	0.48***	0.43***	0.42**	0.42**
Years since diagnosis		-0.34***	-0.33**	-0.33**	-0.33*	-0.33*
RNLI			0.04	0.04	0.5	0.05
GDS-20				-0.09	-0.09	-0.08
Gender					-0.08	-0.08
Age						-0.01
Significance	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
R^2Adj	0.28	0.39	0.38	0.38	0.37	0.36
R^2Change	0.29	0.11	0.00	0.01	0.01	0.00
F Change	29.7	13.7	0.12	0.64	0.41	0.92
Sig F Change	<0.001	<0.001	0.70	0.43	0.41	0.92

Standardized beta coefficients are presented.
SWLS= Satisfaction With Life Scale, SOC= Sense of Coherence, RNLI=Reintegration to Normal Living Index, GDS=Geriatric Depression Scale. Correlation significant at the ***0.0001 level, at the **0.01-level and at the *0.05-level

In summary, the results in Study II showed that there was a wide distribution of scores on the SWLS, and the mean total score was categorized as an average score. SOC and years since diagnosis were significant correlated with the SWLS in the multiple regression analysis, and the model explained 36% of the variance of the SWLS scores. A strong SOC, indicating a person's capacity to adapt to the overall strains of the disease, showed the strongest association with a high level of LS.

Exploring life satisfaction

The results from the first two studies uncovered the need of a greater understanding and thus a different approach to truly understand LS. It can be assumed that there is a great need for PwPD to continuously adapt to their new life situation since PD is a progressive disorder with various consequences in everyday life. Adaptation has been described as an important factor for LS [103], but had not been studied in PwPD. Based on this knowledge and the need for a deeper understanding of the subjective LS, the most suitable approach was thus to continue this thesis by applying a qualitative research design [79].

Qualitative research design is one of several ways to obtain new scientific knowledge. It consists of research strategies suitable to describe and analyse characteristics, attributes, or qualities in the phenomenon in question. Qualitative research is also called interpretative inquiry, and is based on theories of human experiences (phenomenology) or interpretation (hermeneutics) [104]. It includes a wide spectrum of strategies to systematically collect, organize and interpret data with the aim to explore the meaning of different phenomenon. The researcher is an active participant in a development of knowledge which will never be complete, and often results in new questions rather than presenting a universal truth. The qualitative approach deals with perceptions, experiences and meaning, and allows an in-depth understanding of a person's inner perspective [80].

The inductive approach in Studies III and IV was chosen because the area in focus had been poorly investigated and there was a lack of specific knowledge about the experiences and concerns of PwPD. Humans differ as to how the world is experienced, but these differences can be described, communicated, and understood by others. The point of departure for the empirical research was the experienced, unreflected everyday world when living with PD.

The methods and results from the qualitative studies (Studies III and IV) are presented in this chapter and will be described under the brief titles *The meaning of life satisfaction and adaptation* (Study III) and *The process of change and life satisfaction* (Study IV). Studies III and IV are based on the same data collection since the interviews generated sufficiently rich data thus enabling two different studies. An overall description of the data collection is therefore described below.

Participants and data collection

The participants were recruited through the regional and national PD patient organisations Parkinson Skåne and Parkinsonförbundet. The inclusion criteria were a verified diagnosis of PD (ICD10:G20.9) for at least one year, age below 65 years and being able to participate in the interview. Persons with mild cognitive impairments were not excluded. Purposive sampling was done and specifically targeted persons under 65 years in order to explore the research area in focus and the experiences of persons in working age. It was also a strategy to recruit participants from a patient organisation for obtaining rich narratives.

Table 9. Characteristics of the 13 participants with Parkinson's disease in Studies III and IV

	n/years
Gender	
Men	3 (23%)
Women	9 (69%)
Non-binary	1 (8%)
Age (years)	
Mean (SD)	54 (4,9)
Range	47-62
Years with symptoms	
Mean (SD)	7.3 (5.7)
Range	3-24
Years since diagnosis	
Mean (SD)	3.4 (1.7)
Range	1-7
Marital status	
Single	3 (23%)
Married/cohabiting	10 (77%)
Vocational status	
Working[a] or studying	10 (77%)
Old age pension	2 (15%)
Disability pension	0 (0%)
Other[b]	1 (8%)

[a]includes full time, part time and looking for job.
[b]Has chosen not to work or look for work.

The participants received a letter carefully explaining the study, an informed consent form, and a questionnaire including socio-demographics. Prior to the interviews, the signed written informed consent was returned and thereafter a location for the interview was determined, e.g., their own home (n=8) or by digital technique (n=5).

It was somewhat difficult to recruit male participants to meet the ambition to achieve an equal gender distribution. The data had met saturation and the sampling ceased after including 13 participants (9 women, 3 men and 1 non-binary person). The participants had a mean age of 54 years and had lived with the PD diagnosis for an average of 3.4 years. Participants' characteristics are described in Table 9.

The interviews comprised reflective, open-ended questions, and were digitally recorded and transcribed verbatim after each interview. The questions explored the lived experiences of PD and perspectives on LS, for example “Can you please tell me what PD means to you” and “Can you tell me about when you feel satisfied with life?”. There were also follow-up questions like “Can you please tell me something more about…?”. The informants recalled thoughts, emotions and actions from the time they became ill and diagnosed with PD to the time when the interview took place. Due to the open-ended questions, the informants were enabled to vividly relate memories and elaborate on their experiences.

The interviews lasted for 42 to 110 minutes (67 minutes in average) and resulted in 222 pages of transcribed text.

The meaning of life satisfaction and adaptation

The knowledge about LS shows that it is dependent on the individual’s adaptation process [7, 70, 103, 105]. In order to understand LS, it was important to understand the meaning of adaptation, which became the area in focus for Study III. The third study of the thesis thus explored the meaning of LS and adaptation, using a qualitative approach to gain an in-depth understanding of LS. The methods and results of Study III are described in this section.

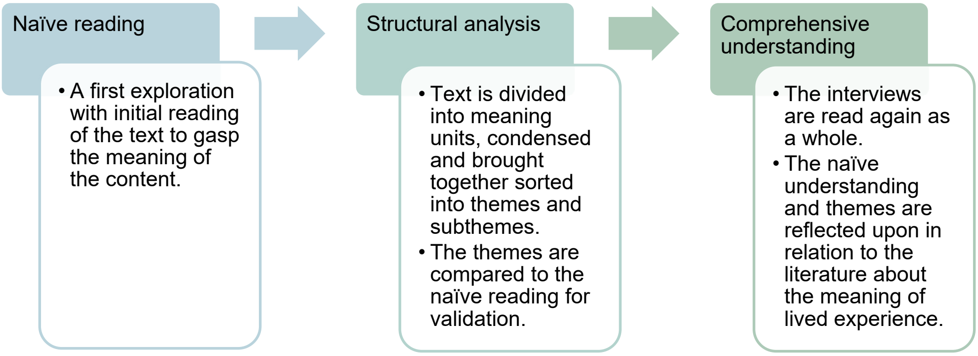
Study design

The third study was designed as an interview study with a phenomenological hermeneutic approach and was based on the philosophy of Ricoeur [106]. The results help us to gain insight about our world and is based on the thought that essential meaning must be revealed in the interpretation of text [107]. The text, in this case, is the transcribed interviews. With this phenomenological hermeneutic approach, we stayed close to the text to explore the meaning of LS and adaptation for PwPD.

The choice of method was made for the explorations of the participants lived experiences, which gives us an inner perspective of the phenomenon LS and adaptation for PwPD. The chosen method of analysis was a phenomenological hermeneutic method by Lindseth and Norberg [107], which was developed in accordance with the philosophy of Ricoeur.

Data analysis and summary of the results

The phenomenological hermeneutic method [107], used in this study, consists of three parts where the interpreter moves through a process of naïve reading, structural analysis and comprehensive understanding. The analysis method is illustrated in Figure 4.



Naïve reading

- A first exploration with initial reading of the text to gasp the meaning of the content.

Structural analysis

- Text is divided into meaning units, condensed and brought together sorted into themes and subthemes.
- The themes are compared to the naïve reading for validation.

Comprehensive understanding

- The interviews are read again as a whole.
- The naïve understanding and themes are reflected upon in relation to the literature about the meaning of lived experience.

Figure 4. The phenomenological hermeneutic analysis method developed by Lindseth and Norberg [107]. The interpreter moves through a process of naïve reading, structural analysis and comprehensive understanding.

Naïve reading

The researchers read the transcribed interviews several times to grasp the meaning of the content in the naïve reading. This revealed how the participants were in the process of adapting to PD and its various consequences in everyday life. There were two quite distinct groups; one where the participants proceeded with their adaptation through general acceptance, and another with participants mostly struggling to resist the disease and its impact on their lives. Adaptation to PD started even before the time of the diagnosis, and went on continuously, moving back and forth in a continual process of change. This was described by one of the informants as:

> *"But of course, it's still a process because I'm not done yet, I'm far from done. Maybe I never will be when living with a disease that can always keep changing."* (Interview No 11)

Structural analysis

The naïve understanding led to a structural analysis of adaptation where the text was divided into meaning units and then condensed, brought together, and sorted into themes and subthemes capturing the meaning of adaptation to PD. The thematic structural analysis, illustrated in Table 10, contains eight themes illustrating the meaning of adaptation as two sides of the same coin, either through acceptance:

> *"You have to learn to live with your disease and if it demands a certain kind of food or that you have to do things differently, then that's what you have to do to live your life. So, I guess that if Mr Parkinson has decided that I must work out every day, then that's what I do. He can decide that, and I decide the rest."* (Interview no 5)

or resistance:

> *"It's so much, I mean you get so tired of this. One day it's this and the other day it's that. You're in pain or you turn into a victim . . . or no . . . it's just a lot."* (Interview No 3)

Comprehensive understanding

The final step in the phenomenological hermeneutic method was the comprehensive understanding. The researchers read the interview text as a whole once again in this step and reflected upon it together with the naïve reading and structural analysis, as well as the literature. Themes were validated in relation to the context of the study and the specific research question [107]. The interpretation of the findings in this step reflected the researcher's pre-understanding as working in a rehabilitation team. The comprehensive understanding of the findings was that living with PD is a transitional adaptation process. This continuing process of change is facilitated by an individual's ability to accept the disease and its consequences in everyday life or can be delayed and obstructed by an individual's resistance towards the disease and its consequences. Resisting appears to be energy consuming and exhausting, whereas acceptance preserves energy that can be used in a constructive manner with self-care activities and eventually leads to moments of contentment and serenity. Interpreting the findings in the light of LS, it appeared evident that adaptation eventually leads to LS, through acceptance. On the contrary, resistance hinders the adaptation to the new life situation. Those who have a profound ability to accept the situation described an ongoing process of adaptation and eventually a higher level of LS, described as the degree to which a person positively evaluates the overall contentment with life [108].

Table 10. Structural analysis of the meaning of adaptation to Parkinson's disease

Main Themes	Sub-Themes	
	Acceptance	**Resistance**
Awaiting the diagnosis	Preparing for the worst	Uncertainty
	Continuing with everyday life	Putting life on hold
Facing the diagnosis	Feeling relieved	Being painfully aware of the progression of the disease
Feeling ashamed	Sharing the illlnes experience	Isolating and avoiding social situations
		Feeling less worthy
		Avoiding
Approaching the new life situation	Accepting that change is necessary	Feeling like a victim of PD
	Accepting one's own responsibility	Hoping for external assistance
	Believing in one's ability	Feeling impotent
Being in transition	Acknowledge the restraints	Experience losses
	Balancing expectations	Being painfully aware of the limitations
	Establishing balance	Struggling
Adjusting to the medication	Scheduling and evaluating doses and effects	Feeling restrained and limited
	Understanding the treatment	Doubting the treatment
Playing the patient role	Performing extensive self-care	Feeling disappointed
	Experiencing continuity	Mistrusting the professionals
		Lacking continuity
Being the same but different	Having the courage to change	Feeling lost
	Keeping one's identity	Mourning the loss of one's role
	Finding a new role in the family	Dwelling on problems and comparing
	Living in the present	Worrying about the work and financial situation
	Experiencing serenity	
	Accepting the changes in work and finances	

In summary, adaptation to PD involves a transitional process characterized by either acceptance or resistance, which influences the individual's LS. Acceptance makes adaptation and a high level of LS possible, whereas resistance constitutes a behavioral barrier to both adaptation and LS.

The process of change and life satisfaction

The new knowledge about the meaning of LS and adaptation from Study III revealed the need to understand the process of change in PwPD. To support PwPD through a successful adaptation, and in turn a high level of LS, we need to understand the process of change and how PwPD deal with it. The fourth study of this thesis was aimed to gain an in-depth understanding of the process of change and its importance for LS and was performed with a qualitative approach. The method and result of the fourth study will be described in this section.

Study design

There were no scientific theories on the process of change when living with PD. Study IV was designed to manage this matter with an inductive approach using Grounded Theory (GT) according to Charmaz [109], based on semi-structured interviews. The scope of phenomena of interest was the experience of the process of change when living with PD. The method was chosen since it is used to generate theories or frame works on human behaviour through analyses on qualitative data. The aim of the method is to generate theories that explains problem solving within a chosen area and conceptualize the process [109]. The method was first used in an inductive approach, where the theoretic model was formulated. Then it was used with a deductive approach through validation interviews, where the model was confirmed, and conclusions could be drawn from the specific theory. By using GT, the process of change when living with PD could be conceptualized to generate a completely new theoretical model.

Participants and data collection

An overall description of the participants and data collection for Studies III and IV are described above. A more detailed description of the data collection according to the GT method is described in this section. The recruitment was performed in four steps, as described by Morse [110], and is illustrated in Figure 5.

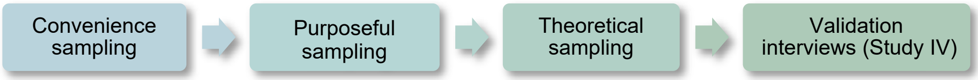


Figure 5. The sampling procedure for the data collection in Studies III and IV.

Convenience sampling

Available adult PwPD from the regional patient organization were recruited to identify the scope, major components, and trajectory of the overall process in the first step of the sampling. The sampling continued in step two after five interviews were completed.

Purposeful sampling

Purposeful sampling was performed to maximise variation of meaning. Persons from the national patient organisation were invited to take part in the study to obtain a nationwide distribution. Five new interviews revealed more in-depth knowledge on how the participants were intertwined with the emerging phenomena, social belonging. A conceptual scheme and its trajectory identified in the convenience sampling was now confirmed as it emerged more clearly. It became clear at this stage that the process of change starts with a desire to comprehend the situation. Comprehension was shown to be the foundations for acceptance, which in turn enabled adaptation and the balancing of the life situation. The sampling process then continued in the next step.

Theoretical sampling

The theoretical sampling was carried out by first recoding the data according to the identified trajectory and the critical junctions, in other words the bridges between the stages. It was clear in this step that the process of change went back and forth driven by uncertainty and coherence, respectively. The emerging categories and the increasing understanding led to directing the final sampling. Targeted questions were thus posed to three more informants concerning the meaning of each concept in order to enable grounded definitions and clarify the link between the categories. There were no true negative cases, i.e., there were no informants who did not respond in the anticipated way.

Validation interviews

The validation interviews were performed with four of the informants after the formation of the theoretical model in study IV. These interviews had a deductive approach, and the informants were asked if the analysis made sense to them and if there was a match between their experiences and the emerging theoretical model. The emerged model was confirmed in all four validation interviews, and the informants helped to explain the loop of coherence and uncertainty. The validation interviews also clarified the link between social belonging and LS.

Data analysis and summary of the results

The initial coding was performed line by line to find words or phrases indicating important categories, qualities or contexts related to the research question [109].

Questions and reflections emerging during the analysis and coding process were logged for each interview. A focused coding process was then conducted, in order to detect and explain the most frequent and significant codes, which illustrated the main concern experienced by the informants. The next step was the theoretical coding, which specified the relationships between the general codes that emerged in the focused coding, and simultaneously the constant comparative method (CCM) was used on data, codes and categories [109]. This resulted in the identification of the process of change and how the informants dealt with it.

The main concern, (i.e., the core) social belonging, summarizes a process wherein the generated grounded theory is presented through four main categories: comprehend, accept, adapt and balance, see Figure 6. A pursuit to achieve social belonging is evident through this process of change. The process starts when the person with PD is diagnosed, and continues until a balance is reached, and social belonging is attained. The PwPD are moving back and forth during this process, due to coherence and uncertainty, the theoretical links between the four main categories.

The four different main categories are dependent on each other, comprehension enables acceptance, which in turn is a pre-requisite for adaptation. It is easier to do all the demanding adjustments in adaptation when one understands the circumstances and things are expected to work out based on one's experiences and understanding. A sufficient adaptation enables balance, and a sufficiently satisfying balance is achieved when expectations and outcomes equate each other. When something unexpected occurs, such as starting a new medication with potential side effects, or when experiencing new or exacerbated symptoms, uncertainty arises and leads to worries about what will happen and how this could interfere with the social belonging. For example, dreaded side effects from the medication are sex abuse or gambling that would affect a person's social relationships. The uncertainty leads to a need for further comprehension and learning, acceptance, adjustments and finally balancing in order to maintain social belonging.

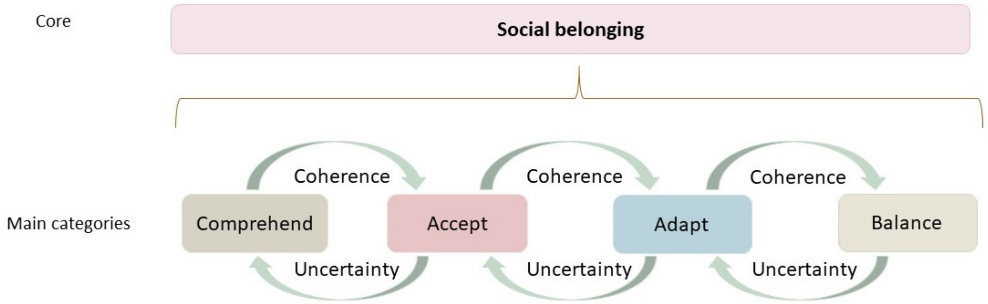
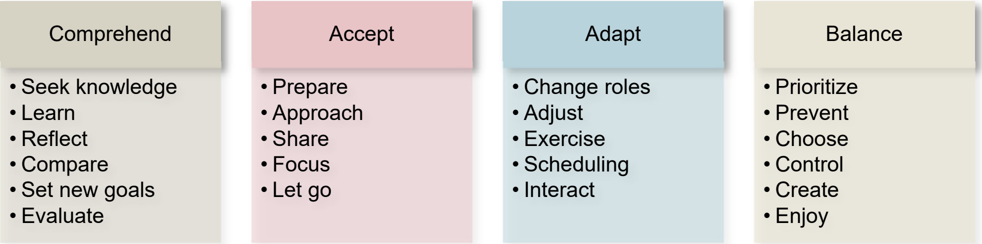


Figure 6. The grounded theory of the process of change among persons living with Parkinson's disease. PwPD are moving back and forth in the process of change due to coherence and uncertainty in their pursuit of social belonging.

The results also suggested a relationship between social belonging and a high level of LS, described by the participants as an experience of an overall contentment with life when having a sense of social belonging. The data validation interviews confirmed that the level of LS is high when the informants succeed with a sufficient balance to maintain social belonging.

> *"Life is good even if you're not always functioning"* (Validation interview no 1)

The main categories consist of several subcategories describing different strategies used by the participants. These subcategories are presented in Figure 7. By using these strategies, PwPD endeavours to comprehend, accept, adapt and balance throughout the pursuit for social belonging, and in turn a high level of LS. The strategies facilitate the experience of coherence and thus enable PwPD to continue with the next step of the process.



Comprehend	Accept	Adapt	Balance
• Seek knowledge	• Prepare	• Change roles	• Prioritize
• Learn	• Approach	• Adjust	• Prevent
• Reflect	• Share	• Exercise	• Choose
• Compare	• Focus	• Scheduling	• Control
• Set new goals	• Let go	• Interact	• Create
• Evaluate			• Enjoy

Figure 7. The main categories consists of several subcategories.
The subcategories decribe different strategies used by PwPD to comprehend, accept, adapt and balance, in their pursuit of social belonging.

In summary, social belonging is the main concern in the process of change for PwPD. They use strategies to comprehend, accept, adapt, and balance in this process of change, in their pursuit of social belonging, which in turn can enhance their LS.

Ethical considerations

Different ethical aspects have been reflected upon throughout this thesis. The primary purpose of all medical research involving human subjects is to understand the causes and effects of diseases and to improve preventive, diagnostic and therapeutic interventions. While the purpose of medical research is to generate new knowledge, this goal can never take precedence over the interest and rights of individual research subjects [111].

All the studies in this thesis were conducted according to the ethical guidelines established by the World Medical Association in the Declaration of Helsinki [111], which are created to ensure that medical research involving human subjects may only be conducted if the importance of the objective outweighs the risks and burdens to the research subject. All the studies in this thesis were also approved by the Regional Ethic Review Authority in Lund, Sweden (Study I: Dnr 2013/118, Study II: Dnr 2013/406, Studies III and IV: Dnr 2018/280 and Dnr 2019-02786).

PwPD might experience cognitive and communicative challenges as part of the disease, which makes them a particularly vulnerable group, and this was taken in to account when they were asked to participate in the studies [111]. The researchers did not exclude participants if they had minor cognitive impairment, or speech or voice impairments, as long as they had the ability to fully participate in the studies. Persons with these impairments might be underrepresented in medical research and they were therefore provided appropriate access to participate [111].

All the participants received a letter with information about the studies and contact details for the researchers and were encouraged to contact the researchers if they had any questions or concerns. They were informed that the participation was voluntary and could be cancelled at any time without having to state reasons for doing so [111]. Written informed consent was obtained from all participants prior all data collection.

Assessing life satisfaction

The participants completed questionnaires in the postal surveys, which can be a burden if the questionnaires are too extensive or complicated [112]. This was taken into account when designing the studies, choosing questionnaires carefully, making sure that the questionnaires were valid and not too extensive. The total number of questionnaires was also limited. Completing questionnaires by oneself, answering questions about one’s life could cause reflection and discomfort. The participants were encouraged to contact the researchers with any questions or concerns in order to minimize and handle the potential discomfort. None of the participants expressed such discomfort.

Exploring life satisfaction

The participants had chosen a location that made them feel comfortable during the interviews. Visits to the participant’s homes were made with respect for their personal integrity and at a time that suited each participant. The interviews could be experienced as time consuming and may have been strenuous for the participants. The participants were offered to take a break at any time during the interview to address this, and several of the participants needed a short break to take their medication at a certain time. The interviewer (LR) was alone during the digital interviews, which entailed no one else being able to hear, and the participants could choose if they wanted to sit by themselves or have a next of kin by their side.

The interview questions were open-ended to allow the participants to speak freely about what they wanted to share, and on several occasions the interviews became deep conversations, during which the participants shared personal and difficult experiences. This was always met with respect and the interviewer offered to continue the conversation after the interview was finished, to make sure that the participants had the opportunity to speak as much as they wanted. If a need for further counselling or medical consultation occurred, the participants received advice and guidance for treatment and when needed, contacts with the rehabilitation clinic or general practitioner were established.

In summary, the overall impression was that the participants experienced the involvement in these studies as beneficial. The participants were eager to share their experiences of living with PD and some of the participants in the interviews described how talking about their lives felt therapeutic and helped them to increase their self-efficacy. These studies are also considered to be beneficial for other PwPD.

Discussion

The overall aim of this thesis was to increase the knowledge and understanding of LS for PwPD. This has been achieved by using quantitative and qualitative methodologies when: evaluating the psychometric properties of the rating tool SWLS (Study I), describing LS and associated factors (Study II), exploring the meaning of LS and adaptation (Study III), and exploring the process of change and LS when living with PD (Study IV). Using this methodological pluralism with a combination of research designs has yielded new insights and a greater perspective with a comprehension of the complexity of LS for PwPD [113]. The knowledge has been expanded from a narrow reductionist point of view to a broad, holistic understanding of LS for PwPD.

The main results of this thesis are that the SWLS has adequate psychometric properties when being used in PwPD, and there was a wide variation of LS, assessed with the SWLS. A strong SOC are associated with higher LS, whereas LS appears to decrease during the disease course. Adaptation to PD involves a process of change characterized by either acceptance or resistance, which influences the individual's LS. Acceptance makes adaptation and a high level of LS possible, whereas resistance constitutes a behavioral barrier to both adaptation and LS. Social belonging is the main concern in the process of change for PwPD. They use strategies to comprehend, accept, adapt, and balance in this process of change, in their pursuit of social belonging, which in turn is important for their LS.

Thus, the knowledge of this thesis shows that achieving and maintaining a high level of LS demands certain components. The important components for LS for PwPD revealed in this thesis are SOC, adaptation, and social belonging, as illustrated in Figure 8. The road towards life satisfaction for PwPD is a continuously ongoing process including these components.

A discussion of the results from the four studies in the light of previous knowledge and research follows in this chapter. The results will mainly be discussed under the subheadings *Assessing LS* (Studies I and II) and *Exploring LS* (Studies III and IV). Methodological considerations are included for each study. Parallels and overlappings between the studies will be weaved in when appropriate.

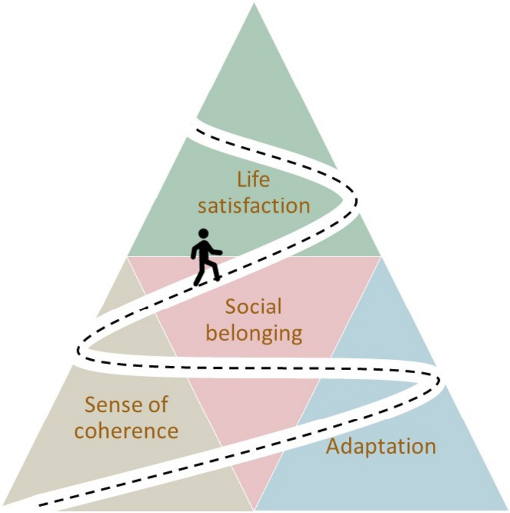


Figure 8. Important components for the life satisfaction of persons with Parkinson's disease
Sense of coherence, adaptation and social belonging are important components along the road for ahieving and maintaining a high level of LS when living with PD. The road towards LS for PwPD is a continously ongoing process including these factors.

One motivation throughout this thesis has been to understand how I, as a physician, can support PwPD to improve their life situation. I will answer this question in the section *Achieving and maintaining a high level of life satisfaction*, which contains distinct suggestions and recommendations for PwPD, as well as healthcare professionals. With these recommendations, the implementation of the National guidelines can be facilitated and hopefully result in a more equal care for PwPD, so that they can achieve and maintain a high level of LS over time.

My ambition is for this discussion to lead to relevant conclusions, clinical implications and suggestions for future perspectives that are adequately related to the results of the thesis. Finally, I summarize my own reflections from working with this thesis in the epilogue.

Assessing life satisfaction

The results of the first two studies add new knowledge on how to assess LS and what factors are associated with LS in PwPD. A discussion on the findings and methodological considerations for Studies I and II follows.

Rating life satisfaction

In order to use LS as an outcome measure for rehabilitation, we need to be able to evaluate it. The amount of research focusing on LS has increased in the last decades [74]. Diener et al. identified a need for the ability to assess LS as a whole, including both past and present experiences. Therefore, they developed the SWLS designed around the idea that one must ask people for an overall judgment of their life in order to assess LS [74]. Quantitative methodologies were the main approach when the SWLS was developed. The basics of quantitative research are to measure and evaluate different factors, for describing, evaluating and drawing conclusions on outcomes and associations. However, can we really measure something as subjective as LS? Quite frankly, I would say that it is not possible. All measurement tools for assessing LS are self-report rating tools, allowing the user to rate different aspects of LS. I would maintain that this is the closest you can come when trying to measure something as subjective as LS.

Rating tools for clinical use or in medical research need to be of high quality, which can be evaluated by studying its validity and psychometric properties [14]. The reliability and validity of the SWLS have been extensively evaluated [7, 74, 75] and the scale has recently also been further evaluated with factor analysis [114] and Rasch analysis [115], showing that the scale is essentially unidimensional. However, the evaluation of the psychometric properties is population dependent and therefore it was essential to also evaluate the psychometric properties of the SWLS in PwPD.

Using the Satisfaction with life Scale for persons with Parkinson's disease

No studies were found on the psychometric properties of the SWLS in PwPD when this project started. However, Lucas Carrasco et al. published their psychometric evaluation on 350 PwPD from five different European countries during the development of Study I [81]. Our study was thus one of the first to explore the psychometric properties of the SWLS in PwPD, and the first one where a test-retest evaluation and the first evaluation in a Swedish population of PwPD was performed.

The results of Study I are in line with those in the previous study by Lucas-Carrasco et al. [81], showing a high level of data completeness and a good internal consistency. The items' means and SDs were roughly parallel, and the score distribution was even. The test-retest reliability, assessed by the ICC was close to the recommended level [90, 91]. This level can be considered acceptable and is comparable with the test-retest evaluation of SWLS in Multiple sclerosis, another progressive neurologic condition [116]. The SEM can be used as a measure for the scale's ability to detect a clinically significant change for a group of people and was calculated to be 3.6 points. This result suggests that SWLS is sensitive enough to detect a group change in LS following an intervention or over time. However, the SDD of 10.0 points illustrates the difficulty in using this rating scale for a single individual [14], as a single individual would need to increase his/her SWLS-score with 10 points in order to be certain that it is a clinically significant change.

The pros of using the SWLS in PwPD are thus that it is a sound rating scale and easy to use, has a high level of reliability and good targeting. It can be used for both research and in group interventions, as well as a screening tool in clinical practice. The cons of the scale are the difficulties in detecting a clinically significant difference for an individual participating in an intervention. In addition, using the SWLS does not provide a deeper understanding of the perceived LS. The psychometric properties of SWLS thus meet the suggested criteria for classical test theory and the scale is a sound and suitable tool for rating LS in PwPD.

Methodological considerations

The mean age and PD duration in this sample of 97 PwPD were similar to those in other studies in terms of age, the onset of the symptoms, and the gender distribution [117]. The exclusion of participants with dementia or severe physical impairments limits the generalization of the results to persons with mild to moderate PD. One could argue that it would be preferable with a larger sample size, but in recommendations for psychometric evaluations it is suggested that a sample size of at least 50 participants is needed [12], which has been met in the present study. The response rate of 56% can be seen as a limitation but is in line with the response rate in other Swedish postal surveys for PwPD [118, 119].

SEM and SDD calculations in this thesis are based on the ICC, as the reliability coefficient. There is however no consensus on whether SEM should be based on ICC [14] or Cronbach’s alpha [120]. Using Cronbach’s alpha in the calculations of SEM and SDD would result in a smaller change to detect clinical significance. One should be aware of this limitation of the scale in clinical practice, even though the limitation might be smaller using Cronbach’s alpha.

The psychometrics method used in this study was Classical Test Theory. The next step in evaluating the psychometric properties of the SWLS in PwPD would be to analyze the construct validity and the uni-dimensionality of the scale in this population, using the Rasch analysis method to generate more detailed information about the scale’s validity and reliability. Data from an ordinal scale that fit the Rasch model will support that ordinal scores can be transformed into linearized, interval scores enabling a summation of the scores and the use of parametric statistics [121]. In addition, other rating scales for assessing LS should be evaluated for examining which rating scale is best suited for use in different situations, in research as well as in clinical practice.

Life satisfaction and associated factors

In order to be able to support persons to achieve and maintain a high level of LS, it is important to gain an understanding of the factors that influence LS as a necessary complement to knowing how to assess LS. After the psychometric evaluation of the SWLS, the natural step was to assess factors associated with LS. There was nothing to be found on this aspect in the literature on LS and associated factors in PwPD at the start of this thesis. The few existing studies on LS and associated factors have been published recently [55, 58, 59]. Figuring out which factors to study in order to find potential associations with LS was thus not a simple task.

I searched the literature to see which factors were associated with LS in other populations by using a rehabilitation medicine approach and the International Classification of Functioning and Health (ICF) [1]. This search revealed that a high level of perceived participation [1] and a strong SOC [15] were associated with LS in other life-long conditions [76, 92, 93]. SOC and perceived participation are generic and not related to a specific disease or impairment, which led me to presume that these factors could also be of importance for LS in PwPD. The choice of evaluating mental and emotional status, using GDS, was made since this factor had shown to be of importance for LS in persons with traumatic brain injury, where depression negatively influences LS [122]. The presence of depressive symptoms is also common in PwPD, and this factor was thus of interest for Study II [123-125].

Life satisfaction in persons with Parkinson's Disease

There was a large variability in LS among the participants in Study II and the mean total sum score can be categorised as an 'average score' according to Diener [83]. This indicates that the persons can be considered to be generally satisfied with life. Only two previous studies had assessed LS with SWLS for PwPD at the time of the publication of Study II [81, 126], including the first study in this thesis. The level of mean total sum scores in Study II was similar to those in the previous studies [81, 126].

The mean score on the SWLS implies that persons with mild to moderate PD can experience that things are going well in their lives although there are areas where they would like to see an improvement [83]. Forty-five percent of the participants had a high or very high score, which is categorised as 'highly satisfied' [83] and promising, despite living with a life-long neurodegenerative disease. On the other hand, 5% of the participants had scores indicating that they were extremely dissatisfied with life. This indicates that some PwPD can be very discontent with their life situation and may be in need of great support and medical rehabilitation even early in their disease course.

It is important to distinguish persons with high or low LS and plan appropriate interventions that may improve and maintain their level of LS in the management and rehabilitation of PwPD. In order to do so, we need to understand what makes some PwPD experience a high level of LS, and how healthcare professionals can support PwPD to achieve and maintain a high level of LS.

Factors associated with life satisfaction

The bivariate correlation analyses showed how perceived participation (assessed with RNLI), SOC (assessed with SOC-13) and depression (assessed with GDS) were correlated to LS, as well as the years since their diagnosis. This was in line with the previous studies on LS and associated factors in other populations with life-long conditions [76, 92-94, 122]. This was the first study to assess LS and associated factors in PwPD.

The multivariate regression analysis resulted in two factors significantly associated with LS: the years since diagnosis and SOC. This indicates that LS may decrease as the disease progresses, which is in line with a recent study by Jonasson et al., where LS was reduced over a 3-year period [59]. The study by these authors also suggests that walking difficulties, general self-efficacy, and depressive symptoms are important predictors of LS in PwPD [59]. A study by Gustafsson et al. also found depressive symptoms to be negatively associated with a high level of LS in PwPD [58]. Depressive symptoms, assessed with GDS, were not significantly associated with LS in our multiregression analysis. However, our results do not differ to the results of the previous studies [58, 59], since we found a bivariate negative correlation between depressive symptoms and LS. Nevertheless, when depressive symptoms work in covariance with SOC in the multivariate regression analysis, the depressive symptoms were of minor importance for LS in PwPD. Further research is needed to understand the importance of depressive symptoms for LS in PwPD. Our results highlight the importance of SOC for LS in PwPD.

The association between life satisfaction and sense of coherence

The strong association between SOC and LS in the multiregression analyses indicates that SOC, as a reflection of a person’s capacity to respond to stressful situations, is an important factor for LS in PwPD. PwPD have shown to have weaker SOC and lower LS compared to control groups [58, 77] and SOC has been associated with QoL [77, 127], but this was the first study on the association between LS and SOC in PwPD.

SOC develops during childhood and adolescence according to Antonovsky [15], and is strengthened by resources such as intelligence, social support, and cultural stability. SOC indicates how well a person handles stress as a result of a disability [128] and a person with a strong SOC views stressful events as less threatening compared to persons with a weaker SOC [129]. Antonovsky describes how the three components comprehensibility, manageability and meaningfulness are the core of SOC [15]. Comprehensibility is regarded as the belief that incoming stimuli are coherent and make cognitive sense to the individual. The stressors will be seen as logical and be predictable. Manageability refers to the resources that the person possesses in order to challenge unexpected demands, within oneself or with help from others. Meaningfulness is the crucial motivation-emotional element of SOC [15]. Posadzki et al. describe this as: persons who have a strong belief in their capabilities approach difficult tasks as challenges to be mastered and worth confronting, and also invest energy in them rather than see them as threats to be avoided [130]. This is an explicit common feature with the adjacent concept self-efficacy (SE) by Bandura [13, 130]. This concept has been shown to be associated with LS in PwPD, where a high level of SE is related to a high LS [55, 59]. The many similarities between SOC and SE supports our results that a strong SOC is important for LS in PwPD. Being able to understand, believe in one's ability to manage the situation, and feeling motivated are thus important features for a high LS for PwPD.

The results from Study II led to the question whether or not it is possible to strengthen SOC through rehabilitation, and thus increase LS. According to the construct of SOC, the three components are proposed as being able to be strengthened through reflection and empowerment, which is a part of self-management rehabilitation [131]. Future studies should therefore explore whether goal-oriented self-management rehabilitation programs could strengthen SOC, and thus increase LS for PwPD.

Methodological considerations

A strength of Study II is the use of a rating scale where the psychometric properties have been evaluated in a population of PwPD. The inclusion of persons with mild to moderate PD however limits the conclusions to those in the earlier phases of their disease course. The conclusions should also be limited to persons without dementia or severe cognitive or physical impairment. Multiple regression requires enough observations (i.e., participants). The number of participants must substantially exceed the number of variables included in the regression. The analyses of Study II have met the criteria of having at least 10 participants per variable [132]. The sample size is thus acceptable in relation to the number of variables.

The bivariate correlations were evaluated together with the Variance Inflation Factor (VIF) and the tolerance for multicollinearity diagnostics. No multicollinearity was found, since the highest bivariate correlation was below 0.6 and none of the variables had a VIF above 0.2 or tolerance below 0.2, which are stated limits in the criteria for multicollinearity diagnostics [9, 102].

The choice of factors assessed in this study was motivated on the basis of previous knowledge about SOC and LS in other life-long conditions. However, the results revealed that these factors only partly explained the variance of LS. Other studies on LS for PwPD have shown that physical impairments, SE, depressive symptoms [59], as well as employment situation [58] are associated with LS. This indicates that LS is a complex phenomenon in PwPD and thus needs to be explored with different approaches. In order to understand a subjective phenomenon such as LS, I needed to study LS from an inner perspective to gain an in-depth understanding. The continued exploration of LS in the second part of this thesis has thus been carried out with a qualitative approach.

Exploring life satisfaction

LS has been explored with qualitative methodology in the second part of this thesis. This adds new in-depth knowledge about LS for PwPD when exploring the meaning of LS and adaptation (Study III) and contributing with a completely new theoretic model on the process of change and LS for PwPD (Study IV). A discussion on the two qualitative studies follows in this chapter, starting with a comprehensive discussion on the use of qualitative methods, since Studies III and IV are based on the same data collection.

Using qualitative methods to explore life satisfaction

The choice to use qualitative methods was made in order to be able to gain an understanding of a person’s experiences, perceptions, expectations and thoughts [104]. Qualitative research is also well suited for exploring dynamic processes such as interaction and development. It also presents itself for sciences where the level of knowledge is low and where the question to be explored is complex [104]. I thus found this approach very suitable for exploring the subjective and complex phenomenon LS, adaptation, and the process of change for PwPD, as the level of knowledge was exceptionally low. With the gained insights and perspectives, we could then use the results to help others to gain new insights about the phenomenon LS for PwPD [107], which makes the results usable in both clinical practice and future research.

Methodological considerations

I aimed at exploring the inner perspective with the qualitative approach to obtain an in-depth understanding of LS for PwPD. The aim of this was to gain knowledge that can be used in clinical practice and the development of rehabilitation interventions, to support PwPD to achieve and maintain a high level of LS.

The sampling was purposeful, where I included participants younger than 65 years, since those who work might have a different perspective on life than retired people. Also, those in working age are more often eligible for interdisciplinary goal-oriented rehabilitation. The data collection was carried out with open-ended interviews, which enabled the participants to vividly relate memories and elaborate on their experiences. The data were very rich and could thus be used for two studies.

With the use of two different qualitative methods, I could stay close to the text and the underlying meaning (Study III), as well as conceptualizing the process of change (Study IV). This made it possible to explore LS for PwPD from different perspectives, which has generated a broad understanding of this phenomenon.

Several important factors for ensuring trustworthiness need to be considered when it comes to qualitative methods [133]. *Credibility* was achieved by including elucidative and descriptive quotations from the long in-depth interviews. In addition, investigator triangulation was performed for the coding, analysis, and interpretation. Data were gathered over a one-year period, both regionally as well as nationally, which were part of the data triangulation [133]. In terms of *transferability*, the results should be limited to persons with a mild to moderate PD and under 65 years of age, living in Sweden or similar cultural and social contexts. The thick description of the participants and the research process enables the reader to assess if the findings are applicable to other settings.

Originality was ensured as the studies present new comprehensive understanding about LS and adaptation in PwPD (Study III) and the process of change to achieve social belonging and LS by means of a novel grounded theoretical model (Study IV). The two studies show a *usefulness* since the findings generate a greater awareness on the meaning of adaptation and LS as experienced through acceptance or resistance, as well as the social process and various strategies adopted to maintain a social belonging and substantially achieve and maintain a high level of LS. These insights can be used in both clinical practice as well as in future research. *Theoretical saturation* was evident after 13 interviews, when sampling of data did not lead to more information [109]. *Dependability* in Study IV was ensured when the participants were let to evaluate the findings in the validation interviews [133].

A strength of the qualitative research designs in this thesis is my pre-understanding, as member of a rehabilitation team and working with persons with life-long disabilities, which strengthens the interpretation of the participants' lived experiences. Previous knowledge has not been a hindrance to being open-minded both in gathering data and in analysing data. We normally possess the ability to consciously suspend our personal understanding of a subject matter in order to understand somebody else's point of view [134].

The meaning of life satisfaction and adaptation

The association between LS and SOC in Study II showed the importance of being able to understand, manage and be motivated to cope with stressful situations when living with a progressive neurological condition. This can also be described as parts of adaptation to the changed life situation. One can assume that the progression and complexity of PD result in a need for PwPD to continuously adapt to their new life situation. Successful adaptation has been linked to a high level of LS and is a key factor for successful rehabilitation [75, 105, 135]. However, how this link is constructed in PwPD was unknown. Study III was the first study to explore the meaning of LS and adaptation in PwPD.

The importance of acceptance for adaptation and life satisfaction

The main findings of Study III are that LS can be achieved through adaptation to the new life situation with PD, and that adaptation involves a transitional process characterised by either acceptance or resistance. Acceptance and resistance describe the experience of adaptation to PD as two sides of the same coin. Acceptance makes it possible to achieve LS when living with PD, whereas resistance constitutes a behavioural barrier to adaptation and LS. This result is supported by previous suggestions that adaptation is a key factor to a high level of LS [75, 105].

Adaptation, as one prerequisite for SWB has been previously been discussed and might be related to what expectations one has on life and how they are achieved [136]. I suggest that adaptation can both improve one's achievements and adjust one's expectations, which then would create a better balance between expectations and achievements, and in turn, result in a high level of LS. Adapting to PD has been described by Soundy et al. [137], where they could see difficulties in coming to terms with the disease and primarily not accepting the situation. When they could accept the diagnosis, PwPD could also accept the different consequences of PD on their lives, including social and vocational identities [137].

After several years of studies on LS, Diener et al., raised the question of what makes some persons adapt while others struggle with the adaptation [136]. Our result suggests that one explanation for this is whether the person is in acceptance or resistance, which is in line with previous research that acceptance is important for adaptation [137, 138]. The challenges of accepting the changed situation when living with PD has also been identified in previous studies [47, 53, 138].

The role of acceptance for adaptation, in a context of palliative care, has been described in terms of a shift where some individuals adjusted the relationship between capability and utility, allowing them to achieve greater utility from a poorer capability state [139]. These results are in line with the results of Study III, where persons in acceptance focused on their abilities and possibilities rather than limitations. On the contrary, persons in resistance focused more on limitations and losses. However, it is not investigated if persons are able to focus more on abilities because they are in acceptance, or if they are in acceptance because of their focus on abilities and possibilities.

One possible explanation for this is that people in acceptance seem to have a higher psychological flexibility [10] making it possible to solve new problems arising as consequences of PD. People in resistance, however, have difficulties solving everyday problems since their known strategies are no longer working for them.

Increasing psychological flexibility by supporting persons to focus on abilities might be one way to support them towards acceptance, adaptation and LS.

I suggest that acceptance is a prerequisite for adaptation, although the question why some persons are in acceptance and others are in resistance, remains and needs to be further investigated. In order to do so, we first need to learn how to recognize persons in acceptance or resistance.

Identifying persons in acceptance or resistance

The result of Study III shows that being in acceptance or resistance affects the ability to adapt and achieve a high level of LS. Acceptance could also affect the outcomes of various interventions. A study exploring the lived experience of DBS showed how the more PwPD felt alienated by their illness, the more they experienced self-estrangement after the surgery [140]. The authors suggested there is an association between self-estrangement and a loss of control and distorted perceptions of capacities, which are characteristics common among participants in resistance in our study. We thus need to recognize a person in acceptance or resistance, which can be done by understanding how the person is comprehending and experiencing the situation. By being able to understand this, we can then support them through the adaptation process and prepare them for the needed interventions.

The thematic structural analysis describes different situations (themes) for persons when living with PD, experienced through either acceptance or resistance (subthemes). This can help us recognise if a person is in acceptance or resistance. For example, when waiting for the diagnosis persons in resistance put life on hold and lived in uncertainty while those in acceptance prepared for the worst whilst they continued everyday life. One can imagine that continuing everyday life might be easier if one does not have to wait too long for a comprehensive explanation of one's symptoms. Furthermore, a long time waiting to meet a neurologist might also increase the uncertainty. This raises the question whether we could minimise the uncertainty by providing a good accessibility to the healthcare services, and thereby facilitating for persons to continue everyday life, i.e., moving towards acceptance. In other words, can we by positive experiences facilitate for PwPD to move from resistance towards acceptance, and thereby facilitate adaptation and LS?

Sense of Coherence as a facilitator for adaptation

Based on the association between LS and SOC in Study II, the results of Study III can be interpreted from a salutogenic perspective [15]. Participants in acceptance appeared to have the ability to understand, manage and were motivated when dealing with stressful events and problems arising as a result of PD. This is the core concepts of a strong SOC, and the participants in acceptance seemed to cope with their new life situation more efficiently than the participants in resistance. The results of Studies II and III show the importance of understanding, managing, and feeling motivated as part of an adaptation process for achieving a high level of LS in the new life situation with PD. I thus suggest that the level of SOC is one personal factor that explains why some PwPD adapt to their new life situation which in turn can lead to a high level of LS, whereas the adaptation process is less successful for others.

With a strong SOC as a potential facilitator for adaptation and LS, strengthening of SOC could lead to increased LS for PwPD. SOC has shown to be strengthened by rehabilitation programmes [141, 142], but strengthening of SOC has never been explored in PwPD. Could SOC be strengthened by interdisciplinary rehabilitation and thereby enable adaptation and a high level of LS for PwPD?

A study like this obviously generates more questions than answers. From a rehabilitation medicine research perspective, Study III highlights the need to understand the process that underlies adaptation in order to support PwPD to go throughout the process of change. To be able to support PwPD through this process of change and understand how this process is related to LS, we need to understand how this process is performed, in other words – how they do it and why.

The process of change and life satisfaction

Study IV was conducted with the GT method to conceptualize how PwPD are doing when they are going through the process of change when living with PD. The results showed that the main concern in the process of change is social belonging, which also is a prerequisite for LS. PwPD are going through the four main categories comprehend, accept, adapt, and balance, in their strive for social belonging. PwPD are continuously moving back and forth in this process due to their coherence or uncertainty as the theoretical links between the main categories.

A continuing process of change

The emerged model showed a chronological order between the main categories. The first step of comprehending was an essential start for the process before being able to accept, adapt and balance the new life situation.

The participants described the importance of seeking knowledge, learning from each other, comparing with others, and learning together with a spouse. These were all strategies for comprehending the situation with PD and have previously been described [138], but this is the first time they have been described in a model of the process of change. There is a similarity between the main category comprehend and the first component of SOC, comprehensibility [15]. To be able to understand one's situation thus seems to be an important part of dealing with the new life situation. It is interesting that comprehending was not only about learning by one-self but specifically involved learning from others and comparing with others. This is in line with the knowledge about learning from the relational frame theory, where it is described how we learn by relating and comparing [143]. Thus, being able to compare and learn from others is important for comprehending situations with PD.

When understanding the situation to the extent that the parts fit together in a natural or reasonable way, PwPD can continue towards acceptance. The role of acceptance for adaptation has been described in Study III, and the present model shows this relationship once again. The generated GT demonstrates how acceptance is essential for moving on and adapting to the new life situation when living with PD. The importance of acceptance for behavioral change is well-known [144]. Accepting the disease has previously been described by PwPD as a gradual process of going through different emotions from denial, anger, and sadness, to slowly accepting and eventually looking at the future with new hope and positive thoughts [138]. Having a positive mind-set and view of the present situation and life has been described in this process as important strategies for acceptance [138]. This is in concordance with the results of Study IV, where focusing on abilities and possibilities whilst letting go of setbacks are strategies used for accepting. In addition to previous results, Study IV adds knowledge of other strategies for accepting, such as preparing for new signs and symptoms of the disease, as well as approaching the symptoms and sharing the experiences of the disease with others. Sharing with friends and family has previously been shown to prevent the loss of friends [50], which could also be beneficial for strengthening the social belonging for PwPD, and thereby increase LS. Thus, accepting is important for adapting and social belonging, and in turn a high level of LS.

When PwPD are able to accept the situation to the degree that it fits together in a reasonable way, they can continue with adapting. The meaning of adaptation and LS has been described in Study III where we described how adaptation enables a high level of LS, while different strategies for adapting (i.e., change roles, adjust, exercise, schedule, interact) are presented in Study IV. It was obvious throughout the data collection that the adaptation is a demanding process that covers every aspect of life. It includes roles at home and at work, as well as strategies for managing everyday activities. It comprises physical training to increase and maintain physical functioning, as well as compensating for physical and mental impairments. In addition, scheduling activities in relation to medication and energy is important in order to optimize functioning, activity and participation by eliminating symptoms and obstacles in the surrounding environment. These approaches with training, compensation and elimination are the core of interdisciplinary neurorehabilitation [145], which can facilitate the adaptation process.

When adapted to the degree that the situation fits together in a reasonable way, PwPD can continue with the last step of the model, balance. This category describes how PwPD strive to find balance in daily life, which can only be experienced if one can comprehend, accept and adapt. The balancing is a delicate project including balance in activity level, balance in expectations and goals, as well as a mental balance to find peace of mind or serenity. Strategies used for balancing are planning, creating new routines and doing things that are meaningful and enjoyable. The importance of creating meaningful activities for PwPD has previously been highlighted [137]. Thus, balancing is an effort to meet not only the physical but also the psychological needs. Balancing needs and demands has previously been described as important for PwPD [47], with a suggestion of changing from a biomedical to a need-based approach to facilitate more person-centred care for facilitating this balance. The results of study IV are in line and supports these suggestions. It is obvious that PwPD need person-centred care with a self-management approach in order to support their process of change to facilitate social belonging and achieve and maintain a high level of LS.

Coherence and uncertainty are important links

Moving forward in the process is possible when the person experiences that the situation fits together in a natural or reasonable way, i.e., experiencing coherence. This is the theoretical link, confirmed by the participants in the validation interviews. Coherence should not be considered equal to SOC. SOC is a concept developed by Antonovsky [15] specifically including the three components comprehensibility, manageability and meaningfulness. The coherence of this GT is when the participants have been able to sufficiently comprehend, accept or adapt to find the situation logical and consistent. Even though coherence and SOC are not completely equal, there are great similarities between these two. The comprehensibility of SOC involves coherence as the quality of finding the situation logical and reasonable [15]. Coherence enables moving forward in the process, increasing social belonging, and in turn LS. This concurs with the results of Study II, where the concept SOC is associated with LS.

On one hand, when looking at the results from a salutogenic perspective, SOC might be one factor explaining why some persons tend to have a successful process of change and adaptation, moving forward in the process with increasing social belonging, towards a high level of LS. The results in Studies II, III and IV show the importance of understanding, managing, and feeling motivated as part of an adaptation process for achieving a high level of LS in the new life situation with PD. I thus suggest that the level of SOC is one personal factor that explains why some PwPD are successfully going through the process of change, which in turn can lead to a high level of LS.

On the other hand, experiencing uncertainty forces PwPD to move backwards in the process. Uncertainty is described as occurring when something unpredictable happens, which raises questions about how the social belonging will be affected. For example, when a person needs new medication to manage the symptoms, he/she can wonder how the medication will be tolerated, if it will give rise to side-effects that may affect the social belonging. When uncertainty occurs, PwPD must, once again, use strategies to comprehend, accept and adapt to the new situation before being able to recover their balance and ensure social belonging. The unpredictability and uncertainty have been described as some of the hardest aspects of dealing with PD [138, 146], and the need for coping with uncertainty has previously been highlighted [47]. The phenomenon uncertainty has been explored in persons with young onset PD [37], where uncertainty for PwPD can be experienced in terms of both their identity and their functioning. Uncertainty can cause both fear and anxiety, and one strategy to cope with this anxiety can be seeking information [147]. One aspect of managing uncertainty has previously been described as being able to understand what to expect of the disease [147]. This is in accordance with our model where PwPD go back to strategies for comprehending when experiencing uncertainty. The model of Study IV is supported by the previous knowledge about uncertainty for PwPD. Coping with uncertainty thus is of major importance for PwPD and could be done by applying the different strategies within our model. By managing uncertainty and thereby ensuring social belonging, PwPD can move towards a high level of LS.

A recently published meta-ethnography on adjusting to PD [148] state that understanding how individuals adapt to living with a chronic condition is important not only to better understand the full implications of the condition but also for enabling early intervention for individuals who are finding adjustment difficult. Supporting individuals to self-manage their condition is not only an approach which empowers individuals with the ability to cope in the face of the illness, it may also maximise individual wellbeing [148] . The results of the meta-ethnography are in line with the results of this thesis and describe aspects like acceptance facilitating proactive coping and adaptation, importance of focusing on abilities and possibilities as well as the need for giving the person responsibility and include them in decision making. Furthermore, the authors cover several other aspects of comprehend, accept, adapt and balance, which supports the results of study IV. However, how these factors and the process of change can be conceptualised and are linked together with coherence and uncertainty has not been described before. Therefore, this novel GT adds important knowledge on how to support PwPD to a successful process of change. In addition, the importance of social belonging for the process of change, and the link to LS, has not been described before.

The importance of social belonging for life satisfaction

The main concern of the process of change, social belonging is described by the participants as belonging to the family, to patient organization, at work or other parts of the community. The social role functioning in PwPD has been described in a review by Perepezko et al. [50]. The review showed how PD symptoms, such as tremor and fatigue, interfere with social relationships and some PwPD lose friends if they try to hide their symptoms instead of being open about it. PwPD has also been shown to precipitate earlier departure from work life. The reduced LS in PwPD described by Gustafsson et al. [58] was related to the employment situation among working-aged individuals. A reduced social participation for PwPD has also been described, where PwPD wished for increased social belonging [47]. The absence of social belonging could thus be one explanation for a reduced LS in PwPD as the disease progresses.

The importance of belonging for wellbeing is presented in the "belongingness hypothesis" by Baumeister et al. [149], where belonging is described as a desire for interpersonal attachments as a fundamental human motivation. They state that "human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships". The importance of social belonging for LS has previously been described [150], where an unmet need for social belonging is related to a lower level of LS. These results support the new GT with social belonging as the drive and motivation for change, and the conclusion that social belonging is a prerequisite for a high level of LS for PwPD.

Achieving and maintaining a high level of life satisfaction

The gained knowledge of this thesis can be used to support PwPD in a successful adaptation process, a high level of social belonging and in turn a high level of LS. To close the loop and respond to the question how I as a rehabilitation physician can support PwPD to a high level of LS, I've chosen to answer this from two approaches:

1) What can PwPD do (to achieve and maintain a high level of LS)?
2) What can healthcare professionals do (to support PwPD to achieve and maintain a high level of LS)?

What can persons with Parkinson's disease do?

When summarising what an individual with PD can do to increase the level of LS, I need to return to the philosophy of Ricoeur [151] who gives us the philosophic frames for person-centralisation when he describes the importance of being acknowledged as a person. The human being owns the ability to speak, handle, tell and take responsibility. She needs to admit that she has responsibility for her own actions. Ricoeur summarizes this as *Homo Capax,* the capable human being. By being responsible for one's own actions, one also acknowledges oneself to be capable of doing so. I believe this is crucial for making the needed changes and managing everyday life with PD, for achieving and maintaining a high level of LS.

Taking responsibility increases capability

Persons in acceptance (Study III) are taking responsibility by accepting that a change is needed, accepting their own responsibility, and believing in their ability. They are actively using strategies to try new problem solving and to perform extensive self-care, which make them able to adapt to the new life situation and thereby achieve a high level of LS.

Since social belonging is both a motivation in the process of change when living with PD, and a prerequisite for LS, PwPD can reflect upon their own social belonging and their need for belonging to find motivation for change. By applying the strategies from Study IV, PwPD can then take responsibility for their own process and be capable of moving towards a greater social belonging, and in turn a high level of LS.

Moving forward in the process of change

To be able to *comprehend* the situation is an essential start of the process of change. PwPD can increase their comprehending by actively seek knowledge, learn from others, reflect upon the situation, compare themselves with others, as well as setting new goals and evaluate the new achievements and performances. They can find support for this not only from the healthcare services but also from patient organisations for PwPD.

By preparing for different aspects of the disease, approaching symptoms and difficulties instead of denying them and sharing the experiences with others, PwPD can increase their *acceptance* of the situation and face the reality they are in, which is important for being capable of managing the situation. Acceptance should not be seen as giving up, but as taking responsibility for the situation they are in.

> *”When you finally accept that you have this disease, it doesn’t mean that you’ve given up.”* (Interview no 5)

PwPD can accept help from others which can include changing roles in the family or at work, in order to *adapt*. There is a strong need for adjusting several aspects of everyday life, such as fewer working hours, diet, lifestyle due to a changed financial status etc. Exercising daily is an important task to manage physical disabilities. It leads to increased strength and mobility, but the amount and type of exercise should be adjusted to the individual’s requirements. By scheduling a lot, PwPD can ensure that the medications have the greatest effect when desired and to minimise side-effects. Scheduling and planning everyday activities according to energy and need for recovery can facilitate the ability to manage everyday life.

In order to experience social belonging, and in turn achieve a high level of LS, PwPD can also *balance* by actively prioritizing in everyday life, chose wisely how to spend time on different tasks and about what is important. Being able to choose their battles and choose to look on the bright side, despite a heavy symptom burden and side-effects from medication, can facilitate the needed balance. One does not have to stop feeling sorry for oneself or being disappointed. It is instead important to acknowledge the things that generate energy, hope and joy. To balance, PwPD can create new routines and learn different ways of doing things as well as create new meaningful activities and situations. Being mindful and staying in the present is important in order to enjoy life as it is.

All these strategies can be seen from a salutogenic approach and could contribute to an increased comprehensibility, manageability and meaningfulness, the three components of SOC [15], which could increase the level of LS.

Support from others

Achieving and maintaining a high level of LS is a very demanding but necessary endeavour and involves the whole life situation. It is evident that the resourceful persons cope and manage their situation from the beginning. Those in acceptance (Study III) have literally made their own rehabilitation plan with structured measures and specific goals. It is debatable whether it is reasonable for us to expect the person to carry out their rehabilitation on their own when living with PD.

Homo capax is not something an individual can just choose to be from one day to another but is something that needs to be aimed for and conquered. Ricoeur also emphasizes that the capable human being must also involve other persons [151]. This is in line with SOC, where Antonovsky describes how the comprehensibility, manageability and meaningfulness involves social interactions with others to find the needed resources, within oneself or with support from others, in order to cope with stressful situations [15]. The need for support from others is evident and PwPD should not have to embark on the process of change on their own. Based on the knowledge from this thesis, the healthcare system has a highly important role to support PwPD in their process of change for achieving and maintaining a high level of LS.

What can healthcare professionals do?

The Swedish National Board of Health and Welfare has published national guidelines for the treatment, care and rehabilitation of PwPD, due to the complexity and progression of the disease [24]. These guidelines suggest that PwPD should be offered interdisciplinary team rehabilitation. However, how these interventions should be carried through is not specified in the guidelines, which could be an obstacle for following the guidelines.

Self-management and rehabilitation

This thesis shows the complexity of living with PD, and why the support of an interdisciplinary team is needed. The rehabilitation is a pedagogical process with behavioural changes within the components of self-management and empowerment, as described in the introduction. This leads us once again to *Homo capax* [151]. By involving a person in his/her treatment and rehabilitation and giving him/her responsibility, we can show the person that we believe that he/she has the capability of managing the situation. Or as one of the participants said:

> *"... the most important thing the healthcare can do, is to actually to give us hope that we can change our own situation, that we are not powerless..."* (Interview no 9)

By using the SWLS as a screening tool, we can find the persons with a low level of LS (Study I). These persons presumably also have problems in adapting to the new life situation and might be in need of support from an interdisciplinary team.

The association between SOC and LS (Study II) shows the importance of being able to comprehend, manage and feel motivated when dealing with stressful situations in everyday life. This explains how empowerment and self-management interventions that support PwPD to understand and confront the nature of the problems arising in their lives as consequences of the disease, could increase LS. Self-management support has recently been suggested to increase LS for PwPD [138] and it is implied that it also helps to maintain LS over time [146]. Empowerment and self-management can be promoted through person-centred interventions based on individual needs and goals, while supporting PwPD throughout the process of change when living with PD.

Support the person through the process of change

Healthcare professionals must first of all focus on how PwPD react then they receive the diagnosis. We can then as soon as possible identify those who adopt a reactive pattern of behaviour as it may delay the necessary adaptation and constitute a barrier to LS. We then need to understand how the person comprehend the situation in order to be able to support him/her where he/she is. This could be done by posing the simple, yet important question, "How do you understand this particular situation with PD?". By listening to the person, we can with the help of the description from Study III start to recognize whether a person is in acceptance or resistance. It is then important for healthcare professionals to support the person in the various steps of the process of change (Study IV).

In order to support the first step, *comprehend*, it is important to give PwPD the opportunity to understand their new situation before presenting numerous strategies for adaptation. This could be done by providing information about PD and the consequences of the disease, encouraging group activities and at some point, inviting family members for learning together. These are all strategies for facilitating the necessary coherence, and the possibility to move forward in the process.

In order to enable the next step, *accept*, we can encourage PwPD to reflect and to share their thoughts with friends and family. They can also be encouraged to join therapy groups or be introduced to patient organisations. A specific intervention could be to apply the principles of Acceptance and Commitment Therapy (ACT) and focus on minimising evasive behaviour and increase psychological flexibility [143, 152]. ACT could support PwPD to develop adaptive strategies to manage daily life and problems arising as a result of the changed life situation. This could be done by listening to the individual and validating his/her experiences, modelling and normalising that some unpleasant experiences might be meaningful for reaching a greater goal. For example, the scheduling of medication can be experienced as limiting but might be necessary in order to be able to participate in meaningful activities. In addition, healthcare professionals could encourage new perspectives by identifying what and why something is important for the person, and thereafter supporting the person to find a new way towards their values and goals [143, 152]. These are all strategies that can be used and should be promoted for PwPD for facilitating the acceptance, making it possible to move forward to adaptation, and gradually increase social belonging, and in turn LS.

In order to support PwPD to *adapt* and find *balance*, a goal-oriented individualised interdisciplinary rehabilitation program could be successful. To adapt and balance involve several areas of life as described above, which could be formulated as various goals and interventions and be supported by an interdisciplinary team of different professionals.

Managing uncertainty and promoting coherence

We also need to validate the uncertainty throughout the process and offer other perspectives. Managing uncertainty will enable a perceived coherence and make it possible to move forward in the process of accepting, adapting, and balancing to increase social belonging, and in turn achieve and maintain a high LS. Therefore, focusing on managing uncertainty and promoting coherence should be priorities in the management and rehabilitation for PwPD. The approach of ACT could also be useful for managing uncertainty [143, 152].

Facilitate social belonging

While supporting PwPD through the process of change, we need to understand each person's specific drive and motivation which could be found in their social belonging. In other words, we need to understand where the person is situated and towards where he/she is going, if we want to help them on their journey.

Social belonging was shown to be important as the drive for change as well as a prerequisite for LS. Increasing social belonging could be performed by offering group-based activities, which has been suggested for rehabilitation interventions for PwPD [47, 50, 138]. This could also be increased by introducing patient organisations, inviting family members and encouraging sharing with friends, work colleagues and family. Supporting PwPD through the four steps above might increase their social belonging, and in turn LS. Rehabilitation interventions have an important role for this need since several studies have shown that conventional PD therapy has little positive effect on social role functioning [50].

Provide continuity and trust

Finally, healthcare professionals should reflect upon their own behaviour and treatment of PwPD throughout the journey towards a high LS. We could learn from the experiences of persons in resistance in Study III: Feeling disappointed, mistrusting the professionals, and lacking continuity. By working to attain a good communication, continuity, and trust, we might be able to support the person towards acceptance, or at least minimise the resistance. I really believe that the following citation from one of the participants truly says something about how important our role is:

> *".. and then it's the healthcare system you know. It kills you. You have to be healthy to be ill, because you have to struggle for everything."* (Interview no 3)

There are many things PwPD can do to achieve and maintain a high level of LS, and the support needed from healthcare professionals includes various actions from different professionals. One appropriate way to meet the complex need of support for PwPD is to apply a person-centred care. With an interdisciplinary goal-oriented approach healthcare professionals might then be able to support PwPD through their process of change to ensure social belonging and a high level of LS.

In summary, SOC, adaptation and social belonging are important components for LS for PwPD. PwPD need support by healthcare professionals through their process of change to comprehend, accept, adapt, and balance, in order to enable social belonging, and in turn a high level of LS. The process may be facilitated by strengthening the components of SOC. This could be achieved by interdisciplinary goal-oriented rehabilitation, which I suggest as an appropriate way for managing PD.

“ No… I refuse to give up. It’s probably a little of that which makes it... It is possible to do it. I will manage to live with it. There are so many things in life that are wonderful!” (Interview No 5)

Conclusions

This thesis has provided new knowledge and understanding about LS for PwPD. This can be used in current clinical management and rehabilitation, as well as in research and for the future development of rehabilitation interventions for PwPD. The conclusions of this thesis are:

- The SWLS is a psychometrically sound and suitable tool for assessing LS in PwPD.
- LS can vary considerably in the earlier phase of the disease course, but PwPD seem to be generally satisfied with their lives, even though there are indications that LS may decrease as the disease progresses.
- The components of SOC, i.e., to comprehend, manage and be motivated are important for LS when living with PD.
- Adaptation to PD involves a transitional process characterized by either acceptance or resistance, which influences a person's LS. Acceptance makes LS possible, whereas resistance constitutes a behavioral barrier to adaptation and LS.
- Trusting the healthcare professionals and experiencing continuity may be important factors for being in acceptance. The treatment and communication with patients are important for avoiding negative experiences that might be a barrier for acceptance, and in turn adaptation and LS.
- Social belonging is the main concern in the process of change for PwPD. In this process of change, they use strategies to comprehend, accept, adapt, and balance in their pursuit of social belonging, which in turn can lead to high level of LS.

Clinical implications

A summary of relevant practical and clinical implications of this thesis follows in this chapter.

- The SWLS can be used as a screening tool to identify persons with a low level of LS and can be a starting point for conversations about the persons' life situations. It can also be used as an outcome measure on group-level before and after interdisciplinary rehabilitation interventions aiming at increasing or maintaining a high level of LS.
- Strengthening the three components of SOC (comprehensibility, manageability and meaningfulness) might increase LS. This may be done by self-management rehabilitation to support PwPD to understand and confront the consequences of the disease.
- It is important to understand how a person comprehends his/her situation with PD. This can be done by asking the simple, yet important, question "How do you understand this particular situation with PD?", and then validate the person's experiences.
- By identifying if a person is in acceptance or resistance, we can find barriers for the essential adaptation. Healthcare professionals should then support PwPD through the process of change, for a successful adaptation, which may increase LS.
- PwPD should be encouraged to share their disease experiences with family, friends, colleagues, or other persons in similar situations, which could be a strategy for accepting the situation and for preventing the loss of social relationships.
- By applying a person-centred open communication and providing access and continuity in the healthcare services, we might facilitate acceptance, and in turn adaptation and a high level of LS. PwPD need to be able to contact the healthcare when needed due to the unpredictable progression. This could, for example, be met by offering a phone line to a PD specialized healthcare professional.
- Managing uncertainty and promoting coherence by self-management and empowerment should be priorities in the management and rehabilitation for

PwPD. By applying the principles of ACT to validate, modulate and present perspectives, healthcare professionals may be able to support the person to increase their psychological flexibility and manage the uncertainty.

- Healthcare professionals should encourage PwPD to take responsibility for their process of change. We can thus show them that we believe that they are capable of influencing their own life situation.
- By supporting the person to focus on abilities and possibilities, we may facilitate for them to accept the situation, which in turn can enable the essential adaptation.
- By identifying the person's needs and goals and listen to how the person is understanding the situation, we can find those who have difficulties managing their life situation. Listening to the person helps us understand the persons motivation and we can then support him/her with goal-specific strategies and a high level of motivation.
- PwPD should receive support from an interdisciplinary rehabilitation team to comprehend, accept, adapt and balance their life situation. This requires a team with professionals such as physician, nurse, counselor, physiotherapist, occupational therapist, speech therapist etc. according to each individual's needs.
- The new grounded theory can be used as a road map to find where the person is situated in the process and in which areas the support is needed. The rehabilitation interventions can then be planned and designed according to each individual's needs. The model can also be used as a pedagogical tool for PwPD to explain the process of change and thereby increase their comprehension.
- Facilitating social interactions with group-activities, promoting patient organisations or focusing on workplace rehabilitation may support participation and social belonging, and high levels of LS. Group-based activities could also contribute to an increased comprehension.
- PwPD need a continuing support and might be in need of recurrent interdisciplinary rehabilitation during the disease course since PD is a progressive disease.
- The Swedish National Guidelines for PD recommend that PwPD should be offered interdisciplinary team rehabilitation. The knowledge from this thesis can be used for facilitating the implementation of these guidelines.

Future perspectives

In this chapter follows a summary of suggestions for future research based on the gained knowledge from this thesis.

- Further evaluation of SWLS could be performed by using for example Rasch analysis to explore the scale's properties.
- Psychometric evaluation of other LS rating tools could explore which rating tools is best suited for different occasions in clinical practice and research.
- For designing interventions specifically aiming at strengthening SOC, further studies should focus on the content of SOC, for example by performing a content analysis on SOC for PwPD to explore the comprehensibility, manageability, and meaningfulness.
- SOC is one explanation as to why some persons seem to cope more effectively with stressful situations than others. There probably are other factors explaining this. Further studies should explore why some persons seem to be more resilient than others and explore how this is related to LS.
- The knowledge on acceptance needs to be increased, since acceptance seems to be an important turning point. Further research should focus on understanding why some persons accept more easily than others, and how acceptance can be facilitated when living with PD.
- ACT has been suggested throughout this thesis as an appropriate approach for increasing psychological flexibility, enabling acceptance, and managing uncertainty. Using ACT as part of the management of PD has not been explored. Further studies should evaluate if ACT could be used for facilitating acceptance and the necessary behaviour change when living with PD, and if ACT could contribute to achieving and maintaining a high level of LS for PwPD.

- The complex symptom panorama and unpredictable progression necessitate further studies on the symptom management for fatigue, pain, stress sensitivity etc. in order to optimize the non-pharmacological symptomatic treatment for PD.
- Further cross-sectional as well as longitudinal studies are also needed to understand how other factors influence LS in PwPD and how LS changes over time as the disease progresses.
- The Swedish National Guidelines for PD were published in 2016 and recommend that PwPD should be offered interdisciplinary team rehabilitation. How this rehabilitation should be performed is, however, not described. Further studies should explore and evaluate rehabilitation interventions for PwPD.

Epilogue

Now I have come to the end of this road, and I still cannot stop thinking about the complexity of LS for PwPD. When studying LS, I have come to understand that this is a multifaceted phenomenon which can be assessed, explored, and be associated with several other phenomena. Above all, LS is highly individual as a subjective evaluation of one's life situation, and there might not be a single explanation of its content. A summary of the knowledge gained in this thesis is that LS for PwPD might be just as complex as the disease itself.

LS is not a constant state, but an ongoing cognitive judgement upon one's life situation, which can always change due to factors within one-self or in the surrounding environment. It is a direction which we can aim and work for, but not a fixed state, where we can stay put without continuing our movement and adaptation. The road towards LS continues throughout life and this thesis can be seen as a map for understanding the road towards LS for PwPD.

The road towards my dissertation has taken me on a fantastic journey. I have crossed mountains of philosophical theories and thoughts on the actual meaning of life, and I have landed in a more pragmatic view, where it is clear that the rehabilitation medicine approach has the prerequisite for supporting persons on their journey for achieving and maintaining a high level of LS.

On the way towards my dissertation, I have grown as a scientist, researcher and person. I view myself as both researcher and clinician in my residency as rehabilitation specialist, and I can see how my research and knowledge can contribute to a better life situation for PwPD.

I am utterly convinced that the right road for PwPD to achieve and maintain LS is through an interdisciplinary rehabilitation approach. My hopes are now that more PwPD should gain access to interdisciplinary rehabilitation, since I see how this could support persons to a high level of LS, over time.

Populärvetenskaplig sammanfattning

Parkinsons sjukdom (PS) är en livslång fortskridande neurologisk sjukdom vars förekomst ökar med åldern. I Sverige lever ungefär 20 000 personer med PS och medelåldern för insjuknande är 65 år, men insjuknande så långt ner som i 30-årsåldern är inte helt ovanligt.

Symptomen vid PS är både så kallade motoriska (stelhet, skakningar och långsamma rörelser) men även icke-motoriska (tex uttalad trötthet, blås- och tarmbesvär, stresskänslighet, sömnbesvär, smärta och blodtrycksfall). Det finns inget botemedel eller någon bromsande behandling för PS idag, men symptomen kan lindras med bland annat läkemedelsbehandling.

PS kan upplevas som oförutsägbar och svår att hantera, med en individuell försämring av både motoriska och icke-motoriska symptom, ofta i ett ojämnt mönster. Trots en väl anpassad medicinering leder sjukdomen och dess konsekvenser till en påverkan på individens vardag och hela livssituation, vilket kan påverka dennes livstillfredsställelse. Personer med PS kan med hjälp av medicinsk rehabilitering få stöd i att hantera sjukdomen och dess konsekvenser. Ett övergripande mål i modern rehabilitering är att förbättra livstillfredsställelse.

Livstillfredsställelse är en subjektiv bedömning av sin egen livssituation utifrån sina egna behov och önskemål. Det har tidigare visats att förmågan att anpassa sig är viktig för livstillfredsställelse, men kunskapen om livstillfredsställelse för personer med PS saknades helt när arbetet med denna avhandling påbörjades.

Denna avhandling har ökat kunskapen om livstillfredsställelse för personer med PS sjukdom genom publikation av fyra vetenskapliga studier. Fyra olika vetenskapliga så kallade kvantitativa och kvalitativa metoder har använts för att analysera och presentera informationen för att få en bred och djup förståelse av livstillfredsställelse för personer med PS.

Den första studien har utvärderat ett skattningsinstruments mätegenskaper för att kunna bedöma livstillfredsställelse. Den andra delstudien har kartlagt livstillfredsställelse och faktorer som påverkar livstillfredsställelse för personer med PS. Den tredje och fjärde delstudien har med hjälp av djupintervjuer utforskat innebörden av livstillfredsställelse och anpassning utifrån personernas egna perspektiv när de lever med PS, samt skapat ett nytt vetenskapligt ramverk för hur personer med PS genomgår en förändringsprocess när de lever med sjukdomen.

Resultatet visade att skattningsinstrumentet Satisfaction With Life Scale (SWLS) är ett stabilt och tillförlitligt verktyg för att bedöma livstillfredsställelse hos personer med mild till måttlig PS. Genom att använda SWLS inom det kliniska arbetet kan vi hitta de personer med låg livstillfredsställelse som behöver extra stöd att hantera sin livssituation.

Det var en stor variation av nivån av livstillfredsställelse hos deltagarna. Ju längre tid som deltagarna hade levt med PS, desto lägre skattade de sin livstillfredsställelse med SWLS. Det salutogena konceptet känsla av sammanhang (KASAM) är relaterat till livstillfredsställelse; ju starkare KASAM deltagarna hade desto högre skattade de sin livstillfredsställelse. KASAM består av de tre delarna begriplighet, hanterbarhet och meningsfullhet. Detta visar att förmågan att förstå och hantera konsekvenserna av sjukdomen samt att känna sig motiverad, är viktigt för livstillfredställelsen.

Djupintervjuerna visade att när personer får diagnosen PS genomgår de en förändringsprocess som karaktäriseras av antingen acceptans eller motstånd. En del personer accepterar sin situation vilket underlättar för förändringen och den nödvändiga anpassning som behövs för att hantera den nya livssituationen och på så vis uppnå och bibehålla en hög livstillfredsställelse. Å andra sidan hamnar en del personer i motstånd och kämpar mot sjukdomen och dess konsekvenser. Detta kan fördröja den nödvändiga anpassningen och försämra möjligheterna för en god livstillfredsställelse. Hälso- och sjukvården måste lära sig att känna igen om personer med PS befinner sig i acceptans eller motstånd, för att sedan kunna stödja dem till en god förändringsprocess.

Drivet genom förändringsprocessen vid PS är att uppleva social tillhörighet, antingen i familjen, på arbetsplatsen, bland vänner, i en patientförening eller andra delar av samhället, vilket är kopplat till hög livstillfredsställelse. I strävan efter att uppleva social tillhörighet arbetar personer med PS aktivt för att förstå, acceptera, anpassa sig och balansera i den nya livssituationen. Detta är ett krävande arbete och hälso- och sjukvården behöver stödja personer med PS igenom denna förändringsprocess för att känna social tillhörighet, och i sin tur en hög livstillfredsställelse. Detta kan göras genom nära samverkan mellan olika professioner i ett så kallat interdisciplinärt team och medicinsk rehabilitering.

Sammanfattningsvis är KASAM, anpassningsförmåga och social tillhörighet viktiga komponenter för livstillfredsställelse för personer med PS. Personerna behöver, till följd av den fortskridande karaktären, ett återkommande stöd för att förstå, acceptera, anpassa sig och balansera i den nya livssituationen för att kunna känna social tillhörighet, och i sin tur en hög livstillfredsställelse. Förändringsprocessen kan underlättas genom att stärka de tre delarna av KASAM, vilket skulle kunna göras genom medicinsk rehabilitering med stöd av ett interdisciplinärt team.

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Appendix

Appendix 1. The Swedish version of the Satisfaction With Life Scale

LIVSTILLFREDSSTÄLLELSE

Här nedan finns fem påståenden som du kan instämma i eller inte. För varje påstående ringa in en siffra från 1 till 7 där 1 betyder ”instämmer absolut inte” och 7 betyder ”instämmer helt och hållet. Var så ärlig som möjligt i dina svar.

Skalan:

1= Instämmer absolut inte

2= Instämmer inte

3= Instämmer oftast inte

4= Instämmer varken eller/neutral

5= Instämmer delvis

6= Instämmer

7= Instämmer helt och hållet

Påståendena:

1. I de flesta avseenden är mitt liv så nära det ideala

1 2 3 4 5 6 7

2. Mina levnadsförhållanden är utomordentliga

1 2 3 4 5 6 7

3. Jag är nöjd och tillfreds med mitt liv

1 2 3 4 5 6 7

4. Hittills har jag uppnått det viktigaste jag önskat i mitt liv

1 2 3 4 5 6 7

5. Om jag kunde leva om mitt liv skulle jag nästan inte ångra någonting

1 2 3 4 5 6 7

Appendix 2. The interview guide for Studies III and IV.

Intervjuguide

Börja väldigt öppet:

- Skulle du vilja börja med att berätta för mig vad Parkinsons sjukdom (PS) är för dig?
- Hur förstår du det här med PS?
    - Hur har du lärt dig om din sjukdom?
- Hur tänker du kring dina symptom eller besvär?
- Hur påverkas din vardag av PS?
    - Hur hanterar du din vardag utifrån PS?
- Vad är att ha det bra för dig nu?
    - När har du det bra? Vad är viktigt för dig för att ha det bra?
- När känner du dig tillfreds med ditt liv?
- Hur har ditt liv förändrats sedan du fick din diagnos?
- Vad är viktigt för dig?
- Hur har dina drömmar och mål i livet förändrats?
    - Hur har du kunnat uppnå dina drömmar och mål?
- Hur ser dina kontakter med vården ut nu?
- Hur ser ditt behov av stöd ut?
- I vilka situationer har du det inte bra eller känner dig inte tillfreds med livet?
- När du har bra stunder eller bra perioder, vad är det som fungerar då?
- När du har sämre stunder eller mindre bra perioder, vad är det som inte fungerar då?

Följdfrågor att utveckla med:

- Hur menar du då?
- Vill du ge något exempel på det?
- Har du fler exempel på…?
- Skulle du kunna utveckla…?
- Hur känns det?
- Hur blir det för dig?
- Hur gör du då?
- Jag förstår att …… har jag förstått det rätt?