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# Activity avoidance, perceived walking difficulties, and use of mobility devices in people with Parkinson's disease

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DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



# **Activity avoidance, perceived walking difficulties, and use of mobility devices in people with Parkinson's disease**

Manzur Kader



**LUND**  
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DOCTORAL DISSERTATION

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To be defended at the Health Sciences Centre, Baravägen 3, Lund

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*Faculty opponent*

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<p><b>Abstract</b></p> <p><b>Background:</b> Parkinson's disease (PD) is a chronic progressive neurodegenerative disease that results in functional loss and disability. People with PD have an increased risk of falling, and most of their falls occur while walking. As yet, there is limited knowledge concerning activity avoidance due to perceived risk of falling in people with PD. In order to quantitatively assess perceived walking difficulties, a psychometrically-sound instrument is necessary. Although the generic Walk-12 scale (the Walk-12G) seems promising, only one prior study has investigated its psychometric properties in people with PD. Moreover, little is known about factors that independently contribute to perceived walking difficulties in people with PD. No study has yet investigated the use and perceived needs of mobility devices (MDs) over a period of time in people with PD.</p> <p><b>Aim:</b> The overarching aim of this PhD thesis was to gain increased knowledge regarding activity avoidance due to perceived risk of falling, perceived walking difficulties, and the use and perceived needs of MDs in people with PD.</p> <p><b>Methods:</b> The thesis was based on a longitudinal cohort survey of participants with PD with a baseline data collection (n=255), using self-administered and structured questions/questionnaires, observations, and clinical assessments, and an equivalent 3-year follow-up (n=165). Statistical analyses included bivariate analyses (Study I), psychometric evaluation (Study II), multivariate analyses (Study III), and descriptive- and follow-up analyses (Study IV).</p> <p><b>Main results:</b> Study I: Activity avoidance due to perceived risk of falling was reported by 30% of the non-fallers whereas the corresponding rate was 57% in recurrent fallers (i.e. <math>\geq 2</math> falls). Twenty-four percent of participants with an early/mild PD stage reported activity avoidance due to the perceived risk of falling which rose to 74% among those in the most severe stages. Moreover, it was reported by 51% of participants with near falls (but no falls). Seventy percent of participants with fear of falling reported that they avoided activities due to the perceived risk of falling. Study II: In the PD sample, the Walk-12G had acceptable missing item responses and floor/ceiling effects, and corrected item-total correlations <math>&gt;0.60</math>. Based on ordinal alpha and Cronbach's alpha, values for internal consistency were <math>&gt;0.95</math>. External construct validity was satisfactory. Study III: The strongest contributing factor to perceived walking difficulties (assessed with the Walk-12G) was freezing of gait, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability. Study IV: Over the 3-year period, MD use increased significantly from 22% to 40% for indoor use, and from 48% to 66% for outdoor use. The perceived need of MDs increased from 5% to 21% in people with PD.</p> <p><b>Conclusion:</b> Activity avoidance due to perceived risk of falling can be reported even when the person has mild PD. The findings imply that this aspect should not only be considered when the person has a history of falls, since a history of near falls appears also to be of importance. This thesis strengthens the recommendation for using the Walk-12G when assessing perceived walking difficulties in people with PD. It appears that freezing of gait and general self-efficacy should be the primary targets when addressing perceived walking difficulties in people with PD. The knowledge gained on the use and perceived needs of MDs over the 3-year period has implications for improving the provision and follow-ups of MDs, as well as for policy making, planning, and health services. However, the findings need to be replicated in other PD-samples as well as in different national contexts.</p>	
Key words: Activity avoidance, assistive devices, difficulty walking, falls, fear of falling, ICF, mSAFFE, near falls, patient outcome assessment, PROM, psychometrics, Parkinson's disease, reliability, validity, Walk-12G, walking aids, wheelchairs, wheeled-walker	
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# **Activity avoidance, perceived walking difficulties, and use of mobility devices in people with Parkinson's disease**

Manzur Kader



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*Dedicated to  
my mother Abida Sultana and my father Iyakub Ullah*

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## Abstract

**Background:** Parkinson's disease (PD) is a chronic progressive neurodegenerative disease that results in functional loss and disability. People with PD have an increased risk of falling, and most of their falls occur while walking. As yet, there is limited knowledge concerning activity avoidance due to perceived risk of falling in people with PD. In order to quantitatively assess perceived walking difficulties, a psychometrically-sound instrument is necessary. Although the generic Walk-12 scale (the Walk-12G) seems promising, only one prior study has investigated its psychometric properties in people with PD. Moreover, little is known about factors that independently contribute to perceived walking difficulties in people with PD. No study has yet investigated the use and perceived needs of mobility devices (MDs) over a period of time in people with PD.

**Aim:** The overarching aim of this PhD thesis was to gain increased knowledge regarding activity avoidance due to perceived risk of falling, perceived walking difficulties, and the use and perceived needs of MDs in people with PD.

**Methods:** The thesis was based on a longitudinal cohort survey of participants with PD with a baseline data collection ( $n = 255$ ), using self-administered and structured questions/questionnaires, observations and clinical assessments, and an equivalent 3-year follow-up ( $n = 165$ ). Statistical analyses included bivariate analyses (Study I), psychometric evaluation (Study II), multivariate analyses (Study III), and descriptive- and follow-up analyses (Study IV).

**Main results:** Study I: Activity avoidance due to perceived risk of falling was reported by 30% of the non-fallers whereas the corresponding rate was 57% in recurrent fallers (i.e.  $\geq 2$  falls). Twenty-four percent of participants with an early/mild PD stage reported activity avoidance due to the perceived risk of falling which rose to 74% among those in the most severe stages. Moreover, it was reported by 51% of participants with near falls (but no falls). Seventy percent of participants with fear of falling reported that they avoided activities due to the perceived risk of falling. Study II: In the PD sample, the Walk-12G had acceptable missing item responses and floor/ceiling effects, and corrected item-total correlations  $> 0.60$ . Based on ordinal alpha and Cronbach's alpha, values for internal consistency were  $> 0.95$ . External construct validity was satisfactory. Study III: The strongest contributing factor to perceived walking difficulties (assessed with the Walk-12G) was freezing of gait, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability. Study IV: Over the 3-year period, MD use increased significantly from 22% to 40% for indoor use, and from 48% to 66% for outdoor use. The perceived need of MDs increased from 5% to 21% in people with PD.

**Conclusion:** Activity avoidance due to perceived risk of falling can be reported even when the person has mild PD. The findings imply that this aspect should not only be considered when the person has a history of falls, since a history of near falls appears also to be of importance. This thesis strengthens the recommendation

for using the Walk-12G when assessing perceived walking difficulties in people with PD. It appears that freezing of gait and general self-efficacy should be the primary targets when addressing perceived walking difficulties in people with PD. The knowledge gained on the use and perceived needs of MDs over the 3-year period has implications for improving the provision and follow-ups of MDs, as well as for policy making, planning, and health services. However, the findings need to be replicated in other PD-samples as well as in different national contexts.

# List of publications

This thesis is based on the following studies:

- I. **Kader M**, Iwarsson S, Odin P, Nilsson MH. Fall-related activity avoidance in relation to a history of falls or near falls, fear of falling and disease severity in people with Parkinson's disease. BMC neurology. 2016;16(1):84.
- II. **Kader M**, Hagell P, Iwarsson S, Odin P, Nilsson MH. Assessing perceived walking difficulties in Parkinson's disease: Psychometric properties of the Walk-12G. (submitted for publication)
- III. **Kader M**, Ullén S, Iwarsson S, Odin P, Nilsson MH. Factors contributing to perceived walking difficulties in people with Parkinson's Disease. Journal of Parkinson's disease. 2017;7(2):397-407.
- IV. **Kader M**, Jonasson SB, Iwarsson S, Odin P, Nilsson MH. Mobility device use in people with Parkinson's disease: a 3-year follow-up study. Acta Neurologica Scandinavica. 2018;00:1-8. DOI: <https://doi.org/10.1111/ane.12942>

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# Abbreviations

CI	Confidence interval
CTT	Classical test theory
FOF	Fear of falling
FOG	Freezing of gait
FOGQsa	Self-administered version of the Freezing of Gait Questionnaire
GDS-15	Geriatric Depression Scale
GSE	General Self-Efficacy Scale
HY	Hoehn and Yahr
ICF	International Classification of Functioning, Disability and Health
MD	Mobility device
MoCA	Montreal Cognitive Assessment
mSAFFE	Modified Survey of Activities and Fear of Falling in the Elderly
NHP-EN	Energy subsection of the Nottingham Health Profile
NMSQuest	Nonmotor Symptoms Questionnaire
PADLS	Parkinson's disease Activities of Daily Living Scale
PD	Parkinson's disease
PROM	Patient reported outcome measure
$r_s$	Spearman's correlation coefficient
SD	Standard Deviation
SEM	Standard Error of Measurement
UPDRS III	Part three of the Unified Parkinson's Disease Rating Scale
QOL	Quality of life
Walk-12G	Generic Walk-12

# Definitions

Falls	“An unexpected event in which the participants come to rest on the ground, floor, or lower level” (1).
Fear of falling	Fear of falling is considered an umbrella term and conceptualized in different ways. In this thesis, a dichotomous question (Yes/No) “Are you afraid of falling” was used to assess fear of falling.
Freezing of gait	“Brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk” (2).
Mobility device or assistive device	Any piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain or improve functional capabilities of individual with disabilities (3).
Near fall	“A fall initiated but arrested by support from the wall, railing, other person etc.” (4).
Psychometric properties	Psychometric properties refer to the reliability and validity of an instrument. Validity refers to what extent the instrument measures the constructs it intends to measure. Reliability refers to what extent the measurement is free from measurement error (5).
Self-efficacy	The belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations (6).
Perceived walking difficulty	Any report of the walking difficulty that comes directly from a person, without interpretation of the person’s response by a clinician or anyone else.

## Preface

My PhD specialises in Physiotherapy within Health Sciences, and was conducted in the research group Active and Healthy Ageing, affiliated with the Center for Ageing and Supportive Environments (CASE) and the Strategic Research Area in neuroscience (MultiPark) at Lund University, Sweden. Furthermore, my learning process was supported by the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH).

I am a registered physiotherapist with a Bachelor's degree in Physiotherapy from Bangladesh. I further deepened my knowledge in the field of Public Health by studying a Master's degree in Public Health Nutrition, and a Master's degree in International Health in Sweden. I then worked as a research officer at the Department of Public Health Sciences at Karolinska Institute in Stockholm. Moreover, I have a long experience of working as a physiotherapist. I gained my first clinical experience of working with people with Parkinson's disease (PD) when I worked as a physiotherapist in a residential care facility (äldreboende) in Stockholm in 2008. I then developed a true interest for rehabilitation for people with PD. I met many persons with PD who tended to avoid or limit many daily activities. I helped them with Physiotherapy assessment of their walking difficulties, and with Physiotherapy treatment to improve their walking ability. Moreover, I assisted many of them in using mobility devices.

I was accepted as a PhD student in June 2014. My PhD thesis focuses on activity avoidance due to perceived risk of falling, perceived walking difficulties, and the use and perceived needs of mobility devices in people with PD. This is a part of a longitudinal project *Home and Health in People Ageing with PD*, which was conceived and designed by my main supervisor M. H. Nilsson and my co-supervisor S. Iwarsson. The baseline data collection for the project was completed in 2013, which was followed by an equivalent 3-year follow-up, completed in 2016. The data collection included a self-administered postal survey followed by a subsequent home visit, which involved interview-administered questions and questionnaires, observations and clinical assessments.

## My contributions and involvements

As I was admitted as a PhD student after the baseline data collection was completed, my first involvement in the data collection preparations and field work was involvement in the ethical application process for the 3-year follow-up survey. Subsequently, I participated in the data collection during the 3-year follow-up together with a project administrator. I conducted majority of the clinical assessments among around 50 participants. I also accompanied the project administrator while conducting other parts of the data collection that is, administering interview-administered questions and questionnaires as well as observation of the home environment.

I have made substantial contributions to the study designs, specification of aims and choice of variables of all the studies (studies I-IV) included in the thesis. I have performed the vast majority of analyses and interpretation of data for all the studies, with increasing independence throughout. Moreover, I have made major contributions to the writing of the manuscripts and responses to journal Editors.

During my PhD studies, I have presented my work at major international conferences, which gave me opportunities to develop my international research capacity and to interact with many participants from diverse academic orientations. I have conducted several scientific and popular science oral presentations at different local and national conferences and seminars. With the guidance from my supervisors, I have achieved scientific writing skills, learned to be more communicative, careful and to organize and plan my time better – I am still learning which might take a while! I believe that this is my first step towards becoming an independent researcher. I wish to continue in academic research, and I believe that the knowledge I gained from writing this thesis is a good way to move forward.



# Background

Parkinson's disease is a complex and progressive disease, and this thesis primarily focuses on activity avoidance due to perceived risk of falling, perceived walking difficulties, and use and perceived needs of mobility devices in people with Parkinson's disease

## Parkinson's disease

Parkinson's disease (PD) is a progressive neurodegenerative disease leading to profound loss of nigrostriatal dopaminergic neurons (7). However, multiple neurotransmitter systems are affected including other parts of the central nervous system (7, 8). The diagnosis is based on clinical observations and post-mortem neuropathological examination (9, 10). According to the UK PD Society Brain Bank Clinical Diagnostic Criteria (10), positive diagnostic features include the presence of bradykinesia and at least one of the other cardinal signs. However, only a post mortem examination of the brain can give 100% certainty for PD (10). The cause of PD is unclear, but it is most likely caused by a complex interplay between genetic and environmental factors (11). A 2015 Global Burden of Disease Study estimated that approximately 6.2 million people were affected by PD; there may be nearly 13 million people with PD by 2040 (12). In 2009, the corresponding value was 22 000 in Sweden (13). The worldwide prevalence ranges between 51 and 177 per 100 000 people (12), and the annual incidence ranges between 10 and 50 per 100 000 person-years (14). Incidence and prevalence increase progressively after age 60 (14).

### *Cardinal motor features*

PD is characterized by four cardinal motor features: bradykinesia, tremor at rest, rigidity and postural instability.

Bradykinesia or slowness of movement is the most characteristic clinical feature of PD and present in 77-98% of cases (15). People with bradykinesia have difficulties with planning, initiating and executing movement as well as performing simultaneous and sequential tasks (9, 16). There is a loss of spontaneous movement, gesturing, facial expression and decreased blinking, as well as reduced arm swing while walking (9, 17).

Tremor at rest (frequency between 4-6 Hz) occurs in around 70% of cases at the time of diagnosis; it usually appears in the distal part of an extremity. Unlike essential tremor, it rarely involves the neck/head or voice (9, 17).

Rigidity is characterized by increased resistance to passive movement of an extremity, and is present in 89% to 99% of cases (15). It can be increased by doing voluntary movements of the contralateral extremity (17). Rigidity can be combined with the cogwheel phenomenon, which is more common in advanced stages.

Both automatic and anticipatory postural responses are reduced in people with PD, which leads to postural instability (18). In PD studies, postural instability is often assessed by using a shoulder pull test (19). The term postural control describes the ability to maintain equilibrium by keeping the centre of body mass over the base of support (20). Balance is often described as a complex motor skill that relies on the interaction between individual, environmental context and task characteristics (21, 22). Some authors use the terms *postural control* and *balance* synonymously (23), whereas others advocate that balance is a broader term (21, 22). In people with PD, postural instability as assessed by the pull test usually occurs after the onset of other clinical features, on average 5 years after the onset of PD and worsens as the disease progresses (9, 17). Postural instability and balance problems may, however, be present early in the course of the disease (18, 24, 25).

### *Non-motor features*

Non-motor features are of clinical significance for people with PD and include more than 30 different symptoms. Some common non-motor symptoms include, for example, cognitive impairment, depression, fatigue, anxiety, pain and autonomic dysfunction such as orthostatic hypotension (26, 27). Whilst overall severity of non-motor symptoms increases with PD duration (28), non-motor features may occur several years before diagnosis with PD, known as the prodromal non-motor symptoms of PD (29).

### *Disease progression and severity*

The variability in functional impairment, activity limitations and participation restrictions between people with PD is considerable and unpredictable (30). Moreover, symptoms become gradually worse over time and new ones may appear. Symptoms develop gradually in no particular order. They begin in one side of the body and then spread to the other side of the body (9, 30). PD progresses more quickly in those who are older when the symptoms first occur and progresses less quickly when the main symptom is tremor (30). The disease last approximately 40 years from the earliest non-motor features to death (31).

There is strong evidence that early prominent postural instability and gait disturbances are associated with an increased severity and rapid progression of disability in PD (30). Disease severity is commonly described according to the Hoehn and Yahr (HY) stages (32), which range from I (unilateral involvement) to V (confinement to bed or wheelchair unless aided). Postural instability is a key feature of HY stages and determines the differentiation between stages I, II and III. That is, a person is classified as HY stage III if postural instability is present, irrespective of whether there are unilateral symptoms (stage I) or bilateral symptoms (stage II) (32). Disease severity assessed with HY has been shown to be significantly associated with spatiotemporal gait parameters in people with PD (33). However, to the best of my knowledge, no study has investigated association between the disease severity and activity avoidance due to perceived risk of falling in people with PD. Such knowledge may facilitate the development of more targeted intervention and rehabilitation programs for people with PD. Not least since clinical physiotherapy guidelines often refer treatment in relation to HY stages (34).

### **Treatment and rehabilitation of people with PD**

There are several treatment options for people with PD. This includes oral medications (e.g. levodopa, dopamine agonists), surgical therapies (e.g. deep brain stimulation) and continuous delivery therapies such as intraduodenal levodopa (7). An interdisciplinary team approach is recommended for people with PD, although there is still limited evidence for its effectiveness (35). Such a team may include a neurologist, nurse, physiotherapist, occupational therapist, speech and language therapist, social worker, psychiatrist, sexologist and dietician (35).

According to the European Physiotherapy Guideline for Parkinson's disease, the major goals for physiotherapy are for example, to support self-management and improve physical capacity at stage HY I. Additionally, to maintain or improve activities (e.g., transfers, gait) at stages II-IV and to maintain vital functions (e.g. breathing) and prevent pressure sores/contractures at the most severe stage (HY V) (34). Swedish Physiotherapy Guidelines for Parkinson's disease were recently published and the recommended interventions can briefly be summarized as follows (36):

- Gait and balance exercises: moderate evidence for improved walking speed, balance and mobility.
- Strength training with defined intensity: high evidence for increased muscle strength, but there is low evidence that strength training as a single intervention improves gait and balance.
- Aerobic exercise with defined intensity (moderate and/or high intensity): moderate evidence for improved fitness.
- Treadmill training: moderate evidence for improved walking speed.
- Cueing (e.g. auditory, visual and somatosensory): moderate to high evidence for improved walking speed.
- Combined exercise (e.g. gait, balance, transfer): moderate evidence for improved walking speed, motor symptoms, mobility and balance.
- Dance: low evidence for improved balance, walking speed, walking distance, freezing episodes, quality of life and motor symptoms. Tango shows low evidence for improved functional mobility.
- Tai Chi: high evidence for improved motor symptoms (short term effect).

Some recent evidence supports the beneficial effects of highly challenging balance exercises (37, 38), dual-task training (38-40), intensive exercise therapy (e.g. resistance/endurance training, resistance with instability) (41, 42) in people with PD.

The International Classification of Functioning, Disability and Health (ICF) (43) may be used as a framework when describing a health condition, assessments and interventions.

## The ICF

The ICF can be used to describe functioning and disability in people with PD (43, 44). The ICF provides a standard language and framework to describe different interacting perspectives of health including biological, individual, and social perspectives. It consists of two interrelated parts. The first part describes functioning and disability, which in turn consists of two components: 1) Body Functions and Structures, and 2) Activities and Participation. According to ICF, body functions are “the physiological functions of the body systems (including the psychological functions)”, whereas body structures “are anatomical parts of the body such as organs, limbs and their components”. Activity is “the execution of a task or action by an individual”, whereas participation is “involvement in a life situation” (43). The second part describes contextual factors i.e. environmental and personal factors. Environmental factors can be described as either facilitators or barriers and include the physical, social and attitudinal environment. Personal factors influence how the individual experiences disability and include for example age, gender, educational level, lifestyle, and self-efficacy (43). Furthermore, the ICF offers two qualifiers for Activities and Participation: capacity and performance. Capacity describes what an individual can do in a ‘standardised’ environment. Performance describes what an individual does in his or her current (day-to-day) environment. Differences between individuals’ capacity and performance are presumed to be due to contextual environmental or personal factors (43). In this thesis, ICF is used as a framework to describe mainly the primary variables in each study.

- Study I addresses activity avoidance due to perceived risk of falling, which is part of activities and participation.
- Studies II-III address perceived walking difficulties, which is part of activities and participation.
- Study IV addresses use of mobility devices, which is part of environmental factors.

## Falls/near falls, fear of falling, and activity avoidance

People with PD have a greater risk of falling than others of the same age (45). Falls is one of the most disabling features of PD (45, 46). In studies that used a 6-month recall period, the proportion of people reporting falls ranged from 33 to 67% (45, 47-49). Most people fall while walking, but falls also occur while turning, moving to/from sitting, bending forwards or reaching (50, 51) as well as under 'dual tasking'

circumstances (52). Falls are often experienced at home or in another familiar environment (50, 51, 53), particularly in recurrent fallers (54). Recurrent fallers are those who report at least two falls during the past 6 or 12 months (45). In this thesis, a person is defined as a recurrent faller if reporting two or more incidents during the past 6 months. In a systematic review that used a 6-month prospective follow-up period, the proportion of recurrent fallers ranged from 14 to 61% (55). Negative consequences of falls are numerous, including soft-tissue injuries, fractures (50, 56), and brain injuries (57), fear of falling (FOF) (58), activity limitations (45) and increased caregiver burden (59).

People with PD commonly experience what is termed near falls. According to Gray & Hildebrand, a near fall is defined as “a fall initiated but arrested by support from a wall, railing, other person etc.” (4). Using this definition, the proportions of people reporting a history of near falls during the past 6 months ranged from 35 to 55% (48, 49), and 26% experienced a near fall, but no fall (60). Near falls mostly occur at home, commonly while turning or while negotiating steps or doorways (53). Previous studies identified a history of near falls as a risk factor for future falls (61, 62).

FOF is also more common in people with PD than in age-matched controls (45, 63, 64). When using a dichotomous (Yes/No) question (Are you afraid of falling?), the proportions of people reporting FOF ranged from 35 to 59% (48, 58, 64). FOF is more common and pronounced in those who have experienced falls (58), but it may also occur among those without prior falls (58). People with PD have described that they experienced more FOF when they were aware of the increased risk of falling and they were afraid of the consequences of falls. Their FOF got worse when they were feeling low, tired or stressed, while they had less or no FOF at times when they were in good spirits (65). FOF has been shown to predict falls and/or near falls (61) as well as recurrent falls (55). FOF affects gait and balance (66), activities of daily living (ADL), the level of physical activity (67, 68), participation (69) and health-related quality of life (QOL) (70) negatively.

While there has been an increased research attention paid to falls and FOF, there is less knowledge about activity avoidance due to perceived risk of falling in people with PD (49, 71, 72). Two previous PD studies identified that activity avoidance due to perceived risk of falling was associated with a history of previous falls and FOF (71, 72). These studies used a self-administered questionnaire: the Modified Survey of Activities and Fear of Falling in the Elderly (the mSAFFE), which assesses activity avoidance due to perceived risk of falling (72). This instrument is

described in more detail in the methods section. When using the mSAFFE, previous studies reported that “going out when it is slippery” and “going to a place with crowds” were the two most commonly-avoided activities in people with PD (49, 71, 72). However, no prior study reported in detail the activities that were avoided among those with a history of falls and those with FOF. There is as yet limited knowledge on the relationship between activity avoidance due to the perceived risk of falling and a history of falls/near falls, FOF as well as disease severity in people with PD. By gaining a greater understanding of the activities that are commonly avoided due to the perceived risk of falling, this may facilitate the early detection of those who are at risk of engaging in sedentary behaviour and limited participation. Moreover, it may enable more tailored PD care and rehabilitation plans for people with PD.

## Walking difficulties in people with PD

*Walking becomes a task, which cannot be performed without considerable attention. The legs are not raised to that height, or with that promptitude which the will directs, so that the utmost care is necessary to prevent frequent falls. —James Parkinson, 1817*

The words gait and walking are often used interchangeably. However, there is a difference. The word walking describes the process of moving, which has been defined as “a repetitious sequence of limb motions that moves the body forward while simultaneously maintaining stance stability” (73). The word gait describes a particular manner or style of walking (74), that is, it describes the ability to perform the different functions needed for walking (e.g. weight-bearing across the joint, angulation and propulsion). According to the ICF, “Walking” is a component of “activities and participation”, it is defined as “moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards, or sideways” (43). Using the ICF, Raggi et al. (75) described profiles of functioning people with PD. The most commonly self-reported problems in activities and participation was in the ICF category of walking (94%), followed by lifting and carrying objects (92%), and dressing (91%).

Walking difficulties are among the earliest signs of motor disability in people with PD (76). About 75% of people with a PD duration of more than five years have gait disturbances (77). These problems may occur early on during the course of the

disease (24, 76). As the disease progresses, walking becomes slower with shuffling, shorter steps, larger step length variability and a bilaterally reduced arm swing. Step length and gait speed further decreases when a cognitive task (dual tasking) is added to walking (78). Walking can be combined with turning and walking around an obstacle (79). People with PD have difficulty in turning and changing direction while walking, which can be observed even at the early stage of PD, when marked functional deficits are not typically present (80).

Two types of gait disturbances occur in PD - continuous and episodic gait disturbances (81). The continuous gait disturbances often include asymmetrically reduced or absent arm swing, reduced and variable step length, as well as a stooped posture (81, 82). Freezing of gait (FOG) is the best described episodic gait disturbance, defined as a “brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk” (2). FOG is often described by the person with PD as if their feet are “glued to the floor” (2, 83). Based on clinical findings, three different manifestations of FOG have been suggested: trembling in place (alternating tremor of the legs), shuffling forward with small steps (the least severe form), and total akinesia (the severest form) (84). FOG typically occurs in the home environment and is provoked by certain activities such as when initiating gait (start hesitation), while turning or just before reaching a target (destination hesitation), and by environmental factors such as being in a confined space (2, 83, 85). Stress can also elicits FOG (85). About half of those in the advanced stages of PD experience FOG (86). A systematic review reported that gait problems constitute the most significant motor symptom predicting overall QOL in people with PD (87). Although several qualitative studies have had their primary focus on walking difficulties in people with PD (88-91), there is a need to be able to assess perceived walking difficulties in large-scale studies. The latter could preferably be achieved by using a patient-reported outcome measure (PROM). This thesis has a specific focus on perceived walking difficulties in daily life assessed by using a PROM: generic Walk-12 (Walk-12G) (92). Perceived walking difficulty refers to any report of walking difficulty that comes directly from a person, without the interpretation of the person’s response by a clinician or anyone else. In order to be able to quantitatively describe perceived walking difficulties, a psychometrically sound instrument is needed.

## **The Walk-12G**

The Walk-12G originates from the 12-item Multiple Sclerosis Walking Scale (MSWS-12) (93), which was later modified into the Walk-12 to suit people with



other neurological disorders (94). The scale was then further modified, mainly by revising its response categories and adapted to be completely generic, i.e. the Walk-12G. The Walk-12G was highlighted in a systematic review (2012) as a promising outcome for use in future physiotherapy trials (95). A prior study investigated the psychometric properties of the Walk-12G in people with PD and Multiple Sclerosis (92). The Walk-12G had acceptable psychometric properties with, for example, 87.5% computable total scores, item-total correlations between 0.62-0.90, < 7% floor/ceiling effects, coefficient alpha > 0.94 and standard errors of measurements (SEM) of 2.3-2.8 (92). When assessing construct validity, the Walk-12G scores showed stronger correlation with most variables related to physical health and mobility (e.g. daily living activities, freezing of gait), and weaker correlation with psychological and demographic variables (e.g. mental health, age). Moreover, the Walk-12G scores differed between those who used and those who did not use walking devices indoors (92). In a recent publication providing recommendations concerning instruments in PD, the authors stated that the Walk-12G needs further evaluation before it can be recommended for use (96). The previous study did not, for example, consider global cognitive functioning or a history of falls when assessing construct validity (92). Cognitive impairment is a common, non-motor symptom of PD (9) and people with PD experience also an increased risk of falling; most of their falls occur while walking (50). Moreover, the former psychometric study (92) lacked common clinical descriptive data (e.g. global cognitive function) for the PD sample. Importantly, it did not account for the fact that the response categories of the Walk-12G are ordinal in nature. For ordinal data, polychoric correlations are recommended (instead of Pearson-based correlations) to compute item-total correlations (scaling assumptions) and coefficient alpha (internal consistency) (97-99). Thus, further studies are necessary to reassess the psychometric properties of the Walk-12G in a new PD sample that take the ordinal nature of data into account.

## **Factors contributing to walking difficulties**

Various factors are associated with walking difficulties in people with PD. In studies that used objective gait measures, FOG contributed to impaired step length and increased variability of step duration in persons with PD as compared to those without FOG (100, 101). Moreover, reduced gait speed has been associated with higher age (102-104), sex (women) (103), depressive symptoms (103, 105), physical fatigue, cognitive impairments, (105-107), disease severity (58, 102, 103), muscle weakness (108), bradykinesia (109), postural instability (110) and FOF (103) in people with PD. Shorter strides and an increased stride variability have been associated with postural instability (110). However, using objective measures of

walking difficulties may not reflect perceived walking difficulties in daily life. Especially so if the data collection is conducted during a short time of period and/or in a standardized setting that mimics capacity more than actual performance in authentic daily-life settings. Several qualitative PD studies have described factors that are perceived as negatively associated with walking difficulties, such as FOG (90, 91, 111-113), fatigue (90, 91), anxiety (90), FOF (91), pain, orthostatic hypotension (114), ineffective medication dose (90) and environmental hazards (e.g. crowds, inclement weather, and uneven/slippery surfaces) (90, 91, 114). On the other hand, use of mobility devices (89, 114), information (e.g. advice/knowledge provided by other people) as well as social and emotional support have been described as facilitating walking ability (115, 116). It would be of interest to investigate whether some of these qualitative findings could be verified in a larger quantitative study. When following large cohorts over time, qualitative analyses are not feasible however survey data including a PROM, such as the Walk-12G, would make it possible to identify factors that explain perceived walking difficulties in daily life. To the best of my knowledge, no study has yet investigated factors that independently contribute to perceived walking difficulties in people with PD. Comprehensive studies are necessary that investigate contributing factors for walking difficulties, taking PD-related, personal and socio-environmental factors into consideration.

## Use of mobility devices in people with PD

As PD progresses, gait and balance problems become more prevalent and can make activities of daily living challenging (9). Mobility devices (MDs) can compensate for gait and balance difficulties and thereby facilitate activity performance (117, 118). According to the ICF, MDs are part of environmental factors (43) and can act as facilitators or barriers for activity performance (119). More specifically, MDs are covered by “personal indoor and outdoor mobility and transportation (e120)” as a subcategory of “Products and Technologies” in the ICF (43).

Various types of MDs with different levels of support may be required depending on the individual’s functioning, level of independence in ADL, his/her activity repertoire and environmental settings (117). Commonly used MDs by people with PD include canes (i.e. walking sticks), wheeled walkers (i.e. rollators) as well as manual and powered wheelchairs (117, 120). Canes are usually suitable for those with milder disability, wheeled walkers for those with moderate disability and powered devices for those with severe disability (117). In experimental PD studies, wheeled walkers have been associated with improved safety and gait speed, and

fewer freezing episodes (120, 121). Cane use has been reported to improve postural recovery from an unpractised slip, characterized by smaller lateral displacement of the body centre of mass in people with PD, compared to matched controls (122). Some MDs are available with a variety of customized features specific to PD, for example a laser-cane that might be helpful for those with start hesitation and freezing (117). While not classified as MDs in the health care context, Nordic walking sticks are becoming increasingly popular in people with PD and exert potential beneficial effects on motor (e.g. FOG) and non-motor symptoms (e.g. pain) (123). In several qualitative studies, participants with PD expressed using a wheelchair as an external facilitator for managing a long distances (90) and using a walker (with brakes, seat and a basket) as a facilitator for participation in activities (114). MDs offer a sense of security and safety (114), and provide a means of retaining independence and mobility (89). Some people expressed the importance of having access to PD-specific expertise when needing MDs (113).

Although MDs are used to compensate for gait and balance problems, several studies have indicated that some MDs may worsen gait characteristics in people with PD. For example, the use of a cane (or a two-wheeled walker) was associated with decreased gait speed (120, 121), whereas gait speed was less impaired with a four-wheeled walker (120). Stride length was reduced when using a cane or non-wheeled walker as compared to walking without any devices (124). Moreover, based on clinical experience, some studies reported that using a cane as well as using a non-wheeled walker induced more FOG episodes than a four-wheeled walker (120, 121). People with PD have expressed that MDs induced feelings of shame, violated social norms and caused stigmatisation. They experienced feelings of anxiety, and fear of being dependent on MDs, particularly using wheelchairs represented a definitive marker of stigma and loss of independence (89). Some experienced it as a major life event when they were able to abandon MDs after being treated with Deep Brain Stimulation (125), which indicates that people do not want to be long-term dependent on MDs but carry a hope of being able to walk independently.

Overall in PD research, studies targeting MD use are scarce. One of the few studies targeting such issues described that people with self-reported PD had a higher use of MDs (55%) than matched controls (30%) (126). However, the study did not find any statistically-significant difference regarding the perceived need of MDs (126). The actual use as well as the perceived need of MDs most likely reflect provision and funding systems (127). In Sweden, the provision of MDs is regulated in the Health Care Act. All municipalities as well as county councils must see to that people in need of such equipment gain access to it, while applying local regulations

for the actual provision. MDs are free of charge for the individual through the national provision system (127), but fees for consultations with health care professionals are becoming common. Overall, the MD provision system in Sweden is considered to work well, but it might nevertheless be challenging for the individual to gain an overview and retrieve the information they need. There is also a growing private market, where people can buy their MDs without any involvement from the public authorities (128).

People with PD have a higher use of MDs (indoors and outdoors) than those with essential tremor or dystonia (129). A higher use of MDs outdoors than indoors has been reported in previous studies in people with PD (69, 130). Most research on needs for MDs involved older adults in general (131-133), while much less is known about people with PD (126). To the best of my knowledge, no study has investigated the use and perceived need of MDs over a period of time in people with PD. Moreover, using multiple MDs has been reported in elderly populations (134, 135). No prior study has reported the pattern of using multiple MDs in a PD population. There is a need of studies based on follow-up design, which will allow us to understand the pattern of use and perceived needs for MDs over a time period in people with PD.

In order to provide optimal treatment, care and rehabilitation for people with PD a better understanding of activity avoidance due to perceived risk of falling, assessment and contributing factors to perceived walking difficulties is essential. Moreover, with no current knowledge on the use and perceived needs for MDs over a time period in people with PD, this thesis aims to address the relevant gaps in the literature on these issues.

# Aim

The overarching aim of this thesis was to gain an increased knowledge regarding activity avoidance due to perceived risk of falling, perceived walking difficulties, and the use and perceived needs of MDs in people with PD in Sweden.

## Specific aims

- Study I: To examine the relationship between activity avoidance due to perceived risk of falling and a history falls/near falls, FOF as well as disease severity in people with PD; a specific focus addresses the activities that are avoided.
- Study II: To reassess and extend the psychometric evaluation of the Walk-12G in a PD sample by using classical test theory approaches that take the ordinal nature of data into account. More specifically, to investigate data completeness, scaling assumptions, targeting, internal consistency reliability and external construct validity.
- Study III: To identify factors that independently contribute to perceived walking difficulties in people with PD.
- Study IV: To investigate the use and perceived needs of MDs in people with PD over a 3-year period.

# Materials and methods

This PhD thesis is a part of a larger longitudinal project *Home and Health in People Ageing with PD* (PI: M. H. Nilsson). Details of data collection and procedures have been published in a study protocol (136). All baseline assessments were carried out November 2012 - November 2013 (n = 255). The participants were invited to participate in an equivalent 3-year follow-up survey which was implemented January 2016 - December 2016 (n = 165).

## Design

- Studies I–II: cross-sectional design using baseline data.
- Study III: psychometric study based on baseline data.
- Study IV: cross-sectional and follow-up design using data from the baseline, as well as making comparisons between the baseline, and the 3-year follow-up.

Study design, aim, main variables and statistical analyses included in Studies I-IV are presented as an overview in Table 1.

**Table 1.** Study design, aim, main variables and statistical analyses included in studies I-IV

Studies	Design	Aim	Main variables	Main statistical analyses
Study I N=251	Cross-sectional study	To examine the relationship between activity avoidance due to the perceived risk of falling and a history of falls/near falls, FOF as well as disease severity in people with Parkinson's disease (PD).	Activity avoidance due to perceived risk of falling (the mSAFFE and a dichotomous question), history of falls past 6 months, history of near falls past 6 months, fear of falling (dichotomous question), disease severity (Hoehn & Yahr stages).	Descriptive statistics, the Mann-Whitney U-test, the Kruskal Wallis test, Chi-Square tests, and Bonferroni Correction
Study II N=249	Cross-sectional, psychometric study	To reassess and extend the psychometric properties (that is, data completeness, scaling assumptions, targeting, internal consistency reliability, and external validity) of the Walk-12G in people with PD, by using classical test theory, taking the ordinal nature of data into account.	Generic Walk-12G (Walk-12G) that assesses perceived walking difficulties in daily life.	Descriptive statistics, corrected polyserial/corrected Pearson item-total correlations, exploratory factor analyses, ordinal/Cronbach's alpha, ordinal/Cronbach's alpha when item deleted, standard error of measurement
Study III N=243	Cross-sectional Study	To identify factors that independently contribute to perceived walking difficulties in people with PD.	<i>Dependent variable</i> Perceived walking difficulties (the Walk-12G). <i>Independent variables</i> Sex, age (years), living situation, general self-efficacy (GSE), PD duration (years), postural instability (UPDRS part III, item 30, scores $\geq 1$ =yes), bradykinesia (UPDRS part III, item 31, scores $\geq 1$ =yes), freezing of gait (FOGQsa, item 3, scores $\geq 1$ =yes), lower extremity function (Chair-Stand Test, sec), depressive symptoms (GDS-15), anxiety (NMSQuest, item 17, dichotomous, yes), orthostatic hypotension (NMSQuest, item 20, dichotomous, yes), fatigue (NHP-EN), cognitive function (MoCA), pain (dichotomous, yes). Use and perceived needs of MDs indoor and outdoor: canes (i.e. walking sticks), crutches, other walking devices without wheels (quadropods, walking frames, etc.), wheeled walkers (i.e. rollators), manual and powered wheelchairs. Additionally, Nordic walking sticks and tricycles for outdoor use only.	Descriptive statistics, simple and multivariable linear regression analyses
Study IV N=255, at baseline N=165, 3-year follow-up study	Cross-sectional, and a 3-year follow-up study	To investigate the use and perceived needs of mobility devices (MDs) in people with PD over a 3-year period.	Use and perceived needs of MDs indoor and outdoor: canes (i.e. walking sticks), crutches, other walking devices without wheels (quadropods, walking frames, etc.), wheeled walkers (i.e. rollators), manual and powered wheelchairs. Additionally, Nordic walking sticks and tricycles for outdoor use only.	Descriptive statistics, McNemar tests

mSAFFE, Modified Survey of Activities and Fear of Falling in the Elderly (17-51, higher=more avoidance); Walk-12G, Generic Walk-12 (0-42, higher=worse); GSE, General Self-Efficacy Scale (10-40, higher=better); UPDRS, Unified Parkinson's Disease Rating Scale (part III=motor examination, 0-4, higher=worse); FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3,0-4, higher=worse); GDS-15, the 15-item Geriatric Depression (0-15, higher=worse); NMSQuest, Nonmotor Symptoms Questionnaire; NHP-EN, Energy subscale of the Nottingham Health Profile, affirming at least one of its three dichotomous (yes/no) questions (tired all the time, everything is an effort, soon out of energy) was classified as having fatigue; MoCA, Montreal Cognitive Assessment (0-30, higher=better).

## Participants and recruitment

### *Baseline*

Participants were recruited from three hospitals in Skåne County, Sweden. The screening procedure was carried out by a specialist PD nurse at each clinic as well as by screening medical records. All those registered with a PD diagnosis (ICD-10: G20.9) for at least one year were considered eligible for inclusion. For the first phase, participants were recruited from the departments responsible for PD care at local hospitals in Kristianstad and Hässleholm. In the second phase, participants were recruited from Skåne University Hospital (Lund), and those that had visited the Department of Neurology as outpatients during 2012 were considered as eligible for inclusion. This recruitment procedure was carried out in order to reach the sample size ( $n = 250$ ) according to the power calculations (136).

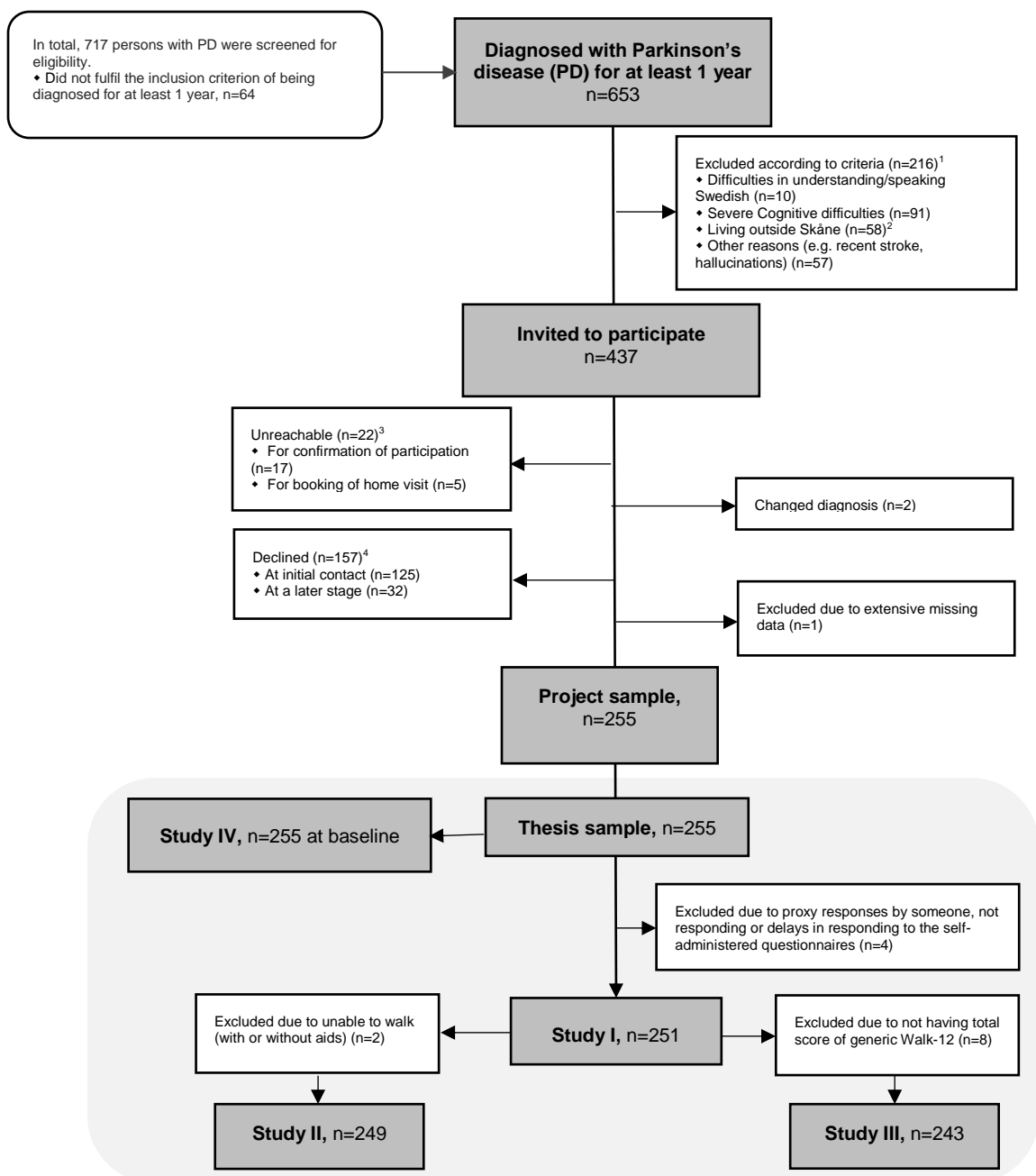
At baseline, a sample of 653 participants met the inclusion criterion. Of these, 216 individuals were excluded according to the criteria described in Figure 1. Potential participants were excluded if not deemed able to give informed consent or partake in the majority of the data collection. This resulted in 437 participants invited to participate however we were unable to reach 22, two had changed diagnosis and 157 declined to participate. An additional participant was excluded due to extensive missing data. Details of the recruitment process at baseline are presented in Figure 1. The final project sample consisted of 255 participants, but the final sample size differs in Studies I-IV as explained in Figure 1. Descriptive information of the participants is provided in Table 2.

When comparing those who declined ( $n = 157$ ) to the final project sample ( $n = 255$ ), there was a statistically significant difference in age ( $P = 0.021$ , independent T-Test), but not in relation to sex ( $P = 0.180$ , Chi-squared test) or PD duration ( $P = 0.398$ , Independent T-Test). That is, those who declined were older than those who participated.

### *3-year follow-up*

All those who completed baseline assessments and had agreed to be contacted again ( $n = 255$ ) were considered eligible for the 3-year follow up. At that time, 22 participants were deceased, three had moved and one was outside the follow-up window (i.e. 3 years  $\pm$  3 months). Thus, 229 people were invited to participate. The recruitment process is presented in Figure 2. At the 3-year follow-up, the final sample consisted of 165 people (Table 2). The sample size was appropriate according to a power analysis described in the study protocol (136)





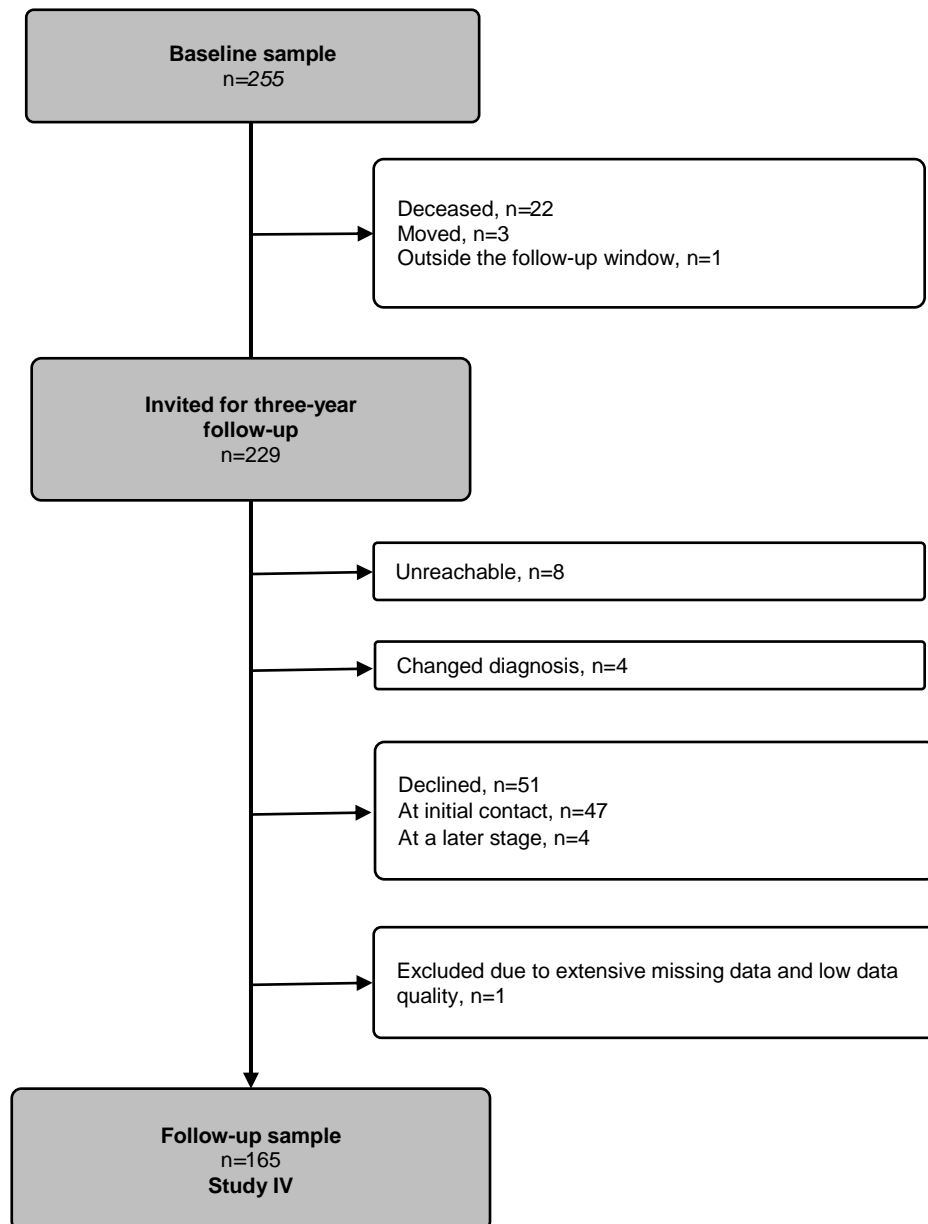
**Figure 1.** Flow diagram: the recruitment process of participants at the baseline, and for studies I-IV

<sup>1</sup>They (66% women) had a mean (SD) age (n=215), and PD duration (n=199) of 71 (10.7) and 12 (7.7) years, respectively.

<sup>2</sup>Used as an exclusion criteria only for the part of the sample recruited from Skåne University Hospital.

<sup>3</sup>They (41% women) had a mean (SD) age of 70 (9.2) years.

<sup>4</sup>They (48% women) had a mean (SD) age, and PD duration (n=129) of 72 (9.8) and 9.2 (6.4) years, respectively.



**Figure 2.** Flow diagram: the recruitment process of participants at the 3-year follow-up

### *Invitation to participate*

The project administrators sent out written information about the study (including the invitation to participate) by post to potential participants. This information emphasized the volunteer nature of participation in the study, the option to terminate the study without giving a reason and that a negative answer (or a future interruption) would not affect continued medical care contacts or assisted living issues. A few weeks after the mail shot, they were contacted by telephone. Because people with PD can potentially fluctuate in the disease condition such as in motor or cognitive functioning, they were asked whether it was appropriate to provide them with verbal information, or if they wished to be called later. The participants were invited to participate in the study only after they had received oral information, and they were offered the option to ask any additional questions about the study. If the participant declined to take part, then no further contact was made.

## Ethical considerations

My thesis work is based on a project involving humans, which requires certain ethical principles. All the studies included in this thesis were carried out in accordance with the ethical requirements of the Swedish Research Council (137). These include, for example, consciously reviewing and reporting the basic premises of the studies, openly accounting for methods and results, not making unauthorized use of the research results and conducting the work without causing harm to people, animals or the environment (137).

After a participant gave verbal consent to participate during telephone contact, the project administrator booked an appointment for a home visit. Written consent was obtained in connection with home visits. Financial compensation was paid for lost income. The intention was to follow-up the participants in the future, they were therefore asked at the end of the home visit if they wished to be contacted again for follow-up (all agreed to be contacted again).

A passkey containing participants' personal data and address information are stored separately and locked in a fire-resistant cabinet at the Health Science Centre, Lund University, accessible only to authorized individuals. All data is collected and held confidentially in accordance with the Personal Data Act (1998: 204). Each participant was assigned an identifying number or code in a database with access

protection. The database is stored on a server with continuous daily security backup. Materials will be archived for 10 years. Published data is presented so that the results cannot be linked to any individual and the results are presented at group level. No tape or video recordings exist.

Both the baseline (No. 2012/558), and the 3-year follow-up (No. 2015/611) surveys were approved by the Regional Ethical Review Board in Lund, Sweden.

## Data collection

Data collection was conducted by two project administrators (experienced registered occupational therapists) who underwent project-specific training. The same project administrators were not used for the 3-year follow-up, but they had undergone a similar training.

The participants who accepted to participate received self-administered questionnaires and questions by post 10 days before a subsequent home visit. At the home visit, the project administrator scrutinized the self-administered questionnaire e.g. checking for missing data. The home visit included interview-administered questions and questionnaires, clinical assessments and observation of the home environment. I participated in the data collection at the home visit during the 3-year follow-up. I then conducted the following clinical assessments: Unified Parkinson's Disease Rating Scale (UPDRS, part III = motor examination), HY, and Chair-Stand Test. I also accompanied the administrator while conducting other parts of data collection, that is, Montreal Cognitive Assessment (MoCA) and all interview-administered questions and questionnaires, as well as observation of the home environment.

Two home visits per day were completed and each home visit usually lasted for two hours. If any participants experienced data collection as too strenuous, they were offered the opportunity to continue on another day within a maximum of 14 days. If exceeding this time limit, the participant was offered a renewed assessment. At baseline, eight participants chose to split data collection over two home visits instead of one. The corresponding value was two participants at the 3-year follow-up. The home visits were scheduled during the time of day when the participants in question stated that they usually felt their best ("on" state).

**Table 2.** Participant characteristics for studies I - IV

Variables	Study I N=251	Study II N=249	Study III N=243	Study IV		
				Cross-sectional sample N=255		Follow-up sample n=165
				Baseline	Baseline <sup>a</sup>	3-year follow-up
Sex (men), n (%)	152 (60.6)	150 (60.2)	150 (61.7)	153 (60.0)	107 (64.8)	107 (64.8)
Age (year), mean (SD)	70 (9.2)	69 (9.1)	70 (9.2)	70.0 (9.2)	68.6 (8.8)	71.6 (8.8)
Living alone (dichotomous, yes), n (%)	66 (26.0)	65 (26.1)	62 (25.5)	68 (26.7)	36 (21.8)	40 (24.2)
Education, n (%)						
elementary	86 (34.3)	86 (34.5)	83 (34.2)	86 (33.7)	48 (29.1)	56 (33.9)
higher secondary	81 (32.3)	80 (32.1)	78 (32.1)	83 (32.5)	56 (33.9)	48 (29.1)
university	84 (33.5)	83 (33.3)	82 (33.7)	86 (33.7)	61 (37.0)	61 (37.90)
General self-efficacy, GSE, median (q1-q3)	29 (24.0-34.0)	29 (24.0-34.0)	29 (24.0-34.0)	29 (24.0-34.0)	30 (25.0-35.0)	30 (24.0-34.0)
Satisfaction with financial situation, median (q1-q3) <sup>b</sup>	7.0 (5.0-9.0)	7.0 (5.0-9.0)	7.0 (5.0-9.0)	7.0 (5.0-9.0)	7.0 (5.0-9.0)	7.0 (5.0-9.0)
Need help from others in daily activities (PADLS, scores $\geq 3$ =yes), n (%)	66 (26.4)	64 (25.8)	62 (25.5)	68 (26.9)	39 (23.6)	59 (36.0)
PD duration (years), median (q1-q3)	8 (5.0-13.0)	8 (5.0-13.0)	8 (5.0-13.0)	8.0 (5.0-13.0)	8.0 (5.0-12.0)	11 (8.0-15.0)
PD severity (HY), median (q1-q3)	3 (2.0-3.0)	3 (2.0-3.0)	3.0 (2.0-3)	3.0 (2.0-4.0)	2.0 (2.0-3.0)	3.0 (2.0-4.0)
Fear of falling (dichotomous, yes), n (%)	121 (48.4)	120 (48.2)	115 (47.3)	123 (48.8)	70 (42.7)	93 (57.1)
Falls past 6 months (yes), n (%)	110 (43.8)	110 (44.2)	107 (44.0)	113 (44.3)	70 (42.4)	82 (49.7)
Motor symptoms (UPDRS, part III), median (q1-q3)	30 (22.0-39.0)	30 (22.0-39.0)	30.0 (22.0-39.0)	30.0 (22.0-39.2)	29.0 (21.0-37.0)	27.0 (21.0-40.0)
Freezing of gait (FOGQsa item 3, scores $\geq 1$ =yes), n (%)	139 (56.0)	139 (56.0)	138 (56.8)	142 (56.6)	89 (54.3)	95 (58.6)
Cognitive function (MoCA), median (q1-q3)	26 (22.0-28.0)	26 (22.0-28.0)	26 (22.0-28.0)	26.0 (22.0-28.0)	26.0 (23.0-28.0)	26.0 (23.0-28.0)
Depressive symptoms (GDS-15), median (q1-q3)	2 (1.0-4.0)	2 (1.0-4.0)	2.0 (1.0-4.0)	2.0 (1.0-4.0)	2.0 (1.0-4.0)	3.0 (1.0-5.0)
Orthostatic hypotension (NMQuest item 20, yes), n (%)	133 (53.0)	133 (53.4)	131 (53.9)	135 (53.1)	83 (50.3)	76 (46.6)
Fatigue (NHP-EN, dichotomized, yes), n (%)	141 (56.4)	139 (56.0)	137 (56.4)	144 (56.9)	86 (52.1)	96 (58.9)

SD, standard deviation; q1-q3, first-third quartile; GSE, General self-efficacy scale; 10-40, higher=better; PADLS, Parkinson's disease Activities of Daily Living Scale (1-5, higher=worse); HY, Hoehn & Yahr (stage I-V, higher=worse); UPDRS, Unified Parkinson's Disease Rating Scale (part III=motor examination, 0-108, higher=worse); Walk-12G, Generic Walk-12 (0-42, higher=worse); FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3, 0-4, higher=worse); MoCA, Montreal Cognitive Assessment (0-30, higher=better); GDS-15, the 15-item Geriatric Depression Scale (0-15, higher=wors); NMQuest, Nonmotor Symptoms Questionnaire; NHP-EN: Energy subscale of the Nottingham Health Profile.

<sup>a</sup>Data for those who were included in the 3-year follow-up. <sup>b</sup>Scored from 0 (very unsatisfied) to 10 (very satisfied). Internal missing data: n=0-6 for the studies I-III; n=0-10 for the total sample at baseline, and n=0-14 for the 3-year follow-up sample.

## Main variables in studies I-IV

### *Activity avoidance due to the perceived risk of falling (Study I)*

Activity avoidance due to the perceived risk of falling was assessed according to the mSAFFE (138). It originates from the Survey of Activities and Fear of Falling in the Elderly (SAFE), which was developed and validated as an interview-administered instrument to assess the role of fear of falling in activity restriction (139). The SAFE was later modified into a shorter self-administered version (i.e. the mSAFFE) to address activity avoidance due to perceived risk of falling (138). In the mSAFFE, 17 activities (i.e. items) are included after omitting 5 activities from the original SAFE (139) to improve its discriminant validity in a better-functioning sample of community-dwelling older adults (138). Each of the 17 items in the mSAFFE has three response categories (scored 1–3): never, sometimes or always avoids. The total mSAFFE score ranges from 17 to 51 (higher = more activity avoidance). In an ICF Linking study, the overall question and response categories of the mSAFFE were linked to the component of activities and participation in the ICF (140). The activities in the mSAFFE have been linked to the following ICF categories: 11 activities to Mobility (d4), 4 activities to Self-care (d5), 3 activities to Domestic life (d6) and 4 activities to Community, social and civic life (d9) (140). According to the ICF linking rules (141), some activities have been used several times for linking multiple meaningful concepts in the ICF. The psychometric properties of the mSAFFE have been shown to be satisfactory in people with PD (49, 72).

In addition, a dichotomous question (Yes/No) addressed activity avoidance due to perceived risk of falling i.e. “Do you avoid activities due to a risk of falling?”

### *Falls, near falls and FOF (Study I)*

Falls: assessed with an interview-administered dichotomous (Yes/No) question that targeted the history of falls during the past 6 months. If the participant answered yes, a subsequent question concerned whether falls had occurred more than once (Yes/No), including providing an estimate of how many times. In this thesis, the European consensus definition of a fall was applied: “an event in which the respondent came to rest on the ground, floor or lower level” (1). A recurrent faller was defined as reporting two or more incidents (45).

Near falls: assessed with a self-administered dichotomous question (Yes/No) that targeted a history of near falls during the past 6 months, using the following definition: “a fall initiated but arrested by support from a wall, railing, or other person, etc.” (4): “Have you during the last six months been close to falling, but have at the last minute managed to grab on to something/someone so that your body did not hit the ground?”

FOF: assessed with a self-administered dichotomous question (Yes/No): “Are you afraid of falling?”

### *PD-severity (Study I)*

Disease severity was assessed according to HY scale (32). The HY scale is one of the most widely-used clinical rating scales to briefly describe disease severity. It is simple and easy to apply and consists of the following five stages:

Stage I: Unilateral disease, regardless of severity.

Stage II: Bilateral disease, no postural instability.

Stage III: Bilateral disease with postural instability, or unilateral disease with postural instability. Functionally somewhat restricted, but physically capable of leading independent lives (i.e. not dependent on help from others or MDs to manage activities of daily living).

Stage IV: Bilateral disease with postural instability. Can rise unassisted (but may need several attempts). Can stand and walk unassisted (even without support from another person), but impaired gait. Falls can be a problem when significant postural reflex impairment occurs. Severe disability markedly incapacitated.

Stage V: Confinement to chair or bed unless aided. Cannot arise and/or stand/walk without assistance. May be able to walk with e.g. visual cues.

In this thesis, the “rate-as-you-see” approach was applied when classifying the HY stages of PD (142). That is, the HY stages were based on all the clinical impairments/disabilities observed regardless of their direct relationship to PD (142). If a person used and needed any MDs indoor, the person was classified as at least HY IV.

### *The Walk-12G (Studies II-III)*

The self-administered Walk-12G includes 12 items that concern perceived walking difficulties over the past two weeks (92). Items 1-3 have three response categories: not at all, sometimes and a lot (scored 0-2, respectively). Items 4-12 have five response categories: not at all, a little, moderately, quite a bit and extremely (scored 0-4, respectively). The total score ranges from 0 to 42 (higher = more walking difficulties). The psychometric properties of the Walk-12G scores were found to be satisfactory in people with PD (92). However, this study did not account for the fact that the response categories of the Walk-12G are ordinal in nature; further psychometric studies are thus needed.

The Walk-12G was used as the dependent variable in Study III; independent variables are presented in Table 1 and are described in more detail under the *Descriptive variables* section.

### *Use and perceived needs of MDs (Study IV)*

The use and perceived needs of MDs were assessed by using structured questions. For each MD, participants were asked to state whether they had the device or not, whether they used it or if they perceived a need of that particular device. The MDs listed (for indoor as well as outdoor use) were: canes (i.e. walking sticks), crutches, other walking devices without wheels (quadropods, walking frames, etc.), wheeled walkers (i.e. rollators), manual and powered wheelchairs, respectively. Two additional devices (Nordic walking sticks, tricycles) were listed for outdoor use only.

### *Descriptive variables (Studies I-IV) and independent variables in Study III*

In this section, variables that were used for descriptive purposes and/or used as independent variables in Study III are specified (see also Table 1).

Data on age (years) and sex were retrieved by the project administrators using participants' social security numbers. Data on PD duration (in years) was collected with a question during the home visit.

General self-efficacy: assessed with General self-efficacy scale (GSE) (143). This consists of 10 items and each item has four response categories (scored 1–4): not at all true, hardly true, moderately true and exactly true. The total GSE score ranges from 10 to 40 (higher = better/stronger general self-efficacy). The GSE has



been shown to be reliable and valid in two PD samples, including the sample used in this thesis (144).

Social support and living situation: social support was assessed with an interview-administered question: “Is there someone around who could assist you if you need some help and support?” The three response categories were recoded as social support from partner, other than partner or none. Living situation was assessed with a dichotomous question: (living alone/not alone).

Education and satisfaction with income: educational level included elementary, higher secondary or university, and satisfaction with financial situation, scored from 0 (very unsatisfied) to 10 (very satisfied), the questions were interview-administered at the home visit.

Need help from others in daily activities: assessed with the self-administered Parkinson’s disease Activities of Daily Living Scale (PADLS) (145), which addresses perceived difficulties and dependence in ADL during the past month. It is a single-item self-reported rating scale with five response categories ranging from 1 (no difficulties with day-to-day activities) to 5 (extreme difficulties with day-to-day activities), but each response category also has a more detailed description. For example, “1) No difficulties with day-to-day activities. For example: Your Parkinson’s disease at present is not affecting your daily living” (145). In the thesis, the PADLS scores were dichotomized into “not needing help from others in daily activities” versus “needing help” (PADLS 1-2 versus 3–5) (146). The PADLS has been found to be a reliable and valid measure of ADL in people with PD (145). Moreover, in a recent psychometric study with the PD sample included in this thesis, it had been found to be well suited to providing a rough indicator of ADL disability (147).

Motor symptoms of PD: clinically assessed according to the motor examination (i.e. part III) of the UPDRS. The total score of UPDRS III ranges from 0 to 108 (higher = worse) (148). It has been reported to be both reliable and valid (149).

Postural instability was assessed by using item 30 (i.e. “postural instability”) of UPDRS part III (148). The examiner is standing behind the participant who is standing erect with eyes open and feet slightly apart. Once in position, the participant is instructed to resist a backwards pull on shoulders and, if necessary, step backward to maintain balance. That is, the patient is prepared. A strong backwards pull is given to both shoulders. The item is scored from 1 to 4 (higher = worse); those with scores  $\geq 1$  were categorized as having postural instability.

Bradykinesia: assessed with the item 31 (i.e. bradykinesia) of UPDRS part III (148). The item is scored from 1 to 4 (higher = worse); those with scores  $\geq 1$  were

categorized as having bradykinesia. The bradykinesia score is based on combining slowness, hesitancy, decreased arm swing, small amplitude and poverty of movement in general.

FOG: Assessed with the self-administered version (150) of the FOG Questionnaire (151), i.e., FOGQsa, scored 0-24, higher = worse. The FOGQsa, consists of six items (each item scored 0-4, higher = worse). Those scoring  $\geq 1$  in the item 3 of the FOGQsa were also categorized as “freezers” (48).

Lower extremity function: assessed with the Chair-Stand Test (152). The test was done with arms folded across their chest using a standard chair with arms and with a seat height of approximately 46 cm. One trial was conducted. The time (seconds) for completing five repetitions as fast as possible was registered.

Cognitive functioning: Global cognitive functioning was clinically assessed with the MoCA (153) at the home visit. MoCA covers different cognitive domains. The total score of MoCa ranges from 0 to 30 (higher = better) (153). MoCA has been shown to be efficient in detecting cognitive symptoms in people with PD (154, 155), and it has been suggested to be superior to the Mini-Mental State Examination (MMSE) in people with PD (154).

Depressive symptoms: assessed with the interview-administered 15-item Geriatric Depression Scale (GDS-15) (156). Each item has a dichotomous (Yes/No) response category, and the total score ranges from 0 to 15 (higher = worse). The GDS-15 has previously been shown to be effective in screening for depressive symptoms in PD (157, 158).

Anxiety and orthostatic hypotension: Anxiety was assessed with the dichotomous (No/Yes) question (item 17, feeling anxious, frightened or panicky) of the self-administered Nonmotor Symptoms Questionnaire (NMSQuest) (159). Orthostatic hypotension was assessed with the dichotomous (No/Yes) question (Item 20, feeling light headed, dizzy or weak standing from sitting or lying) of the NMSQuest (159).

Fatigue: assessed with the self-administered Energy subscale of the Nottingham Health Profile (NHP-EN) (160). Those who affirmed at least one out of the three dichotomous (Yes/No) questions (tired all the time, everything is an effort, soon out of energy) were classified as having fatigue (161).

## Statistical analyses

Descriptive statistics were computed for all the variables included in Studies I-IV. Categorical variables are described by number of participants (percentage), while ordinal and continuous variables are expressed by medians (first and third quartiles, q1-q3), or means (Standard deviation, SD) depending on the distribution of the data. Normality was assessed visually, for example by the frequency distribution (histogram), and quantile-quantile (Q-Q) plot as well as through the Shapiro-Wilk test in the SPSS (162).

### Study I - bivariate analyses

Non-parametric tests (the Kruskal-Wallis test and/or Mann-Whitney U-test) for ordinal or continuous variables), and the Chi-Square test for dichotomous or categorical variables were used for comparing different sub-groups. Initially, the Kruskal Wallis or the Chi-Square tests were used for comparisons of more than two sub-groups. If the P value then was statistical significant, subsequent tests (Mann-Whitney tests or additional Chi-Square tests) were corrected for multiple comparisons, using the Bonferroni Correction. Moreover, in this study HY stage IV (n = 56) and stage V (n = 6) were merged due to reasons of distribution as there were few participants in HY stage V.

### Study II - psychometric analyses

Psychometric properties of a rating scale are of importance in order to evaluate whether the scale is of high quality and suitable for the sample in question (5). Classical test theory (CTT) is a body of related psychometric theory to test the validity and reliability of a rating scale based on its items. In the context of PROM, CTT assumes that a person's test score is comprised of their "true" score plus some measurement error (5). PROMs should be selected based on the strength of their measurement properties (e.g. validity and reliability), which should be established in the population of interest. Validity refers to what extent an instrument measures the constructs it intends to measure (5, 163).

Validity is specific for a particular population in which the questionnaire was first developed and used. If a scale is used in a different population and context, the

original results of validation may not apply and further studies are necessary (164). Thus, an instrument needs to be validated several times, with different populations in different contexts (164). Moreover, reliability is the "consistency" or "repeatability" of your measures, defined as to what extent the measurement is free from measurement error (5, 163). The COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) group developed a consensus-based checklist to evaluate the methodological quality of studies on measurement properties (165).

In this thesis, the Walk-12G was analysed psychometrically according to CTT (166). The analyses were designed to replicate and extend the previous psychometric study of the Walk-12G in PD (92), but taking the ordinal nature of item data into account (97, 98). Traditional parametric statistics were also computed to allow for comparisons with the previous psychometric data.

Data completeness was determined by the percentage of missing item and total score data (5, 167); which should be less than 10% to be considered acceptable among responders (168).

Scaling assumptions were explored by examining the legitimacy of summing the Walk-12G item scores into a total score. That is, it was examined whether each item contributed sufficiently to the total score (i.e. corrected item-total correlations  $\geq 0.30$ ) (5), and whether items appeared to represent a common construct (i.e. unidimensionality, which is supported if corrected item-total correlations are  $\geq 0.40$ ) (5, 167). To account for the ordinal nature of item-level data, item-total correlations were computed based on polychoric correlations. Item-total correlations were also computed based on Pearson correlations to allow for comparisons with previous psychometric data (92). Unidimensionality was further examined by exploratory factor analyses (EFA) using minimum rank factor analysis (MRFA) based on a polychoric correlation matrix, and parallel analysis (based on 500 random permutations) to determine the number of factors (169).

Targeting was assessed by studying score distribution, skewness and floor and ceiling effects. Targeting was assessed by studying score distribution, skewness, and floor and ceiling effects. A well-targeted scale should have an average total score close to the scale midpoint (i.e. 21), with scores spanning most of the scale's full potential range (i.e. 0-42) without excess skewness (preferably between -1 and +1) (5, 167). Floor and ceiling effects (i.e. the percentage of respondents with the

lowest and highest possible Walk-12G scores, respectively) should preferably not exceed 15–20% (5, 170).

Internal consistency reliability was assessed by the polychoric-based ordinal version of coefficient alpha (97, 98) and traditional Cronbach's alpha (171);  $> 80$  is considered acceptable (5, 172). Moreover, the SEM was calculated ( $SD \times \sqrt{1 - \text{reliability}}$ ) (5, 170) based on both the ordinal and traditional coefficient alpha. SEM was also expressed as a percentage of the possible score range:  $SEM/42 \times 100$ .

External construct validity was examined by evaluating convergent, divergent and known-group validity. Convergent and divergent validity were addressed by examining the patterns of Spearman correlations ( $r_s$ ). Based on a priori hypotheses, it was anticipated that the Walk-12G scores would correlate strongly ( $r_s \geq 0.6$ ) with ADL (PADLS) and FOG (FOGQsa) scores (92). In relation to divergent validity, it was anticipated that the Walk-12G would correlate more weakly ( $r_s < 0.4$ ) with age (92, 93, 173), and cognitive function (MoCA) (94, 174). Known-groups validity was assessed by examining whether the Walk-12G scores could distinguish between participants reporting a history of falls and those reporting no fall. We anticipated that those with a history of falls would have higher Walk-12G scores than those with no falls (61). To examine the potential difference, the Mann–Whitney U-test was applied.

### **Study III - multivariate analyses**

Initially, the basic assumptions (linear relationship, independent and normally-distributed residuals with constant variance) for linear regression were checked. Pearson ( $r$ ) or Spearman ( $r_s$ ) correlations were used to assess relationships among all independent variables in order to identify any multi-collinearity. Because the results from both correlation matrices were almost the same, Pearson ( $r$ ) correlations were used throughout. The presence of multi-collinearity was considered if there was  $r > 0.7$  between two variables. There was a sign of multi-collinearity between 'Postural response (item 30, UPDRS)' and 'Disease severity' as well as between 'Social support' and 'Living alone'. Disease severity (HY) was omitted since it is not a modifiable factor, whereas social support was omitted due to a skewed distribution of data (only two participants did not receive any social support).

Univariable linear regression analyses were used to investigate the unadjusted relationship of each independent variable and the dependent variable (the Walk-12G scores). In order to avoid leaving out a confounding variable, all variables with a P-value < 0.3 were then entered into a multivariable linear regression model. The P-values for all independent variables were inspected and the variable with the highest P-value was manually removed. This procedure continued until all independent variables in the model had P-values < 0.1, which became the final model. The strength of the relationship between each independent variable and the dependent variable was assessed by the standardized regression coefficient ( $\beta$ ).

## **Study IV - descriptive and follow-up analyses**

Descriptive statistics used for the number of participants, including proportion (%). McNemar tests were used to determine whether there was a significant change in the proportion of participants who reported using MDs over the 3-year period.

Data was analysed using SPSS Windows 23.0 (IBM SPSS Inc., Chicago, IL, USA). In addition to SPSS, Study III was analysed using R version 3.4.0 (“psych” package version 1.7.5; [www.r-project.org](http://www.r-project.org)), and FACTOR, Release Version 10.8.02 (<http://psico.fcep.urv.es/utilitats/factor/>). The alpha level of significance was set at 0.05; P values were presented exactly except when below 0.001.

# Results

## Activity avoidance due to perceived risk of falling

When using the dichotomous question: “Do you avoid activities due to a risk of falling?”, 102 out of 251 (41%) participants reported activity avoidance due to perceived risk of falling. The median mSAFFE score was 22 (range = 17-50). In the total sample, the highest proportions of participants avoided the following activities due to the perceived risk of falling: “Going out when it is slippery” (74%), “Reaching for something above your head” (50%), and “Walk a kilometer” (49%) (Table 3).

### **Activity avoidance due to the perceived risk of falling in relation to a history of self-reported falls, near falls and fear of falling**

The most commonly avoided activity was “Going out when it is slippery” when addressing those who reported a single fall, near falls but no falls as well as fear of falling. The second most frequently-avoided activity was “Go to a place with crowds” for single fallers (52%) and for those who reported near falls but no falls (61%). For recurrent fallers and those reporting FOF, the second most frequently avoided activity was “Reach for something above your head” (71% and 75%, respectively) (Table 4).

The extent of activity avoidance due to perceived risk of falling differed significantly ( $P < 0.001$ ) among those reporting no falls, a single fall or recurrent falls (i.e.  $\geq 2$  falls) (Table 5). Median mSAFFE score was 20, 25 and 28, respectively. Subsequent Mann-Whitney U-tests (Bonferroni correction criterion  $P < 0.016$ ) showed that activity avoidance due to perceived risk of falling was significantly higher in recurrent fallers as compared to the other two sub-groups. There was no statistical significant ( $P = 0.295$ ) difference between those who reported no falls and those who reported a single fall. Moreover, there was a significant ( $P < 0.001$ ) difference in the proportions of participants who reported

activity avoidance due to perceived risk of falling in relation to a history of falls: non-fallers (30%), single fallers (50%) and recurrent fallers (57%) (Table 5).

The participants who had a history of near falls (but no falls) reported significantly ( $P < 0.001$ ) more activity avoidance due to perceived risk of falling than those without such incidents; median (q1-q3) mSAFFE score was 25 (19-33) versus 19 (17-22). The corresponding proportions of participants that reported activity avoidance due to perceived risk of falling were 51% versus 17 % ( $P < 0.001$ ) (Table 5).

Those with FOF reported significantly ( $P < 0.001$ ) more activity avoidance due to perceived risk of falling than those without (median mSAFFE score was 30 versus 19); the proportions of participants who reported activity avoidance due to perceived risk of falling were 70 % versus 13 % ( $P < 0.001$ ) (Table 5).

### **Activity avoidance due to perceived risk of falling in relation to disease severity**

The extent of activity avoidance due to perceived risk of falling differed significantly ( $P < 0.001$ ) in relation to disease severity (Table 5); median (q1-q3) mSAFFE score ranged from 19 (17-25) in HY I to 32 (26-39) in HY Stages IV-V. Subsequent Mann-Whitney U-tests (Bonferroni correction criterion of  $P < 0.0083$ ) showed significant differences for all comparisons except between HY Stages I and II. The proportion of participants who reported activity avoidance due to perceived risk of falling was significantly ( $P < 0.001$ ) higher in the more severe disease stages; it rose to 74% in the most severe group. The subsequent comparisons were statistically significant (Bonferroni criterion of  $P < 0.0083$ ), except between stages HY I and II, and I and III.



**Table 3.** Activity avoidance (including a ranking order) according to mSAFFE items, N=251

Item	Activity	Response category, n (%)				Ranking (1-17) most avoided ranked as 1
		would never avoid	sometimes avoid	always avoid	sometimes+always (merged)	
		n (%)	n (%)	n (%)	n (%)	
1	Go to the shops <sup>1</sup>	152 (62)	77 (31)	18 (7)	95 (38)	11
2	Clean your house <sup>1</sup>	146 (59)	83 (34)	18 (7)	101 (41)	8
3	Prepare simple meals <sup>2</sup>	187 (76)	54 (22)	5 (2)	59 (24)	14
4	Go to the doctor or dentist <sup>2</sup>	208 (85)	32 (13)	6 (2)	38 (15)	17
5	Take a bath <sup>3</sup>	159 (65)	52 (21)	34 (14)	86 (35)	12
6	Take a shower <sup>1</sup>	194 (79)	45 (18)	8 (3)	53 (21)	15
7	Go for a walk <sup>4</sup>	147 (59)	85 (34)	16 (7)	101 (41)	9
8	<b>Go out when it is slippery<sup>1</sup></b>	<b>63 (26)</b>	<b>105 (42)</b>	<b>79 (32)</b>	<b>184 (74)</b>	<b>1</b>
9	Visit a friend or relative <sup>1</sup>	171 (69)	68 (28)	8 (3)	76 (31)	13
10	<b>Go to a place with crowds<sup>4</sup></b>	<b>133 (54)</b>	<b>85 (34)</b>	<b>30 (12)</b>	<b>115 (46)</b>	<b>4</b>
11	Go up and down stairs <sup>4</sup>	145 (58)	78 (32)	25 (10)	103 (42)	7
12	Walk around indoors <sup>1</sup>	199 (81)	44 (18)	4 (1)	48 (19)	16
13	<b>Walk a kilometer<sup>2</sup></b>	<b>126 (51)</b>	<b>67 (27)</b>	<b>53 (22)</b>	<b>120 (49)</b>	<b>3</b>
14	<b>Bend down to get something<sup>4</sup></b>	<b>141 (57)</b>	<b>92 (37)</b>	<b>15 (6)</b>	<b>107 (43)</b>	<b>5</b>
15	Travel by public transport <sup>4</sup>	145 (58)	64 (26)	39 (16)	103 (42)	6
16	Go out to a social event <sup>4</sup>	149 (60)	88 (36)	11 (4)	99 (40)	10
17	<b>Reach for something above your head<sup>4</sup></b>	<b>124 (50)</b>	<b>92 (37)</b>	<b>32 (13)</b>	<b>124 (50)</b>	<b>2</b>

mSAFFE, modified Survey of Activities and Fear of Falling in the Elderly, each item (i.e. activity) has three response categories: never, sometimes or always avoid; Top five avoided activities are marked in bold.

<sup>1</sup>n=4 missing values, <sup>2</sup>n=5 missing, <sup>3</sup>n=6 missing and <sup>4</sup>n=3 missing.

**Table 4.** Activity avoidance (the mSAFFE items) in relation to a history falls/near falls, and fear of falling, N=251

Item	Activity <sup>3</sup> ( sometimes+ always avoided)	Falls past six months				Near falls <sup>1</sup> (but no falls) past six months				Fear of falling <sup>2</sup>			
		No	Single	Rk	Recurrent	Rk	No	Yes	Rk	No	Yes	Rk	
		n=41	n=38		n=72		n=88	n=51		n=129	n=121		
1	Go to the shops, n (%)	36 (26)	15 (40)	10	44 (61)	5	14 (17)	22 (43)	11	18 (14)	77 (65)	6	
2	Clean your house, n (%)	42 (31)	15 (40)	9	44 (61)	6	17 (20)	25 (49)	8	28 (22)	73 (62)	11	
3	Prepare simple meals, n (%)	19 (14)	9 (24)	14	31 (44)	14	7 (8)	12 (24)	15	12 (9)	47 (40)	14	
4	Go to the doctor or dentist, n (%)	17 (12)	5 (13)	17	16 (23)	17	6 (7)	11 (22)	16	7 (5)	31 (27)	17	
5	Take a bath, n (%)	39 (29)	13 (34)	12	34 (48)	12	16 (19)	23 (46)	10	23 (18)	63 (54)	12	
6	Take a shower, n (%)	27 (20)	5 (13)	16	21 (29)	16	10 (12)	17 (33)	14	10 (8)	43 (36)	15	
7	Go for a walk, n (%)	44 (32)	16 (42)	7	41 (57)	9	17 (20)	27 (53)	6	27 (21)	74 (62)	9	
8	Go out when it is slippery, n (%)	96 (70)	27 (71)	1	61 (86)	1	51 (59)	45 (88)	1	72 (56)	112 (95)	1	
9	Visit a friend or relative, n (%)	32 (23)	12 (32)	13	32 (44)	13	13 (15)	19 (38)	13	17 (13)	59 (50)	13	
10	Go to a place with crowds, n (%)	52 (38)	20 (52)	2	43 (60)	7	21 (24)	31 (61)	2	33 (26)	82 (69)	4	
11	Go up and down stairs, n (%)	50 (36)	15 (39)	11	38 (53)	10	25 (29)	25 (49)	7	26 (20)	77 (65)	7	
12	Walk around indoors, n (%)	17 (12)	9 (24)	15	22 (31)	15	8 (9)	9 (18)	17	12 (9)	36 (31)	16	
13	Walk a kilometer, n (%)	56 (41)	19 (50)	4	45 (63)	4	26 (30)	30 (59)	3	35 (27)	85 (72)	3	
14	Bend down to get something, n (%)	48 (35)	16 (42)	8	43 (60)	8	24 (28)	24 (47)	9	31 (24)	76 (64)	8	
15	Travel by public transport, n (%)	37 (27)	20 (52)	3	46 (64)	3	16 (18)	21 (41)	12	24 (19)	79 (66)	5	
16	Go out to a social event, n (%)	45 (33)	19 (50)	5	35 (49)	11	18 (21)	27 (53)	5	25 (19)	74 (62)	10	
17	Reach for something above your head, n (%)	56 (41)	17 (45)	6	51 (71)	2	27 (31)	29 (57)	4	35 (27)	89 (75)	2	

mSAFFE, modified Survey of Activities and Fear of Falling in the Elderly, each item (i.e. activity) has three response categories: never, sometimes or always avoid; the response categories sometimes and always are merged; Rk, Ranking order (1-17; 1 denotes the most avoided activity).

<sup>1</sup>Top five avoided activities are marked in bold.

<sup>2</sup>h=2 missing values, <sup>3</sup>n=1 missing and <sup>3</sup>n=3-6 missing (For further details regarding missing data see footnote in Table 3).

**Table 5.** Activity avoidance due to perceived risk of falling in relation to a history falls/near falls<sup>1</sup>, fear of falling<sup>2</sup> and disease severity, N=251

Variable	Activity avoidance due to perceived risk of falling		
	The mSAFFE <sup>3</sup> median (q1-q3)	Dichotomous question (yes) n (%)	P-value
History of fall			<0.001 <sup>a</sup>
No fall, n=141	20 (18-28) <sup>4</sup>	42 (30) <sup>2</sup>	<0.001 <sup>a</sup>
Single fall, n=38	25 (17-31)	19 (50)	
Recurrent falls (>1), n=72	28 (22-35) <sup>5</sup>	41 (57)	
History of near fall			<0.001
No near falls or falls, n=88	19 (17-22) <sup>6</sup>	15 (17)	<0.001
Near falls, but no falls, n=51	25 (19-33) <sup>1</sup>	26 (51)	
Fear of falling			<0.001
No, n=129	19 (17-22) <sup>6</sup>	17 (13)	<0.001 <sup>b</sup>
Yes, n=121	30 (23-35) <sup>4</sup>	85 (70)	
Disease severity, HY stages			<0.001 <sup>b</sup>
I, n=50	19 (17-25)	12 (24)	<0.001 <sup>b</sup>
II, n=72	19 (17-24) <sup>2</sup>	14 (19)	
III, n=67	23 (19-31) <sup>6</sup>	31 (46)	
IV + V, n=62	32 (26-39) <sup>4</sup>	45 (74) <sup>2</sup>	

q1-q3, first-third quartile; mSAFFE, modified Survey of Activities and Fear of Falling in the Elderly (17-51, higher=more avoidance); HY, Hoehn and Yahr (1-5, higher=worse).

<sup>a</sup>All subsequent unpaired comparisons showed a statistical significant difference (Bonferroni correction criterion of P<0.016) except between no fall-single fall for the mSAFFE, and except between no fall-single fall and single fall-recurrent fall for dichotomous question

<sup>b</sup>All subsequent unpaired comparisons showed a statistical significant difference (Bonferroni correction criterion of P<0.0083) except between HY I-II for the mSAFFE, and except between HY I-II and I-III for the dichotomous question.

<sup>1</sup>n=2 missing values, <sup>2</sup>n=1 missing, <sup>3</sup>n=11 missing, <sup>4</sup>n=7 missing, <sup>5</sup>n=4 missing and <sup>6</sup>n=3 missing.

## Perceived walking difficulties (the Walk-12G)

### Psychometric properties of the Walk-12G

Missing item responses ranged from 0.4 % (e.g. Items 1 and 4) to 2.4 % (Item 3). Close to 98% of participants had computable Walk-12G total scores (Table 6). Scaling assumptions were supported by roughly similar item median (q1-q3) scores as well as item mean scores (SDs), and corrected item–total correlations  $> 0.60$ . Moreover, EFA results provided support for the unidimensionality of the Walk-12G. That is, the first and second empirical factors explained 82.0% and 6.4% of the common variance as compared to 25.6% and 21.6% for the first two factors from random data (Table 6).

Targeting analyses found that the median Walk-12G score was below the scale midpoint (i.e. 21), but the scale midpoint was within the interquartile range, and scores spanned the full range of possible scale scores. Floor and ceiling effects were 4.9% and 1.2%, respectively (Table 6).

Internal consistency reliability was high; the ordinal alpha was 0.96 whereas the Cronbach's alpha coefficient was 0.95. Corresponding SEM values were 2.2 and 2.5 respectively (Table 6).

Results regarding external construct validity are shown in Table 7. As hypothesized, the Walk-12G scores correlated strongly ( $r_s \geq 0.6$ ) with ADL and FOG, and weakly ( $r_s < 0.4$ ) with age and cognitive function. The Walk-12G scores were significantly ( $P < 0.001$ ) higher (i.e. worse) in those who reported a history of falls than in those with no falls (Table 7).

**Table 6.** Descriptive and psychometric data of the Generic Walk-12 in people with Parkinson disease, N=249

Item	Median (q1-q3)	Missing values n
1. Have you found that you need to use support when walking indoors (e.g. holding on to furniture, using a stick, etc.)?	1 (0-1)	1
2. Have you found that you need to use support when walking outdoors (e.g. using a stick, a frame, etc.)?	0 (0-2)	2
3. Have you been limited in your ability to run?	2 (0-2)	6
4. Have you found it difficult to stand when doing things?	1 (0-2)	1
5. Have you been limited in your ability to climb up and down stairs?	1 (0-2)	1
6. Have you had problems balancing when standing or walking?	1 (1-2)	2
7. Have you been limited in your ability to walk?	1 (0-2)	2
8. Has your walking been effortful?	1 (1-2)	2
9. Has the smoothness of your walking been affected?	1 (1-2)	1
10. Have you needed to concentrate on your walking?	1 (0-2)	1
11. Have you been limited in how far you are able to walk?	2 (0-3)	1
12. Has your walking been slow?	2 (1-2)	1
<b>Data completeness</b>		
Missing item responses, min-max % <sup>a</sup>	0.4-2.4	
Computable total scores, % <sup>b</sup>	97.6 (missing n=6)	
<b>Scaling assumptions</b>		
Item mean scores, min-max	0.71-1.72	
Item SD, min-max	0.76-1.38	
Item median, min-max	0-2	
Corrected polychoric item-total correlations, min-max <sup>c</sup>	0.63 (i3)-0.90 (i7)	
Corrected Pearson item-total correlations, min-max <sup>c</sup>	0.61 (i3)-0.89 (i7)	
<b>Item EFA (MRFA)</b>		
F1 loadings, min-max <sup>d</sup>	0.72-0.92	
F1/F2 % common variance explained	82.0/6.4	
F1/F2 % common variance explained from parallel analysis	25.6/21.6	
<b>Targeting</b>		
Total score, mean (SD) <sup>e</sup>	15.8 (11.0)	
Total score, median (q1-q3) <sup>e</sup>	14.0 (7.0-24.0)	
Total score, min-max <sup>f</sup>	0-42	
Total score skewness (SE) <sup>g</sup>	0.45 (0.16)	
Total score floor-/ceiling effects, % <sup>h</sup>	4.9/1.2	
<b>Reliability</b>		
Ordinal alpha <sup>i</sup>	0.96	
Ordinal alpha when item deleted, min-max <sup>j</sup>	0.95-0.96	
Cronbach's alpha <sup>i</sup>	0.95	
Cronbach's alpha when item deleted, min-max <sup>j</sup>	0.95-0.95	
SEM, ordinal alpha based (% of total score) <sup>k</sup>	2.2 (5.2)	
SEM, traditional alpha based (% of total score) <sup>k</sup>	2.5 (5.9)	

q1-q3, first-third quartile; SD, standard deviation; EFA, exploratory factor analyses;

MRFA, minimum rank factor analysis; F, factor; SE, standard error; SEM, standard error of measurement.

<sup>a</sup> Should be ≤10%; <sup>b</sup> Should be close to 100%; <sup>c</sup> Should be ≥0.30–0.40;

<sup>d</sup> Kaiser-Meyer-Olkin measure of sampling adequacy=0.95; <sup>e</sup> Should be close to scale midpoint (i.e., 21);

<sup>f</sup> Should span most of the possible range (i.e. 0-42); <sup>g</sup> Should be between -1 and +1; <sup>h</sup> Should be ≤20%; <sup>i</sup> Should

be ≥0.80; <sup>j</sup> Should not increase compared with alpha for the total score; <sup>k</sup> Should be less than half of the total

score SD; computed based on ordinal / traditional coefficient alpha (SD×√1- reliability).

**Table 7.** External construct validity of the Generic Walk-12 (the Walk-12G) in people with Parkinson's disease, N=249

Variables	A priori hypotheses	Correlations ( $r_s$ ) with the Walk-12G	P-value
<b>Convergent validity</b>			
Activities of daily living (PADLS)	$r_s \geq 0.6$	0.67	<0.001
Freezing of gait (FOGQsa)	$r_s \geq 0.6$	0.77	<0.001
<b>Divergent validity</b>			
Age	$r_s < 0.4$	0.34	<0.001
Cognitive function (MoCA)	$r_s < 0.4$	-0.30	<0.001
<b>Known-groups validity</b>			
<b>History of falls during the past six months</b>			
Walk-12G score	Yes, n=107	No, n=136	
Median (q1-q3)	19 (9-27)	12 (5-19)	<0.001

$r_s$ , Spearman's correlation coefficient; PADLS, Activities of Daily Living Scale (1-5, higher=worse); FOGQsa, self-administered version of the Freezing of Gait Questionnaire (0-24, higher=worse); MoCA, Montreal Cognitive Assessment (0-30, higher=better); q1-q3, first-third quartile.

## **Factors contributing to perceived walking difficulties**

The mean (SD) Walk-12G score was 15.8 (11.0). A total of 15 variables were included in univariable analyses, and they all turned out to be significant ( $P < 0.05$ ) (Table 8). All 15 variables were entered into the multivariable linear regression model.

The multivariable linear regression analyses resulted in eight statistically-significant, independent variables that explained 56.3% of the variance in perceived walking difficulties (Table 9). The strongest independent variable was FOG ( $\beta = 0.265$ ,  $P < 0.001$ ), which was followed by general self-efficacy ( $\beta = -0.242$ ,  $P < 0.001$ ) (Table 9).

Since 31 participants (whereof 19 in HY stage IV and 3 in stage V) were unable to perform or complete the chair-stand test, we reran the analyses without using this as an independent variable. This rendered a model with seven, statistically-significant independent variables, which explained 53.4% of the variance in perceived walking difficulties. The strongest independent variable was FOG ( $\beta = 0.275$ ,  $P < 0.001$ ), which was followed by fatigue ( $\beta = 0.236$ ,  $P < 0.001$ ) (Table 10). None of the final multivariable models included any participant in HY stage V.

**Table 8.** Simple linear regression analyses with Generic Walk-12 scores as the dependent variable in people with Parkinson’s disease (PD), N=243

Independent variables	Unstandardized Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value
Sex (women)	3.56 (0.72, 6.39)	0.157	0.014
Age (year)	0.38 (0.24, 0.53)	0.321	<0.001
Living alone (dichotomized, yes)	4.50 (1.35, 7.64)	0.178	0.005
General self-efficacy (GSE)	-0.72 (-0.90, -0.54)	-0.455	<0.001
PD duration (years)	0.63 (0.43-0.83)	0.367	<0.001
Postural instability (UPDRS III item 30, scores $\geq 1$ =yes)	8.06 (4.98-11.13)	0.316	<0.001
Bradykinesia (UPDRS III item 31, scores $\geq 1$ =yes)	7.44 (4.71, 10.16)	0.327	<0.001
Freezing of gait (FOGQsa item 3, scores $\geq 1$ =yes)	11.22 (8.79-13.65)	0.505	<0.001
Lower extremity function (Chair-Stand Test, seconds)	0.44 (0.29-58)	0.370	<0.001
Depressive symptoms (GDS-15)	1.63 (1.19, 2.07)	0.428	<0.001
Anxiety (NMSQuest item 17, yes)	6.66 (3.64, 9.69)	0.270	<0.001
Orthostatic hypotension (NMSQuest item 20, yes)	7.64 (5.01, 10.26)	0.346	<0.001
Fatigue (NHP-EN, dichotomized, yes)	10.99 (8.55, 13.43)	0.496	<0.001
Cognitive function (MoCA)	-0.87 (-1.18, -0.55)	-0.330	<0.001
Pain (dichotomized, yes)	6.16 (3.29, 9.01)	0.263	<0.001

GSE, General Self-Efficacy Scale (0-40, higher=better); UPDRS, Unified Parkinson’s Disease Rating Scale (part III= motor examination, item 30 and 31, 0-4, higher=worse); FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3, 0-4, higher=worse); GDS-15, the 15-item Geriatric Depression Scale (0-15, higher=worse); NMSQuest, Nonmotor Symptoms Questionnaire; NHP-EN, Energy subscale of the Nottingham Health Profile, those who affirmed at least one of its three dichotomous (yes/no) questions (tired all the time, everything is an effort, soon out of energy) were classified as having fatigue; MoCA, Montreal Cognitive Assessment (0-30, higher=better).



**Table 9.** Multiple linear regression analyses with Generic Walk-12 scores as the dependent variable in people with Parkinson’s disease (PD), N=212<sup>a</sup>

Independent variables <sup>1</sup>	Unstandardized Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value	R square <sup>b</sup> %	Adjusted R square <sup>b</sup>
Freezing of gait (FOGQsa item 3, scores $\geq 1$ =yes)	5.39 (3.31-7.47)	0.265	<0.001	56.3	54.5
General self-efficacy (GSE)	-0.35 (-0.50, -0.20)	-0.242	<0.001	25.1	24.7
Fatigue (NHP-EN, dichotomized, yes)	4.14 (2.05, 6.24)	0.204	<0.001	14.0	13.8
PD duration (years)	0.30 (0.14-0.47)	0.178	<0.001	6.6	6.4
Lower extremity function (Chair-Stand Test, sec)	0.15 (0.03, 0.27)	0.130	0.013	3.7	3.5
Orthostatic hypotension (NMSQuest item 20, yes)	2.56 (0.51, 4.61)	0.126	0.014	3.2	3.0
Bradykinesia (UPDRS III item 31, scores $\geq 1$ =yes)	2.46 (0.45, 4.48)	0.120	0.017	1.2	1.0
Postural instability (UPDRS III item 30, scores $\geq 1$ =yes)	2.59 (0.34-4.84)	0.112	0.024	1.3	1.1
				1.2	1.0

FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3, 0-4, higher=worse); GSE, General Self-Efficacy Scale (0-40, higher=better); NHP-EN, Energy subscale of the Nottingham Health Profile, affirming at least one of its three dichotomous (yes/no) questions (tired all the time, everything is an effort, soon out of energy) were classified as having fatigue; NMSQuest, Nonmotor Symptoms Questionnaire; UPDRS, Unified Parkinson’s Disease Rating Scale (part III=motor examination, item 30 and 31, 0-4, higher=worse).

<sup>1</sup>The following 15 independent variables were included: sex, age, living alone, general self-efficacy, PD duration, postural instability, bradykinesia, freezing of gait, lower extremity function, depressive symptoms, anxiety, orthostatic hypotension, fatigue, cognitive function, and pain.

<sup>a</sup>The final model included the participants who had data for lower extremity function (whereof 36 participants in HY stage IV and none in stage V).

<sup>b</sup>Stepwise linear regression was conducted with all the independent variables included in the final model to get the change in R<sup>2</sup> values.

**Table 10.** Multiple linear regression analyses with Generic Walk-12 scores as the dependent variable in people with Parkinson’s disease (PD) after excluding the variable chair stand test, N=243

Independent variables <sup>1</sup>	Unstandardized B Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value	R square <sup>a</sup> %	Adjusted R square <sup>a</sup>
Freezing of gait (FOGQsa item 3, scores $\geq 1$ =yes)	6.02 (3.85-8.19)	0.275	<0.001	53.4	51.9
Fatigue (NHP-EN, dichotomized, yes)	5.17 (2.97, 7.38)	0.236	<0.001	25.4	25.1
General self-efficacy (GSE)	-0.35 (-0.51, -0.20)	-0.225	<0.001	13.6	13.4
PD duration (years)	0.29 (0.13-0.45)	0.173	<0.001	6.2	6.0
Bradykinesia (UPDRS III item 31, scores $\geq 1$ = yes)	3.66 (1.58, 5.74)	0.164	0.001	3.5	3.3
Postural instability (UPDRS III item 30, scores $\geq 1$ = yes)	2.70 (0.34-5.06)	0.107	0.025	2.6	2.4
Orthostatic hypotension (NMSQuest item 20, yes)	2.25 (0.15, 4.35)	0.103	0.036	1.2	1.0

FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3, 0-4, higher=worse); NHP-EN, Energy subscale of the Nottingham Health Profile, affirming at least one of its three dichotomous (yes/no) questions (tired all the time, everything is an effort, soon out of energy) was classified as having fatigue; GSE, General Self-Efficacy Scale (0-40, higher=better); UPDRS, Unified Parkinson’s Disease Rating Scale (part III= motor examination, item 30 and 31, 0-4, higher=worse); NMSQuest, Nonmotor Symptoms Questionnaire.

<sup>1</sup>The following 14 independent variables were included: Sex, age, living alone, general self-efficacy, PD duration, postural instability, bradykinesia, freezing of gait, depressive symptoms, anxiety, orthostatic hypotension, fatigue, cognitive function, and pain.

<sup>a</sup>Stepwise linear regression was conducted with all the independent variables included in the final model to get the change in R<sup>2</sup> values.

## Use and perceived need of mobility devices

### **At baseline - the total sample**

At baseline, 75 of 253 participants (30%) reported that they used some kind of MD indoors (Table 11), whereas 133 of 254 participants (52%) reported using some kind of MD outdoors (Table 12). Wheeled walkers were the most commonly-used MD indoors as well as outdoors, followed by canes (indoors) and Nordic walking sticks (outdoors). Eleven participants (4%) expressed a perceived need of one or more MD (indoors,  $n = 2$ ; outdoors,  $n = 8$ ; both indoors and outdoors,  $n = 1$ ).

### **Comparisons for those with complete data at the baseline and in the 3-year follow-up**

The overall use of MDs increased significantly ( $P < 0.001$ ) indoors as well as outdoors over the 3-year period (Tables 11-12). Indoor use of some kind of MD was reported by 36 of 164 participants (22%) at baseline as compared to 66 (40%) 3 years later ( $P < 0.001$ ). As to specific MDs, wheeled walkers and manual wheelchairs were the only types for which the indoor use increased significantly ( $P = 0.002$  and  $0.001$ , respectively). At both time points, wheeled walkers were the most commonly used MD indoors, followed by canes (Table 11).

Outdoor use of some kind of MD was reported by 79 of 165 participants (48%) at baseline as compared to 108 of 163 (66%) 3 years later ( $P < 0.001$ ). Manual wheelchairs were the only MD for which outdoor use increased significantly ( $P < 0.001$ ). At both time points, wheeled walkers were the most commonly-used MD outdoors, followed by Nordic walking sticks (Table 12).

**Table 11.** Use of mobility devices indoors in people with Parkinson's disease

Mobility device	Cross-sectional sample N=255 Baseline	3-year follow-up sample n=165 Baseline <sup>a</sup> 3-year follow-up		P-value <sup>b</sup>
	n (%)	n (%)	n (%)	
Any mobility device	75 (30)	36 (22)	66 (40)	<0.001
Cane	24 (9)	12 (7)	20 (12)	0.152
Crutches	12 (5)	11 (7)	10 (6)	1.000
Other walking device without wheels (quadropod, walking frame, etc.)	8 (3)	3 (2)	9 (5)	0.070
Wheeled walker	54 (21)	22 (13)	41 (25)	0.002
Wheelchair, manual	8 (3)	5 (3)	19 (12)	0.001
Powered wheelchair	1 (0.4)	1 (1)	3 (2)	0.500

Note: As participants commonly reported using multiple mobility devices, numbers and percentages cannot be added up. <sup>a</sup>Data for those included in the 3-year follow-up; <sup>b</sup>McNemar test for difference over 3-year follow-up. Missing data: n=0-2 for total sample at baseline, and n=0-4 for the 3-year follow-up sample.

**Table 12.** Use of mobility devices outdoors in people with Parkinson's disease

Mobility device	Cross-sectional sample N=255 Baseline	3-year follow-up sample n=165 Baseline <sup>a</sup> 3-year follow-up		P-value <sup>b</sup>
	n (%)	n (%)	n (%)	
Any mobility device	133 (52)	79 (48)	108 (66)	<0.001
Nordic walking sticks	43 (17) <sup>c</sup>	31 (20) <sup>d</sup>	38 (23) <sup>e</sup>	0.265
Cane	28 (11)	19 (12)	27 (16)	0.201
Crutches	14 (6)	9 (5)	15 (9)	0.180
Other walking device without wheels (quadropod, walking frame, etc.)	0 (0)	0 (0)	0 (0)	-
Wheeled walker	70 (28)	36 (22)	41 (25)	0.458
Tricycle	2 (1)	1 (1)	3 (2)	0.625
Wheelchair, manual	21 (8)	10 (6)	28 (17)	<0.001
Powered wheelchair	14 (6)	9 (5)	13 (8)	0.219

Note: As participants commonly reported using multiple mobility devices, numbers and percentages cannot be added up.

<sup>a</sup>Data for those included in the 3-year follow-up; <sup>b</sup>McNemar test for difference over 3-year follow-up;

<sup>c</sup>35 participants reported Nordic walking sticks as their only mobility device outdoors;

<sup>d</sup>25 participants reported Nordic walking sticks as their only mobility device outdoors;

<sup>e</sup>23 participants reported Nordic walking sticks as their only mobility device outdoors.

Missing data: n=0-2 for total sample at baseline, and n=0-3 for the 3-year follow-up sample.

Of 161 participants, 82 (51%) reported using MDs indoors and/or outdoors at baseline as compared to 109 participants (68%) 3 years later (Table 13). A more detailed description of numbers of users and non-users of MDs both indoors and outdoors, including transition of MDs, is presented in the form of cross-tabulation in Table 13.

Among the users at both time points, the majority used a single MD, followed by 2 MDs, and then 3 or more MDs (for details see Figures 3a-b). If using more than one MD, the most common combination was using a cane and a wheeled walker; this applied to both indoors and outdoors and at both time points.

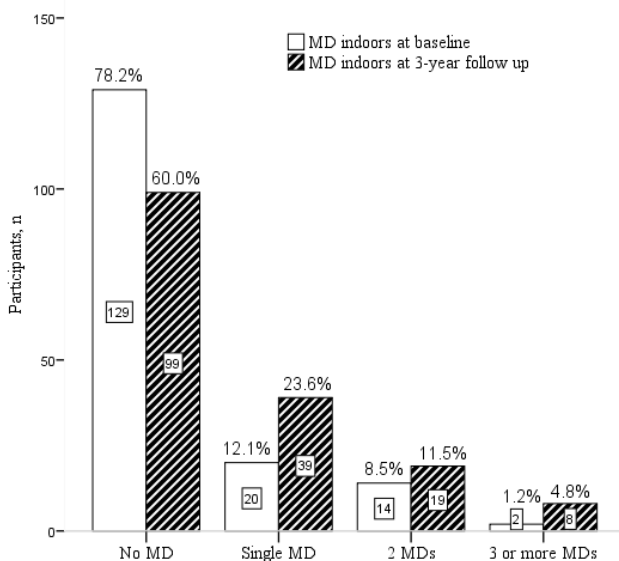
Eight participants (5%) expressed a perceived need of one or more MD at baseline (indoors, n = 2; outdoors, n = 5; both indoors and outdoors, n = 1). Thirty-four participants (21%) expressed a perceived need 3 years later (indoors, n = 8; outdoors, n = 20; both indoors and outdoors, n = 6).

**Table 13.** Cross-tabulation of numbers of users and non-users of any mobility device indoors and outdoors at baseline and the 3-year follow-up, n=161<sup>a</sup>

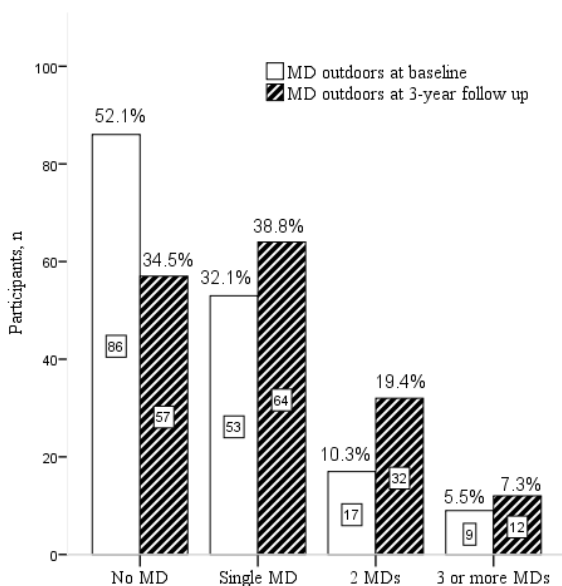
3-year follow-up, n	Baseline <sup>1</sup> , n				Total
	Non-user	User indoors only	User outdoors only	User both indoors and outdoors	
Non-user	46	1	4	1	52
User indoors only	2	0	0	0	2
User outdoors only	18	0	21	4	43
User both indoors and outdoors	13	3	21	27	64
Total	79	4	46	32	161

<sup>a</sup>n=161 (out of n=165) due to missing data.

<sup>1</sup>Data for those included in the 3-year follow up.



**Figure 3a.** The number and proportion of participants using single or more mobility devices (MDs) indoors at baseline, and 3-year follow up



**Figure 3b.** The number and proportion of participants using single or more mobility devices (MDs) outdoors at baseline, and 3-year follow up

# Discussion

The overarching aim of this thesis was to gain increased knowledge regarding activity avoidance due to perceived risk of falling, perceived walking difficulties and the use and perceived needs of MDs in people with PD. The results suggest that activity avoidance due to perceived risk of falling is related to a history of self-reported falls/near falls, fear of falling and disease severity. The thesis also contributes to the methodological knowledge in this research field. That is, the Walk-12G scale has satisfactory data completeness, scaling assumptions, targeting, internal consistency and external construct validity when used in a PD sample. Regarding perceived walking difficulties, the strongest contributing factor is FOG, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability. The use and perceived need of MDs increase over a 3-year period, with transition of MD towards more assistive potential.

## Activity avoidance due to perceived risk of falling

As to the level of detail regarding activity avoidance due to perceived risk of falling as assessed by the mSAFFE, study I extends those reported in a previous PD-study (71). That is, these results add more detailed knowledge regarding whether the participants sometimes or always avoid the activities and identify the activities that are avoided when reporting falls, near falls (but no fall) and FOF. To the best of my knowledge, the study I is the first study that reports activity avoidance due to the perceived risk of falling in relation to PD severity. In addition, as compared to previous PD studies that used the mSAFFE (n ranged from 20 to 130) (49, 71, 72, 175), this study included the largest sample size.

In agreement with previous PD-studies (49, 71, 72), the most frequently avoided activity due to the risk of falling was “Going out when it is slippery” (study I). This indicates that people with PD seem to avoid activities that they presumably consider as risky, which can be a sound strategy. It was also common to avoid activities that

involved situations with large numbers of people (e.g. crowds and public transport). Avoiding such situations may restrict participation. Moreover, one fifth of the study participants reported that they always avoided walking a kilometre due to the risk of falling. This indicates the importance of addressing activity avoidance due to perceived risk of falling in order to promote physical activity. These findings highlight the activities and participation component of the ICF (43) and that people with PD may be at risk for limited activity and restricted participation in society. In a previous study activity avoidance due to perceived risk of falling (i.e. the mSAFFE scores) was the largest independent significant predictor of sedentary behaviour in older adults with chronic musculoskeletal pain (176).

Although activity avoidance due to perceived risk of falling seems to increase with increased severity of PD, it needs to be underlined that this result is based on cross-sectional data. The findings that fallers reported more activity avoidance due to perceived risk of falling than non-faller corroborates previous studies that involved people with PD (71, 72) as well as older community-living people in general (177). That activity avoidance due to perceived risk of falling was related to FOF is in accordance with a previous PD study that used a dichotomous FOF question (72). Importantly, an interesting finding is that activity avoidance due to perceived risk of falling is more prevalent and pronounced among those who report near falls (but no falls) as compared to those without any near falls or fall incidents. In fact, some participants without a history of falls reported activity avoidance due to a perceived risk of falling. This suggests that researchers and clinicians should pose questions not only about falls, but also about near falls, as well as address whether people with PD report activity avoidance due to perceived risk of falling, irrespective of whether they report fall incidences. One important, new finding is that people with PD report activity avoidance due to perceived risk of falling as early as HY Stages I and II. This suggests that activity avoidance due to perceived risk of falling needs to be addressed early in order to prevent sedentary behaviour and participation restrictions; safe activity performance should be promoted.



# Perceived walking difficulties

## Psychometric properties of the Walk-12G

The results of the psychometric study (Study II) in the thesis provide extended support for the CTT-based psychometric properties of the Walk-12G in people with PD.

Data completeness showed to be satisfactory. That is, there were few missing item responses and total scores were computable for all but six participants. The proportion of computable total scores was higher than that previously reported in a PD sample (87.5%) (92). This facet of the results shows that careful planning and execution of data collection, including instructions to the data collectors to screen all self-reported ratings and ask participants to add responses if missing values were detected, pays off in terms of data completeness. Item 3 (i.e. limited ability to run) had the highest proportion of missing data ( $n = 6$ ) and the lowest corrected polychoric item-total correlation. This may mirror that running is a more difficult item or that the concept of running is different from the concept of walking, for example, walking has a period of double support while running does not (178).

The results of study II provide support for the legitimacy of summing the Walk-12G item scores into a total score according to CTT assumptions. That is, corrected item-total correlations as well as polychoric based EFA with parallel analysis supported the unidimensionality of the Walk-12G. These observations are in line with and strengthen previous findings on the Walk-12G in people with PD (92).

Targeting the Walk-12G was satisfactory. Although participants on average scored below the Walk-12G midpoint (i.e. 21), skewness was acceptable (5) and floor and ceiling effects were negligible (5). Low floor and ceiling effects are encouraging as they provide further support for the scale's ability to detect group differences and changes over time (167). In a previous study of the Walk-12, notably higher floor effects (18.5-28.6%) were found in people with other neurological disorders (94), which might lead to an underestimation of clinical changes for the better (5). Taken together, our results corroborate (92) that the Walk-12G is well targeted to assess perceived walking difficulties in people with PD.

The results showed high ordinal and Cronbach's alpha values, exceeding the recommendation ( $> 80$ ) (5). As to measurement error, the ordinal alpha based SEM was lower than that based on Cronbach's alpha. This finding further strengthens the support for interpretation of differences in the Walk-12G scores. That is, a difference should exceed 2 points in order to exceed the measurement error. It is suggested that SEM provides a value that may be a reasonable approximation of a minimally-important difference (179). However, it should be noted that the assumptions underpinning CTT cannot be tested (5) and SEM is not the same for all scores (164). That is, measurement error increases as the scores deviate from the median/mean.

According to the COSMIN checklist of psychometric properties, factor analyses is of importance for evaluating internal consistency as well as for structural validity; the latter is part of construct validity (165). Convergent, divergent and known-groups validity are also part of construct validity (164). In study II, convergent and divergent validity were supported by the patterns of correlations across variables, which are in general agreement with previous studies of the MSWS-12, the Walk-12 and the Walk-12G (92-94, 173, 174). A new finding was that Walk-12G scores could distinguish between participants reporting a history of falls compared to those reporting no falls. This probably mirrors that most people with PD fall while walking (50).

## **Factors contributing to perceived walking difficulties**

To the best of my knowledge, study III is the first study that investigated factors that independently contributed to perceived walking difficulties in people with PD. This contributes with new knowledge to this research field. The findings indicate that FOG should be the primary target when addressing perceived walking difficulties in people with PD. FOG being of importance for walking difficulties corroborates previous findings of quantitative studies that used objective measures (100, 101) as well as qualitative studies (90, 91, 111-113). For example, people with PD have described that FOG influences community walking and perceived participation (90, 113) negatively. The current findings further underline the importance of addressing FOG if aiming to improve walking ability in people with PD. For example, cueing strategies may facilitate walking if the person has FOG episodes (34, 180). General self-efficacy was the second strongest contributing factor to perceived walking difficulties, which to the best of my knowledge is a new finding in my thesis. Based on data from the larger project (136) that this study is part of, general self-efficacy has shown to contribute independently to life satisfaction (181), but not to concerns

about falling (182). Previous studies also showed that self-efficacy was of importance for engagement in exercise (183) and self-management in people with PD (184). Further studies are necessary to examine whether a self-management approach is beneficial for walking ability in people with PD. People with high self-efficacy are more likely to pursue an active role in goal-setting and coping, determining their health status and health care, and adherence to prescribed regimens (185). Within the ICF model, personal factors can act as either facilitators or barriers (43). One such personal factor is self-efficacy, which is a predictor of behaviour that influences choice of activities and motivation (186). All considered, our findings suggest that general self-efficacy is an important aspect to consider in PD care and rehabilitation.

Study III showed that fatigue was the third strongest contributing factors to perceived walking difficulties. Previous PD studies have shown that fatigue is associated with walking economy (187), and with lower levels of self-reported (188, 189) as well as objectively-measured (190) physical activity. Moreover, lower limb muscle fatigue (i.e. physical fatigue) has been shown to be associated with objectively-measured gait parameters in people with PD (106). Although further studies are needed to understand the association between fatigue and walking difficulties, one potential explanation may be that fatigue induces difficulties in maintaining attention (191). Attention has been shown to be of importance for walking in people with PD (192, 193). Although attention is a cognitive function, global cognitive functioning (as assessed with MoCA) did not contribute to perceived walking difficulties.

In study III, lower extremity function independently contributed to perceived walking difficulties, which needs some specific attention. Lower extremity function was assessed by using the chair stand test (152, 194), and it should be noted that 31 participants (whereof 19 in HY stage IV and 3 in stage V) were unable to perform or complete this test. After excluding this variable in the multivariable analyses, the results remained largely similar. This consistency indicates that all the identified factors independently contribute to perceived walking difficulties regardless of their interaction with lower extremity function. The fact that lower extremity function turned out to be a significant contributing factor might highlight the need of promoting lower extremity strength (195, 196). According to recommendations (37, 38, 42), strength training in people with PD should be combined with training that includes other components such as balance. This is further underlined by the fact that postural instability independently contributed to perceived walking difficulties in this study. Postural instability was assessed in relation to an external perturbation. Several studies showed that training in responding to an external

perturbations (197-199) has some effect on gait, balance and activity performance. Balance training should challenge the person with PD (38), and training in a home-based setting seems to have no beneficial effect in people with PD (200).

## The use and perceived needs of mobility devices

To the best of my knowledge, study IV is the first study that provides detailed information on the use and perceived needs of MDs in people with PD over a time. As could be expected in people with a chronic progressive disease that affects gait and balance, the results show an increased use as well as increased perceived needs of MDs over a 3-year period.

Wheeled walkers were the most commonly-used MD indoors as well as outdoors, which was the case at baseline as well as 3 years later. This finding is in agreement with another Swedish PD study (69), but contradicts a study based on a European sample (i.e. Sweden, Germany, the United Kingdom, Hungary and Latvia) where the cane was the most commonly-used MD (126). It should be noted that the latter study included a small sample of very old people ( $n = 20$ ) with self-reported PD (75–89 years) who were single and living in urban areas 2003-2004 (201). Canes (i.e. walking sticks) have been reported as the most commonly-used MD in people with a first-ever stroke (202), middle-aged and older adults with multiple sclerosis (203), as well as in older adults in the United States (134) and in Europeans (135). These discrepancies suggest that people with PD require MDs with more support than other populations, but might also reflect that using a wheeled walker may be more advantageous than a cane for people with PD. For example, wheeled walkers have been associated with fewer freezing episodes, improved safety and gait speed (120, 121), whereas canes induced more freezing episodes (120).

Although most of the participants used a single MD, several did in fact use multiple MDs. The latter might be due to a variability in symptoms (e.g. "on" versus "off" periods), environmental circumstances or activity characteristics (e.g. walking at home versus travelling longer distances out of home). To the best of my knowledge, the pattern of using multiple MDs has not been previously described in any PD-study. This knowledge is beneficial, especially for those who prescribe MD and train the use of MDs in people with PD. Follow-ups of MD use is needed for safety assessment, also in relation to using multiple MDs, and for identifying any changes in circumstances (e.g. activity characteristics and variability in symptoms) requiring

additional MDs. It must be underlined that potential negative consequences associated with the use of an MD may include, for example, increased number of falls (58, 130), reduced walking speed (121) and more freezing episodes while using a cane (120) or a non-wheeled walking device (121). Further studies are necessary to explore whether using multiple MDs facilitates activity performance and participation in people with PD.

Study IV shows a higher use as well as a higher perceived needs of MDs outdoors rather than indoors. The higher use of MDs outdoors is in agreement with previous studies in people with PD (69, 130) and in single-living older people (135). Using MDs outdoors can be a strategy for necessary and valued activities such as shopping (204). Moreover, outdoor walking poses greater challenges than walking indoors due to more complex and demanding environments, such as traffic, other pedestrians and cyclists, uneven surfaces, wind and rain (90).

In study IV, some participants (about 15%, see footnotes in Table 12) reported Nordic walking sticks as their only MD outdoors. Walking with Nordic walking sticks is becoming increasingly popular as a form of everyday physical activity (205). A recent systematic review suggested that it positively affects motor (e.g. freezing of gait) and non-motor symptoms (e.g. pain) in people with PD, however the authors highlighted the need of further, well-designed and larger-scale studies (123). Readers might question whether the participants reported using Nordic walking sticks as an exercise tool or as an MD. However, the included question in the thesis specifically addressed the use of Nordic walking sticks as an MD. All considered, it seems important to consider Nordic walking sticks when asking people with PD about MD use outdoors.

At the 3-year follow-up (Study IV), the majority of new users of MDs used MDs only outdoors, followed by using MDs both indoors and outdoors. Moreover, an increased proportion of participants used MDs with more assistive potential (i.e. wheeled walker and manual wheelchair) over time. These results are in line with previous findings in a study of single-living older adults (135).

At baseline (study IV), the perceived need of MDs (5%) was minor. Similar proportions have been reported in people with self-reported PD and their matched controls in a European context (126). A plausible explanation for the low proportion of perceived need of MDs in this study is the well-functioning, publicly-funded MD provision system in Sweden. In Sweden, the need of MDs is assessed by qualified

health care professionals (i.e. occupational therapists, physiotherapists), equal for all without any influence due to the person's socioeconomic situation (127). The needs assessment is usually carried out in close consultation with the user, his/her family members, taking the physical environment in housing and the close neighbourhood into account. A study in very old people in five European countries showed differences in the levels of needs among the countries, with more needs in countries in Eastern Europe (132). For example, the lowest proportion of perceived need of MDs was reported in the Swedish sample (2%) as compared to the Latvian sample (7%) (132). Consequently, assessment of need of MDs is a delicate matter, most likely dependent on national policies and services as well as the information provided on how to access such support. On the other hand, the present finding might reflect a lack of awareness of different MDs and their potential benefits. That is, people with PD and their family members might need improved information about MDs in order to express their needs. The perceived need of MDs did, however, increase from 5% to 21% over a 3-year period. This increase probably reflects the progression of gait and balance problems in PD, as demonstrated by the descriptive data in the sample (e.g. increased the Walk-12G scores, number of fallers (see Table 2). Importantly, a perceived need of MDs might not be equivalent to a need as assessed by health care personnel. Thus, the evaluation should include both the person's perceived needs and an assessment by health care personnel. Some participants had an MD that they did not use, which may reflect that an MD might not always act as a facilitator but might become a barrier for safe activity performance (43). These findings highlight the complexity inherent in MD provision for people with PD, requiring specific competence and efficient follow-up routines.

## Strengths and limitations

One strength of my thesis was the relative large sample size, and all included studies fulfilled the power requirements reported in the project protocol (136). The studies in this thesis included participants who represented the full spectrum of PD severity (i.e., HY stages I-V). Those in stages IV-V represent the frailest portion of the PD-population and they are in fact most commonly excluded in PD-research (206). However, non-respondent analysis of baseline data showed that those who declined to participate were older ( $P = 0.016$ ) than those who agreed to participate. This reflects the difficulties of involving frail older people in a research project. Still, the included participants represented both sexes with different socio-demographic

background (e.g., educational level, income), with a wide spread in age (more than 45 year) and PD duration (more than 40 years).

Participants were excluded if not deemed able to give informed consent or partake in the majority of the data collection. They were not excluded based on pre-specified comorbidities (e.g., arthritis or a previous stroke) or cut-off scores in relation to cognitive functioning. Still, the used procedure implies that those having severe comorbidities or cognitive difficulties may not be represented, and the results should be interpreted with this in mind. The exclusion of participants was based on the PD-nurse's knowledge of the person but also by screening of medical records, which was done by the PD-nurse. A strength was that the PD-nurses who selected the participants were involved in regularly follow-ups of the potential participants.

The cross-sectional study design in studies I-III limits the ability to establish causality between exposures or variables and the outcome of interest. Turning to another limitation, using only quantitative methods in this thesis does not allow participants to explain their choices, reasons, motivations or giving their opinions in more depth (207). All four studies were carried out in a Swedish context, and the findings may not be applicable across different cultural contexts. For example, cultural differences might influence the psychometric properties of an instrument (208). Moreover, MD provision systems vary considerably across countries (209).

Some of the variables used in this thesis may be considered rather coarse indicators such as fatigue and FOF. Another limitation is related to the questionnaires based on PROM (e.g. the mSAFFE, the Walk 12-G). According to the Food and Drug Administration (FDA), "use of a PRO instrument is advised when measuring a concept best known by the patient or best measured from the patient perspective" (210). Responses may vary due to cultural differences in relation to the targeted construct (208) and using a PRO instrument may be disadvantageous for people with disabilities and low levels of literacy (211). In addition, assessing PD duration was based on self-reporting that is subject to recall bias.

The use of bivariate analyses in study I can be considered a limitation since it does not allow assessing complex relationships. A strength of using multivariable analyses in study III is therefore that it enables investigating complex relationships with multiple interacting factors, which provides advantages over bivariate analyses. Although the sample size in study III allowed us to consider a broad variety of explanatory factors, there might be additional independent variables of

interest for perceived walking difficulties in people with PD. For example, the included social environmental factors represent a limited portion of the wide range of possible environmental factors that might be of importance for perceived walking difficulties, e.g., physical environmental barriers, crowds, inclement weather and uneven/slippery surfaces (90, 91, 114).

Study II is the first psychometric study of the Walk-12G that takes its ordinal nature of data into account. The Pearson based approach tends to yield biased correlations when the item-level data are ordinal in nature, which can be avoided by using polychoric correlations (97, 98). The importance of providing sufficient sample characteristics (including disease specific characteristics) in order to judge the external validity of psychometric evaluations has been emphasized in various guidelines (165, 172). It is therefore a strength that we present detailed clinical data about the participants such as UPDRS part III scores, HY ratings and MoCA scores. The former psychometric study of the Walk-12G in people with PD (92) lacked descriptive data on cognitive functioning. Cognitive impairments are common in people with PD (9) and may influence scores on PROMs (211); it is therefore an important disease characteristic to report. However, cognitive functioning did not independently contribute to the Walk-12G scores in study III. It needs to be noted that study II does not cover all psychometric aspects, for example, responsiveness or test-retest reliability.

A strength of study IV is the follow-up design, which enables the description of changes in use and perceived need of MDs over a 3-year period. The sample size was considerably larger than previous experimental or cross-sectional studies addressing MD use in PD, where sample sizes ranged from  $n = 19$ -77 (120, 121, 126, 129). As to limitations, we did not consider any socio-demographic factors. Considerable differences in MD use in terms of age, education, income, ethnicity and multi-morbidity have been reported in previous studies involving older people (212).

## Main conclusions and clinical implications

Activity avoidance due to perceived risk of falling appears to be related to a history of self-reported falls/near falls, fear of falling and disease severity in people with PD. Importantly, activity avoidance due to perceived risk of falling is also present among those who report near falls but without any history of falls, and as early as



the milder stages of PD. These findings imply that it seems important to not only address a history of falls but also a history of near falls. Not least since a history of near falls has been shown to be a risk factor for future falls in people with PD (61). An increased knowledge on activity avoidance due to the perceived risk of falling may help clinicians to identify those who are at risk of sedentary behaviours and participation restrictions.

The results of this thesis further demonstrate that the Walk-12G has satisfactory data completeness, scaling assumptions, targeting, internal consistency reliability and external construct validity in people with PD. This strengthens the recommendation for using the Walk-12G as a clinical routine and in research studies that involves people with PD.

Both motor (e.g. FOG) and non-motor (e.g. fatigue) symptoms as well as personal factors (i.e. general self-efficacy) contribute to perceived walking difficulties in people with PD, although longitudinal studies are necessary in order to identify predictive factors. The current findings suggest that FOG should be the primary target when addressing perceived walking difficulties in people with PD. Furthermore, personal factors (i.e. general self-efficacy) should also be in focus. However, both motor and non-motor symptoms, as well as personal factors, might be of importance. This indicates that a multidisciplinary approach might be beneficial. Future intervention studies are necessary to support or refute the proposed implications.

The use of MDs increases significantly over a 3-year period, with transition of MD towards more assistive potential (i.e. wheeled walker and manual wheelchair). The perceived needs of MDs is low but increases over time in people with PD. The knowledge gained by this study may facilitate improvement of the provision and regular follow-ups of MDs over time in people with PD. Moreover, current findings might have implications for policy making, planning, health and social services.

## Suggestions for future research

Since the findings of this thesis refer to a particular PD-sample and a Swedish context, the findings need to be replicated in other PD-samples as well as in different national contexts.

- Future longitudinal studies of activity avoidance due to perceived risk of falling should use multivariable analyses, which consider a broad variety of factors in order to identify predictive factors. For example, physical environmental factors might be of importance for activity avoidance due to perceived risk of falling in people with PD. These suggestions and remarks also apply for studies that address perceived walking difficulties and/ or the use and perceived needs of MDs.
- Future psychometric studies of the Walk-12G should consider using Rasch measurement theory (213), which has been argued to be superior to traditional approaches (5). Future studies should also assess responsiveness of the Walk-12G, which has been recommended by Bloem et. al. (96).
- In study III, postural instability was assessed in relation to an external perturbation (i.e. item 30 of the UPDRS part III). Since balance problems are complex and incorporate several aspects (21, 22), future studies should preferably also incorporate additional aspects of balance control that might be of importance for perceived walking difficulties. It might be also of interest to incorporate assessments of different types (i.e. mental and physical) of fatigue (214, 215).
- Further studies are required to investigate how MD use influence activity and participation in people with PD. Studies are needed to investigate changes of use and perceived need, including transitions of MDs at individual level over a time of period. Future studies should also concern safety or risk assessment of MDs use.
- Future qualitative studies might be required in order to dive deeper into the investigated problems and to bring depth of understanding. However, the choice of methods depends on the research question and not the other way around.

# Svensk sammanfattning/Swedish summary

Det övergripande syftet med denna avhandling var att öka kunskapen om aktivitetsundvikande på grund av upplevd fallrisk, upplevda gångsvårigheter samt användande och upplevda behov av gånghjälpmedel hos personer med Parkinsons sjukdom

Parkinsons sjukdom (PS) är en progressiv neurodegenerativ sjukdom. Gång- och balans problem är vanligt förekommande vid PS. Personer med PS har en ökad fallrisk jämfört med andra i samma ålder, och de flesta fallen sker då de går. Även så kallade nära fall incidenter är vanliga. Många forskningsstudier berör deras ökade fallrisk, men det finns inte många studier vad gäller aktivitetsundvikande på grund av upplevd fallrisk. Det saknas detaljerad information om vilka aktiviteter som undviks på grund av en upplevd fallrisk hos dem som har fallit/varit nära att falla eller har en rädsla för att falla. Det saknas även kunskap om hur aktivitetsundvikande på grund av upplevd fallrisk relaterar till sjukdomens svårighetsgrad. Delstudie I visade att aktivitetsundvikande på grund av upplevd fallrisk var signifikant relaterad till tidigare fall/nära fall, rädsla att falla, och sjukdomens svårighetsgrad. Aktivitetsundvikande på grund av en upplevd fallrisk förekom även hos dem som inte hade fallit och även vid mild PS. Detta indikerar att vi bör beakta aktivitetsundvikande tidigt i sjukdomsförloppet och även hos dem som inte har fallit. En begränsande faktor är att studien är en tvärsnittsstudie.

Det finns många publicerade studier som fokuserat på olika gångparametrar (t.ex. gånghastighet, stegbredd) vid PS, och det finns även intervjustudier kring deras upplevda gångsvårigheter. Det finns dock ett behov av att undersöka upplevda gångsvårigheter i vardagslivet även i stora enkätstudier. En lovande skattningsskala inom området är Gång12:an (The Generic Walk-12, the Walk-12G), men det har rekommenderats att Gång 12:an utvärderas ytterligare när det gäller personer med PS. Delstudie 2 visade att Gång12:an hade goda psykometriska egenskaper såsom till exempel, legitimitet för summering av item till en totalpoäng, acceptabel golv- och takeffekt samt intern konsistens (reliabilitet) och stöd för unidimensionalitet. Sammantaget styrker studiens resultat att Gång12:an kan användas då man utvärderar upplevda gångsvårigheter hos personer med PS. Delstudie III visade att

flera olika faktorer kan förklara deras upplevda gångsvårigheter. Frysningsepisoder under gång hade det starkaste förklaringsvärdet, följt av låg generell självtillit., trötthet (fatigue), sjukdomsduration, nedre extremitetsfunktion, blodtrycksfall (ortostatisk hypotension), långsamma rörelser (bradykinesi) och postural instabilitet. Många olika faktorer tycks inverka på upplevda gångsvårigheter vid PS; resultaten indikerar dock att åtgärder bör fokusera på frysningsepisoder och stärka personens generella självtillit.

Trots att deras gångproblem är påtagliga och ökar över tid så saknas det studier inom PS-fältet som studerat användande och upplevda behov av olika slags gånghjälpmedel över tid. Efter tre år (delstudie IV) hade användandet av gånghjälpmedel ökat från 22% till 40% inomhus, och från 48% till 66% i utomhus. Det upplevda behovet av gånghjälpmedel ökade från 5% till 21%. Studiens resultat indikerar vikten av regelbundna uppföljningar vad gäller användande och behov av förflyttningshjälpmedel. Förhoppningen är att avhandlingens resultaten kommer att utgöra en viktig kunskapsbas för framtida åtgärder och insatser inom hälso- och sjukvården, särskilt rehabilitering.

### **Metod**

Avhandlingsarbetet baseras på en longitudinell kohortstudie med personer med Parkinsons sjukdom. Datainsamling (baslinje  $n = 255$ , och 3-års uppföljning,  $n = 165$ ) skedde med hjälp av självadministrerade- och intervjuadministrerade frågor/frågeformulär, observationer och kliniska bedömningar. Studie I-III är tvärsnittsstudier med baslinjedata, studie IV innefattar båda baslinjedata och 3-års uppföljning. Studie I innefattar jämförelser mellan grupper. Studie II innefattar psykometriska analyser. Studie III innefattar linjär regressionsanalys, och i studie IV jämförs användningen av olika gånghjälpmedel vid baslinje och efter 3 år.

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# Study I







RESEARCH ARTICLE

Open Access



# Fall-related activity avoidance in relation to a history of falls or near falls, fear of falling and disease severity in people with Parkinson's disease

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## Abstract

**Background:** There is limited knowledge concerning fall-related activity avoidance in people with Parkinson's disease (PD); such knowledge would be of importance for the development of more efficient PD-care and rehabilitation. This study aimed to examine how fall-related activity avoidance relates to a history of self-reported falls/near falls and fear of falling (FOF) as well as to disease severity in people with PD.

**Methods:** Data were collected from 251 (61 % men) participants with PD; their median (min-max) age and PD duration were 70 (45–93) and 8 (1–43) years, respectively. A self-administered postal survey preceded a home visit which included observations, clinical tests and interview-administered questionnaires. Fall-related activity avoidance was assessed using the modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE) as well as by using a dichotomous (Yes/No) question. Further dichotomous questions concerned: the presence of FOF and the history (past 6 months) of falls or near falls, followed by stating the number of incidents. Disease severity was assessed according to the Hoehn and Yahr (HY) stages.

**Results:** In the total sample ( $n = 251$ ), 41 % of the participants reported fall-related activity avoidance; the median mSAFFE score was 22. In relation to a history of fall, the proportions of participants ( $p < 0.001$ ) that reported fall-related activity avoidance were: non-fallers (30 %), single fallers (50 %) and recurrent fallers, i.e.  $\geq 2$  falls (57 %). Among those that reported near falls (but no falls), 51 % (26 out of 51) reported fall-related activity avoidance. Of those that reported FOF, 70 % reported fall-related activity avoidance. Fall-related activity avoidance ranged from 24 % in the early PD-stage (HY I) to 74 % in the most severe stages (HY IV–V).

**Conclusions:** Results indicate that fall-related activity avoidance may be related to a history of self-reported falls/near falls, FOF and disease severity in people with PD. Importantly, fall-related activity avoidance is reported among those that do not fall and already in mild PD-stages (HY I–II). Although further studies are needed, our findings indicate that fall-related activity avoidance needs to be addressed early in order to prevent sedentary behavior and participation restrictions.

**Keywords:** Activity avoidance, Falls, Fear of falling, Hoehn and Yahr stages, mSAFFE, Near falls, Parkinson's disease

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## Background

Parkinson's disease (PD) is a chronic progressive neurodegenerative disease that results in a gradual progression of functional loss and disability due to motor symptoms (i.e. tremor, rigidity, bradykinesia and postural instability) as well as non-motor symptoms (i.e. fatigue, depression, sleep disturbance and cognitive dysfunction) [1, 2]. The severity of PD is most commonly described by using the Hoehn and Yahr (HY) stages [3], which range from stage I (unilateral involvement) to stage V (confinement to bed or wheelchair unless aided). Since PD treatment guidelines [4] often refer to disease severity, it is important to have a thorough understanding of how different problems relate to the HY stages.

People with PD have an increased risk for falling as compared to others of the same age [5]. In studies that used a 6-month recall period, the proportion of fallers ranged from 24 to 67 % [5–7]. Falls have been identified as one of the most disabling features of PD [5, 8]. Studies that involved people with PD have shown that fear of falling (FOF) predicts falls and/or near falls [6] as well as recurrent falls [9]. FOF negatively affects activities of daily living, the level of physical activity [10, 11], health-related quality of life [12] and participation in meaningful activities [13]. It is plausible that the increased risk for falls and FOF could induce fall-related activity avoidance in people with PD.

While there is an increased research attention towards falls and FOF, less is known about fall-related activity avoidance in people with PD [14–16]. The modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE) instrument targets self-rated activity avoidance due to the risk of falling in relation to 17 activities [17]. Previous PD-studies that used the mSAFFE reported that “going out when it is slippery” and “going to a place with crowds” were the two most commonly avoided activities [14–16]. Two previous PD-studies identified that fall-related activity avoidance was associated with a history of previous falls and FOF; the latter assessed by using a dichotomous question [15, 16]. However, none of these studies reported in detail which activities that were avoided among fallers and those reporting FOF. Moreover, to the best of our knowledge, no study has yet investigated how disease severity is related to fall-related activity avoidance in people with PD.

It is also common that people with PD experience near falls, which can be defined as “a fall initiated but arrested by support from a wall, railing, other person, etc.” [18]. Using this definition, the proportions of people with PD that report a history of near falls during a 6-month recall period range from 35 to 45 % [6, 15, 19, 20]. Although previous studies have investigated near falls as a risk factor for future falls [6, 21], they did not report how a history of near falls may relate to fall-related activity avoidance in people with PD.

The aim of this study was to investigate how fall-related activity avoidance relates to a history of self-reported falls/near falls and FOF as well as to disease severity in people with PD; a specific focus addressed which activities that were avoided.

## Methods

The current study used baseline data collected for the project “Home and Health in People Ageing with PD”. Further details regarding the design, inclusion and exclusion criteria, recruitment process, ethical considerations, procedure and data collection were published in a study protocol [22].

### Participants and recruitment

A sample of 653 participants (recruited from three hospitals in Region Skåne, Sweden) met the inclusion criterion of being diagnosed with PD (G20.9) for at least 1 year. Out of these, 216 individuals were excluded according to the following criteria: difficulties in understanding/speaking Swedish ( $n = 10$ ), severe cognitive difficulties ( $n = 91$ ), living outside Skåne ( $n = 58$ ) or other reasons ( $n = 57$ ) (e.g., hallucinations or a recent stroke). The exclusion of participants due to severe cognitive difficulties was done by specialist PD-nurses and screening of medical records. Even if cognitive data was available in many cases, we did not use a specific cut off score regarding global cognitive functioning (e.g., Mini-Mental State Examination or the Montreal Cognitive Assessment) for exclusion. We rather relied on the clinical estimation of the patient's capacity to give informed consent or take part in the majority of the data collection by the PD-nurse and additional information in the medical records. That is, a potential participant was excluded if not deemed to be able to give an informed consent or partake in the majority of the data collection. Among the remaining 437 individuals who were invited to participate 157 declined, 22 were unreachable, two had their PD diagnosis revised and one was excluded due to extensive missing data. For the present study, another four participants were excluded due to: did not respond to any of the self-administered questionnaires, someone else had in fact responded and severe delays in responding. Accordingly, the study sample consisted of 251 (61 % men) participants; participant's median (min-max) age was 70 (45–93) years, and the PD duration was 8 (1–43) years. Descriptive information of the total sample is provided in Table 1

### Data collection and instruments

The data collection included a self-administered postal survey followed by a subsequent home visit that involved interview-administered questions and questionnaires, observations and clinical assessments. The data collection was administered and performed by two trained project administrators (experienced reg. occupational therapists).

**Table 1** Participant characteristics (*N* = 251)

Variable	Median (q1-q3) unless otherwise stated	Missing value, n
Age (years)	70 (65–77)	-
Sex (men), n (%)	152 (61)	-
Education (elementary/higher secondary/university), n (%)	86 (34)/81 (32)/84 (34)	-
Social support (from partner/other than partner/none), n (%)	156 (62)/92 (37)/3 (1)	-
Living alone (yes), n (%)	66 (26)	-
PD duration (years)	8 (5–13)	-
PD severity (H&Y)	3 (2–3)	-
Freezing (FOGQsa item 3, dichotomized, yes), n (%) <sup>a</sup>	139 (56 %)	3
Motor symptoms (UPDRS III)	30 (22–39)	4
Cognitive function (MoCA)	26 (22–28)	6
Depressive symptoms (GDS-15)	2 (1–4)	5
Fall-related activity avoidance (mSAFFE)	22 (18–31)	11 <sup>b</sup>
Fall-related activity avoidance (yes), n (%)	102 (41)	1
Fear of falling (yes), n (%)	121 (48)	1
Falls past 6 months (yes), n (%)	110 (44)	-
Falls past 6 months in relation to H&Y stages (yes), n (%)		
I, <i>n</i> = 50	16 (32)	-
II, <i>n</i> = 72	29 (40)	-
III, <i>n</i> = 67	31 (46)	-
IV + V, <i>n</i> = 62	34 (55)	-
Near falls past 6 months (yes), n (%)	141 (57)	3
Near falls past 6 months among non-fallers (yes), n (%)	51 (37)	2

q1-q3 first-third quartile, PD Parkinson's disease, H&Y Hoehn & Yahr (1–5, higher = worse), FOGQsa self-administered version of the Freezing of Gait Questionnaire, UPDRS III Unified Parkinson's Disease Rating Scale (motor examination, 0–108, higher = worse), MoCA Montreal Cognitive Assessment (0–30, higher = better); GDS-15 = Geriatric Depression Scale (0–15, higher = worse), mSAFFE modified Survey of Activities and Fear of Falling in the Elderly (17–51, higher = more avoidance);

<sup>a</sup>Those who scored  $\geq 1$  on item 3 of FOGQsa were classified as having freezing. <sup>b</sup>Missing value for total scores of mSAFFE

### Fall-related activity avoidance and fear of falling (FOF)

The self-administered modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE) [17] addresses fall-related activity avoidance in relation to 17 activities. Each item (i.e. activity) has three response categories (scored 1–3): never, sometimes, or always avoids. The total mSAFFE score ranges from 17 to 51 (higher = worse). The mSAFFE has been shown to be reliable and valid in people with PD [15, 16]. In addition, two self-administered dichotomous (Yes/No) questions were used. One targeted fall-related activity avoidance: “Do you avoid activities due to a risk of falling?” whereas the other concerned FOF: “Are you afraid of falling?”

### Falls and near falls

An interview administered dichotomous (Yes/No) question targeted the history of falls during the past 6 months. If the participant answered yes, a subsequent question concerned whether falls had occurred more than once (Yes/No), including providing an estimate of how many times. The European consensus definition of a fall was applied; “an event in which the respondent came to rest on

the ground, floor, or lower level” [23]. In this study, a person was defined as a recurrent faller if reporting two or more incidents. A self-administered question (Yes/No) concerned experiences of near falls during the past 6 months, using the following definition: “a fall initiated but arrested by support from a wall, railing, or other person, etc.” [18].

### Disease severity

Disease severity was assessed (in “on-state”) according to HY [3], which includes five stages: HY I (unilateral involvement only usually with minimal or no functional disability); HY II (bilateral involvement without impairment of balance); HY III (unilateral or bilateral + postural instability); HY IV (severely disabled; still able to walk or stand unassisted); and HY V (confined to bed or wheelchair unless aided).

### Descriptive variables

Descriptive variables included age, sex, education, type of social support, living alone or not, PD duration, freezing of gait (FOG), motor symptoms, cognitive function,

and depressive symptoms. The presence of FOG was assessed by using item 3 (i.e., freezing) of the self-administered version [24] of the Freezing of Gait Questionnaire [25] (FOGQsa); those who scored  $\geq 1$  were classified as having FOG [15, 20, 26]. Assessments included part III (motor symptoms) of the Unified Parkinson's Disease Rating Scale (UPDRS III) [27] and the Montreal Cognitive Assessment (MoCA) [28]. Depressive symptoms were assessed with the Geriatric Depression Scale (GDS-15) [29].

### Statistical analyses

Descriptive statistics were computed for all variables. The findings are reported with medians and quartiles to describe ordinal data (deviated from normal distribution, except age) and frequencies and percentages to describe group proportions. HY stage IV ( $n = 56$ ) and stage V ( $n = 6$ ) were merged due to reasons of distribution. Non-parametric tests (the Kruskal-Wallis test and/or Mann-Whitney  $U$ -test for ordinal variables) or the Chi-Square test for dichotomous or categorical variables were used for sub-group comparisons. Initially, the Kruskal-Wallis or the Chi-Square tests were used for comparisons of more than two sub-groups. If the  $p$ -value then was statistical significant, subsequent tests (Mann-Whitney tests

or additional Chi-Square tests) were corrected for multiple comparisons, using the Bonferroni Correction.

All  $p$ -values reported are based on two-tailed comparisons where applicable; the alpha level of significance was set at 0.05;  $p$ -values were presented exactly except when below 0.001. All statistical analyses were computed by using SPSS v. 22 software for Windows (IBM Corporation, Armonk, NY, United States).

### Results

In the total sample ( $n = 251$ ), based on the dichotomous question 41 % reported fall-related activity avoidance; the median mSAFFE score was 22 (ranged from 17 to 50). The highest proportions of participants avoided "Going out when it is slippery" (74 %), "Reaching for something above your head" (50 %), and "Walk a kilometer" (49 %) (see Table 2).

### Fall-related activity avoidance in relation to a history of falls, near falls and fear of falling

Overall, the most frequently avoided activity (sometimes or always avoided according to mSAFFE items) was "Going out when it is slippery" (71–95 %). The second most frequently avoided activity was "Go to a place with crowds" for single fallers (52 %) and for those that reported near

**Table 2** Activity avoidance (including a ranking order) according to mSAFFE items ( $N = 251$ )

Item no.	Activity	Response category, n (%)				Ranking (1–17), most avoided ranked as 1
		Would never avoid	Sometimes avoid	Always avoid	Sometimes + always (merged)	
		n (%)	n (%)	n (%)	n (%)	
1	Go to the shops <sup>a</sup>	152(62)	77 (31)	18 (7)	95 (38)	11
2	Clean your house <sup>a</sup>	146 (59)	83 (34)	18 (7)	101 (41)	8
3	Prepare simple meals <sup>b</sup>	187 (76)	54 (22)	5 (2)	59 (24)	14
4	Go to the doctor or dentist <sup>b</sup>	208 (85)	32 (13)	6 (2)	38 (15)	17
5	Take a bath <sup>c</sup>	159 (65)	52 (21)	34 (14)	86 (35)	12
6	Take a shower <sup>a</sup>	194 (79)	45 (18)	8 (3)	53 (21)	15
7	Go for a walk <sup>d</sup>	147 (59)	85 (34)	16 (7)	101 (41)	9
8	<b>Go out when it is slippery<sup>a</sup></b>	<b>63 (26)</b>	<b>105 (42)</b>	<b>79 (32)</b>	<b>184 (74)</b>	<b>1</b>
9	Visit a friend or relative <sup>a</sup>	171 (69)	68 (28)	8 (3)	76 (31)	13
10	<b>Go to a place with crowds<sup>d</sup></b>	<b>133 (54)</b>	<b>85 (34)</b>	<b>30 (12)</b>	<b>115 (46)</b>	<b>4</b>
11	Go up and down stairs <sup>d</sup>	145 (58)	78 (32)	25 (10)	103 (42)	7
12	Walk around indoors <sup>a</sup>	199 (81)	44 (18)	4 (1)	48 (19)	16
13	<b>Walk a kilometer<sup>b</sup></b>	<b>126 (51)</b>	<b>67 (27)</b>	<b>53 (22)</b>	<b>120 (49)</b>	<b>3</b>
14	<b>Bend down to get something<sup>d</sup></b>	<b>141 (57)</b>	<b>92 (37)</b>	<b>15 (6)</b>	<b>107 (43)</b>	<b>5</b>
15	Travel by public transport <sup>d</sup>	145 (58)	64 (26)	39 (16)	103 (42)	6
16	Go out to a social event <sup>d</sup>	149 (60)	88 (36)	11 (4)	99 (40)	10
17	<b>Reach for something above your head<sup>d</sup></b>	<b>124 (50)</b>	<b>92 (37)</b>	<b>32 (13)</b>	<b>124 (50)</b>	<b>2</b>

mSAFFE modified Survey of Activities and Fear of Falling in the Elderly, each item (i.e. activity) has three response categories: never, sometimes or always avoid;

Top five avoided activities are marked in bold

<sup>a</sup> $n = 4$  missing values, <sup>b</sup> $n = 5$  missing, <sup>c</sup> $n = 6$  missing and <sup>d</sup> $n = 3$  missing

falls but no falls (61 %). For recurrent fallers and those reporting FOF, the second most frequently avoided activity was "Reach for something above your head" (71 and 75 %, respectively). For further details, see Table 3.

The extent of fall-related activity avoidance differed significantly ( $p < 0.001$ ) among those reporting no falls, a single fall or recurrent falls (see Table 4); the median mSAFFE score was 20, 25 and 28, respectively. Subsequent Mann-Whitney U-tests (Bonferroni correction criterion  $p < 0.016$ ) showed that fall-related activity avoidance was significantly higher in recurrent fallers as compared to the other two sub-groups. There was no statistical significant ( $p = 0.295$ ) difference between those that reported no falls and those that reported a single fall. Moreover, the proportions of participants that reported fall-related activity avoidance differed significantly ( $p < 0.001$ ) among those that reported no falls (30 %), a single fall (50 %) or recurrent falls (57 %). After Bonferroni correction ( $p < 0.016$ ), the proportions between those that reported no falls versus recurrent falls were significantly ( $p < 0.001$ ) different (see Table 4).

Those that reported a history of near falls (but no falls) reported significantly ( $p < 0.001$ ) more fall-related activity avoidance than those without such incidents; the median (q1-q3) mSAFFE score was 25 (19–33) versus 19

(17–22). The corresponding proportions of participants that reported fall-related activity avoidance were 51 versus 17 % ( $p < 0.001$ ), (see Table 4).

Those with FOF reported significantly ( $p < 0.001$ ) more fall-related activity avoidance than those without (median mSAFFE score was 30 versus 19); the proportions of participants that reported fall-related activity avoidance were 70 versus 13 % ( $p < 0.001$ ) (see Table 4).

#### Fall-related activity avoidance in relation to disease severity

The extent of fall-related activity avoidance differed significantly ( $p < 0.001$ ) in relation to disease severity (see Table 4); the median (q1-q3) mSAFFE score ranged from 19 (17–25) in HY I to 32 (26–39) in HY stages IV-V. Subsequent Mann-Whitney U-tests (Bonferroni correction criterion of  $p < 0.0083$ ) showed significant differences for all comparisons except between HY stages I and II. The proportion of participants that reported fall-related activity avoidance was significantly ( $p < 0.001$ ) higher in the more severe disease stages; it mounted to 74 % in the most severe group. The subsequent comparisons were statistically significant (Bonferroni criterion of  $p < 0.0083$ ), except between stages HY I and II and III.

**Table 3** Activity avoidance (mSAFFE items) in relation to a history falls/near falls, and fear of falling ( $N = 251$ )

Item no.	Activity <sup>c</sup> (sometimes + always avoided)	Falls past 6 months					Near falls <sup>a</sup> (but no falls) past 6 months			Fear of falling <sup>b</sup>		
		No	Single	Rk	Recurrent	Rk	No	Yes	Rk	No	Yes	Rk
		<i>n</i> = 141	<i>n</i> = 38		<i>n</i> = 72		<i>n</i> = 88	<i>n</i> = 51		<i>n</i> = 129	<i>n</i> = 121	
1	Go to the shops, n (%)	36 (26)	15 (40)	10	44 (61)	<b>5</b>	14 (17)	22 (43)	11	18 (14)	77 (65)	6
2	Clean your house, n (%)	42 (31)	15 (40)	9	44 (61)	6	17 (20)	25 (49)	8	28 (22)	73 (62)	11
3	Prepare simple meals, n (%)	19 (14)	9 (24)	14	31 (44)	14	7 (8)	12 (24)	15	12 (9)	47 (40)	14
4	Go to the doctor or dentist, n (%)	17 (12)	5 (13)	17	16 (23)	17	6 (7)	11 (22)	16	7 (5)	31 (27)	17
5	Take a bath, n (%)	39 (29)	13 (34)	12	34 (48)	12	16 (19)	23 (46)	10	23 (18)	63 (54)	12
6	Take a shower, n (%)	27 (20)	5 (13)	16	21 (29)	16	10 (12)	17 (33)	14	10 (8)	43 (36)	15
7	Go for a walk, n (%)	44 (32)	16 (42)	7	41 (57)	9	17 (20)	27 (53)	6	27 (21)	74 (62)	9
8	Go out when it is slippery, n (%)	96 (70)	27 (71)	<b>1</b>	61 (86)	<b>1</b>	51 (59)	45 (88)	<b>1</b>	72 (56)	112 (95)	<b>1</b>
9	Visit a friend or relative, n (%)	32 (23)	12 (32)	13	32 (44)	13	13 (15)	19 (38)	13	17 (13)	59 (50)	13
10	Go to a place with crowds, n (%)	52 (38)	20 (52)	<b>2</b>	43 (60)	7	21 (24)	31 (61)	<b>2</b>	33 (26)	82 (69)	<b>4</b>
11	Go up and down stairs, n (%)	50 (36)	15 (39)	11	38 (53)	10	25 (29)	25 (49)	7	26 (20)	77 (65)	7
12	Walk around indoors, n (%)	17 (12)	9 (24)	15	22 (31)	15	8 (9)	9 (18)	17	12 (9)	36 (31)	16
13	Walk a kilometer, n (%)	56 (41)	19 (50)	<b>4</b>	45 (63)	<b>4</b>	26 (30)	30 (59)	<b>3</b>	35 (27)	85 (72)	<b>3</b>
14	Bend down to get something, n (%)	48 (35)	16 (42)	8	43 (60)	8	24 (28)	24 (47)	9	31 (24)	76 (64)	8
15	Travel by public transport, n (%)	37 (27)	20 (52)	<b>3</b>	46 (64)	<b>3</b>	16 (18)	21 (41)	12	24 (19)	79 (66)	<b>5</b>
16	Go out to a social event, n (%)	45 (33)	19 (50)	<b>5</b>	35 (49)	11	18 (21)	27 (53)	<b>5</b>	25 (19)	74 (62)	10
17	Reach for something above your head, n (%)	56 (41)	17 (45)	6	51 (71)	<b>2</b>	27 (31)	29 (57)	<b>4</b>	35 (27)	89 (75)	<b>2</b>

mSAFFE modified Survey of Activities and Fear of Falling in the Elderly, each item (i.e. activity) has three response categories: never, sometimes or always avoid; the response categories sometimes and always are merged; Rk = Ranking order (1–17; 1 denotes the most avoided activity). Top five avoided activities are marked in bold

<sup>a</sup>*n* = 2 missing values, <sup>b</sup>*n* = 1 missing and <sup>c</sup>*n* = 3–6 missing (For further details regarding missing data see footnote in Table 2)

**Table 4** Fall-related activity avoidance in relation to a history falls/near falls<sup>a</sup>, fear of falling<sup>b</sup> and disease severity (N = 251)

Variable	Fall-related activity avoidance		Dichotomous question (yes)	
	mSAFFE <sup>c</sup> median (q1-q3)	p-value	n (%)	p-value
History of fall		<0.001*		<0.001*
No fall, n = 141	20 (18–28) <sup>d</sup>		42 (30) <sup>b</sup>	
Single fall, n = 38	25 (17–31)		19 (50)	
Recurrent falls (>1), n = 72	28 (22–35) <sup>e</sup>		41 (57)	
History of near fall		<0.001		<0.001
No near falls or falls, n = 88	19 (17–22) <sup>f</sup>		15 (17)	
Near falls, but no falls, n = 51	25 (19–33) <sup>a</sup>		26 (51)	
Fear of falling		<0.001		<0.001
No, n = 129	19 (17–22) <sup>f</sup>		17 (13)	
Yes, n = 121	30 (23–35) <sup>d</sup>		85 (70)	
Disease severity, HY stages		<0.001**		<0.001**
I, n = 50	19 (17–25)		12 (24)	
II, n = 72	19 (17–24) <sup>b</sup>		14 (19)	
III, n = 67	23 (19–31) <sup>f</sup>		31 (46)	
IV+ V, n = 62	32 (26–39) <sup>d</sup>		45 (74) <sup>b</sup>	

q1-q3 first-third quartile, mSAFFE modified Survey of Activities and Fear of Falling in the Elderly (17–51, higher = more avoidance), HY Hoehn and Yahr (1–5, higher = worse)

\*All subsequent unpaired comparisons showed a statistical significant difference (Bonferroni correction criterion of  $P < 0.016$ ) except between no fall-single fall for mSAFFE, and except between no fall-single fall and single fall-recurrent fall for dichotomous question

\*\*All subsequent unpaired comparisons showed a statistical significant difference (Bonferroni correction criterion of  $P < 0.0083$ ) except between HY I-II for mSAFFE, and except between HY I-II and I-III for the dichotomous question

<sup>a</sup>n = 2 missing values, <sup>b</sup>n = 1 missing, <sup>c</sup>n = 11 missing, <sup>d</sup>n = 7 missing, <sup>e</sup>n = 4 missing and <sup>f</sup>n = 3 missing

## Discussion

Our study suggests that people with PD with a history of self-reported falls or near falls and FOF report significantly more fall-related activity avoidance than those without. Moreover, those that do not fall also report fall-related activity avoidance. People with PD seem to avoid activities that they presumably consider as being risky (e.g., going out when it is slippery), which can be a sound strategy. However, it is also common to avoid activities such as walking 1 km or activities that involve situations with large numbers of people (e.g., crowds and public transport), indicating that people with PD may be at risk for restricted participation in society. Although fall-related activity avoidance seems to increase with an increased severity of PD, it is noteworthy that it is reported in HY stages I and II. Accordingly, this suggests that fall-related activity avoidance needs to be addressed early in order to prevent sedentary behavior and participation restrictions.

As to the level of detail regarding activity avoidance as assessed by mSAFFE, our findings extend those reported by Rahman et al. [14]. That is, the present results add more detailed knowledge regarding whether the participants sometimes or always avoid the activities and identify which activities that are avoided if reporting falls, near falls (but no fall) and FOF. To the best of our knowledge, this

is the first PD-study that reports such details of fall-related activity as well as how it relates to PD severity. In addition, as compared to previous PD-studies that used the mSAFFE (n ranged from 20 to 130) [14–16, 30], our study included the largest sample size.

In agreement with previous PD-studies [14–16], the most frequently avoided activity due to the risk of falling was “Going out when it is slippery”. In our total sample the second most frequently avoided activity was “Reaching for something above your head” whereas “Go to a place with crowds” was noted in other PD studies [14–16]. In our total sample “Go to a place with crowds” was ranked fourth, while it was ranked as the second most commonly avoided activity among single fallers, as well as among those that reported near falls but no fall. Such discrepancies among studies might be explained by methodological differences regarding inclusion- and exclusion criteria, recruitment procedures, sample characteristics and analysis approaches.

It needs to be noted that the ranking order between some items mirror only small differences and should therefore not be given unmotivated attention. For example, after merging two response categories (sometimes, always avoided), in the total sample there is only 1 % difference between the activity ranked as 2 (“Reach for something above your head”) and the activity ranked as 3 (“Walk a

kilometer"). The important message here is that more than one fifth of our participants reported that they always avoid walking a kilometer due to the risk of falling, highlighting the importance of addressing fall-related activity avoidance in order to promote physical activity.

In the present study, fallers reported more fall-related activity avoidance than non-fallers. This corroborates the findings of previous studies using samples that targeted people with PD [14, 16] as well as older community-living people in general [31]. Fall-related activity avoidance was related to FOF which is in accordance with a previous PD-study that used a dichotomous FOF-question [16]. Importantly, a novel and interesting finding is that fall-related activity avoidance is more prevalent and pronounced among those that report near falls (but no falls) as compared to those without any near falls or fall incidents. In fact, our results show that participants without a history of falls report fall-related activity avoidance. This suggests that researchers and clinicians should pose questions not only about falls, but also about near falls, as well as address whether people with PD report fall-related activity avoidance, irrespective of whether they report fall incidences. Moreover, our findings indicate that fall-related activity avoidance is related to PD severity. An important and novel finding is that people with PD report fall-related activity avoidance already in HY stages I and II, which suggests that fall-related activity avoidance needs to be addressed early.

Based on the cross-sectional study design used in this study we were not able to determine any causal directions of the relationships investigated. With the ambition to follow up our sample longitudinally [22], we will later on be in a position allowing for further studies with the potential to explore these intriguing dynamics. We acknowledge that other variables than those investigated in the present study may also be of interest. For example, Rahman et al. considered four potential explanatory factors and found that anxiety independently contributed to fall-related activity avoidance [14]. Future longitudinal studies that use a multivariate analysis should preferably consider a broad variety of factors (e.g. motor and non-motor symptoms, environmental aspects and personal factors) that may contribute to fall-related activity avoidance in people with PD. Turning to another study limitation related to the questions used in this type of studies, self-reported data are subject to recall bias and might be influenced by either an over- or under-estimation by the individual [32].

## Conclusions

Fall-related activity avoidance seems to be related to a history of self-reported falls/near falls, FOF and disease severity in people with PD. Importantly, fall-related activity avoidance is reported also among those that do not fall and already in the early phases of PD. Our findings

suggest that fall-related activity avoidance should be addressed early and irrespective of whether people with PD report falls in order to prevent sedentary behavior and participation restrictions. Further studies are needed that use multivariate analysis and have a longitudinal design.

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## Availability of data and materials

All relevant data are within the manuscript. Raw data cannot be shared due to the fact that longitudinal data collections are ongoing; no additional supporting files are available. The data is stored at the Department of Health Sciences, Lund University, Lund, Sweden.

## Authors' contributions

MK, SI, PO and MHN conceived and designed the study, which is a part of the larger project "Home and Health in People Ageing with Parkinson's Disease" designed by MHN (principal investigator) and SI. MHN and SI planned and monitored the data collection, data entry and quality control processes. MK and MHN analyzed the data and drafted the initial manuscript, which was subsequently reviewed by all authors. MHN and SI repeatedly revised the article critically for important intellectual content. All authors read and approved the final manuscript.

## Competing interests

PO declares the following competing interest: PO has given lectures and expert advice against honoraria for the following companies: AbbVie, Britannia, Lundbeck, Nordic Infucare, Orion Pharma and TEVA. All other authors declare no competing interests.

## Ethics and consent to participate

The study was approved by the Regional Ethical Review Board in Lund, Sweden (No. 2012/558), and all participants provided written informed consent.

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## Study II





## **Assessing perceived walking difficulties in Parkinson's disease: Psychometric properties of the Walk-12G**

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## Study III





## Research Report

# Factors Contributing to Perceived Walking Difficulties in People with Parkinson's Disease

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### Abstract.

**Background:** While walking difficulties are common in people with Parkinson's disease (PD), little is known about factors that independently contribute to their perceived walking difficulties.

**Objective:** To identify factors that independently contribute to perceived walking difficulties in people with PD.

**Methods:** This study involved 243 (62% men) participants; their mean (min-max) age and PD duration were 70 (45–93) and 8 (1–43) years, respectively. A postal survey preceded a home visit that included observations, clinical tests, questions and questionnaires that were administered as a structured interview. Perceived walking difficulties (dependent variable) were assessed with the self-administered generic Walk-12 (Walk-12G, scored 0–42, higher = worse). Independent variables included personal (e.g., age and general self-efficacy) and social environmental factors (e.g., social support and living situation) as well as disease-related factors including motor (e.g., freezing of gait (FOG) and postural instability) and non-motor symptoms (e.g., fatigue and orthostatic hypotension). Linear multiple regression analysis was used to identify factors that independently contributed to perceived walking difficulties.

**Results:** Eight significant independent variables explained 56.3% of the variance in perceived walking difficulties. FOG was the strongest significant contributing factor to perceived walking difficulties, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability.

**Conclusion:** Motor and non-motor symptoms as well as personal factors (i.e., general self-efficacy) seem to be of importance for perceived walking difficulties in PD. These findings might nurture future interventions that address modifiable factors in order to enhance walking ability in people with PD.

**Keywords:** Difficulty walking, fatigue, Parkinson Disease, patient outcome assessment, regression analysis, self-efficacy

## BACKGROUND

Walking difficulties are among the earliest signs of disability in people with Parkinson's disease (PD) [1]

and include, for example, reduced gait speed, step length and arm swing as well as gait asymmetry [2, 3]. Freezing of gait (FOG) is also common and is experienced as “if the feet were glued to the floor” [4]. FOG most frequently occurs in the home environment and is provoked by certain activities (e.g., turning around while walking) and environmental factors such as

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being in a confined space [5]. Several PD studies have identified contributing factors to objectively measured walking difficulties (e.g., assessed by using an electronic walkway system) [6–9]. To the best of our knowledge, no prior study has considered a broad diversity of factors (e.g., personal, social environmental, and disease related factors) to identify those that are independently associated with perceived walking difficulties among people with PD.

In studies that used objective gait measures, FOG has been shown to contribute to impaired step length and increased variability of step duration in persons with PD [6, 10]. Moreover, reduced gait speed has been associated with fear of falling [11], postural instability [7], disease severity [11, 12], bradykinesia [8], cognitive impairments, physical fatigue [9, 13], depressive symptoms [11, 13], and muscle weakness in people with PD [14]. In addition to reduced gait speed, shorter strides as well as an increased stride variability have been associated with postural instability [7]. Reduced arm swing while walking has been associated with bradykinesia [15]. Using objective measures of walking difficulties may not capture perception of walking difficulties in the complexity of daily life circumstances. Especially so if the collection of data using objective measures was conducted during a short time period and/or in a standardized setting that mimics capacity more than actual performance in authentic daily life settings.

Several qualitative PD studies have described factors that are perceived as negatively associated with walking difficulties such as FOG [19–23], fatigue [19, 22], anxiety [22], FOF [19], pain, orthostatic hypotension [24], ineffective dose of medication [22] and environmental hazards (e.g., crowds, inclement weather, and uneven/slippery surfaces) [19, 22, 24]. On the other hand, informational support (e.g., advice/knowledge provided by other people) may influence that people with PD participate in physical activity, and social as well as emotional support can facilitate that they engage in taking a walk [25]. It would be of interest to investigate whether some of these qualitative findings could be verified in a larger quantitative study. When following large cohorts, qualitative data collections and analyses are not feasible, but survey data that includes a patient-reported outcome measure would make it possible to identify factors that explain perceived walking difficulties in daily life. A better understanding of the factors associated with perceived walking difficulties may facilitate to develop individually targeted rehabilita-

tion and may result in more efficient physical activity prescriptions for people with PD. Accordingly, this study aimed to identify factors that independently contribute to perceived walking difficulties in people with PD.

## MATERIALS AND METHOD

This study was based on a cross sectional study design. It was based on baseline data collected for the project “Home and Health in People Ageing with PD”, which aimed to generate knowledge on home and health dynamics in people with PD, with an explicit attention to PD-specific symptomatology. The project design, inclusion and exclusion criteria, recruitment process, ethical considerations, procedure and data collection have been described in detail in the study protocol [26].

The data collection included a self-administered postal survey and a subsequent home visit that involved interview-administered questions and questionnaires, observations and clinical assessments. The home visits were scheduled during the time of day when the participant in question stated that he/she usually feels best (“on” state). Two trained project assistants (experienced reg. occupational therapists) conducted the data collection.

The project was conducted in accordance with the Helsinki Declaration and was approved by the Regional Ethical Review Board in Lund, Sweden (No. 2012/558). All participants provided their written informed consent.

### *Participants and recruitment*

Participants were recruited from three hospitals (outpatient registers) in Region Skåne in southern Sweden; 653 participants met the inclusion criterion of being diagnosed with PD (G20.9) for at least one year. Out of these, 216 individuals were not eligible due to the exclusion criteria: difficulties in understanding/speaking Swedish ( $n = 10$ ), severe cognitive difficulties ( $n = 91$ ), living outside Skåne ( $n = 58$ ) or other reasons ( $n = 57$ ) (e.g., severe hallucinations, recent stroke). That is, a potential participant was excluded if not deemed to be able to give an informed consent or partake in the majority of the data collection. The remaining 437 persons were invited to participate. However, 22 were impossible to reach and two had their PD diagnosis revised. That is, 413 participants that had a PD diagnosis were contacted whereof 157 (38%) declined to participate.

One participant was excluded due to extensive missing data. In the present study, four additional participants were excluded since they did not respond to any of the self-administered questionnaires, stated that someone else had responded or had severe delays in responding. Yet another eight were excluded since they had no total score (i.e., had not responded to all items) of the generic Walk-12 (Walk-12G), i.e. the used PROM and the dependent variable in the present study. Accordingly, the final sample consisted of 243 (62% men) participants. Their mean (min-max) age was 70 (45–93) years, and the PD duration was 8 (1–43) years. When comparing the final sample to those who that declined to participate ( $n = 157$ ), there was a statistically significant difference in age ( $p = 0.016$ , Independent  $T$ -Test), but not in relation to sex ( $p = 0.066$ , Chi-squared test) or PD-duration ( $p = 0.487$ , Independent  $T$ -Test), see Table 1 for details. Figure 1 illustrates the recruitment process of the participants.

#### Data collection

#### Variables and Instruments

In addition to the instrument descriptions below, details regarding the self-administered question-

naires, interview questions, observations and clinical assessments are presented as footnotes in Table 1 and in the study protocol [26].

#### Perceived walking difficulties

Perceived walking difficulties was assessed by using the Walk-12G [27]. This instrument includes 12 items that concern perceived walking difficulties during the past two weeks in relation to, for example, the need for support when walking (indoors and outdoors), stair climbing, maintaining balance, distance, slowness, effort, and the need for concentration. Items 1–3 have three response categories (scored 0–2) whereas items 4–12 have five (scored 0–4). The possible total score ranges from 0 to 42 (higher = worse). The Walk-12G has been shown to be reliable and valid in people with PD [27].

#### Independent variables

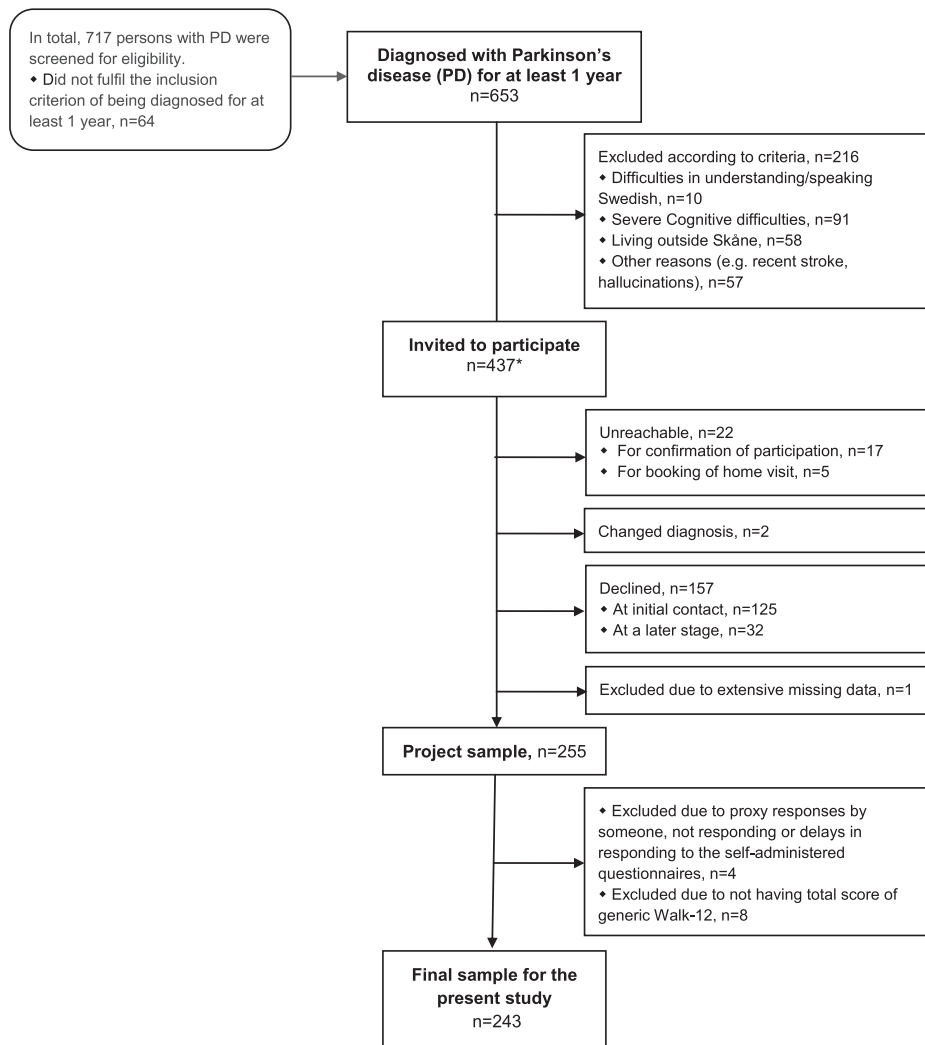
The independent variables represented personal, social environmental and disease-related factors. They were selected based on findings from prior research [6–8, 11–22, 24, 25] and/or their clinical relevance for rehabilitation.

Table 1  
Participant characteristics,  $n = 243$

Variables	Mean (SD) unless otherwise stated	Missing value, $n$
<i>Dependent variable</i>		
Walking difficulties (Walk-12G) <sup>a</sup>	15.8 (11.0)	
<i>Personal and social environmental factors</i>		
Sex (men), $n$ (%)	150 (61.7%)	–
Age (years)	70 (9.2)	–
General self-efficacy (GSE) <sup>b</sup>	28.6 (6.8)	8
Social support (from partner/other than partner/none), $n$ (%)	152 (62.6%) / 88 (36.2%) / 3 (1.2%)	–
Living alone (yes), $n$ (%)	62 (25.5%)	–
<i>PD-related factors</i>		
PD duration (years), median (q1–q3)	8 (5–13)	–
PD severity (H&Y) <sup>c</sup> , median (q1–q3)	3 (2 – 3)	–
Postural instability (UPDRS III item 30, scores $\geq 1$ = yes), $n$ (%) <sup>d</sup>	181 (75.1%)	2
Bradykinesia (UPDRS III item 31, scores $\geq 1$ = yes), $n$ (%) <sup>e</sup>	152 (62.6%)	–
Freezing of gait (FOGQsa item 3, scores $\geq 1$ = yes), $n$ (%) <sup>f</sup>	138 (56.8%)	–
Lower extremity function (Chair-Stand Test, sec), median (q1–q3)	16 (13–20)	31 <sup>i</sup>
Depressive symptoms (GDS-15) <sup>g</sup> , median (q1–q3)	2 (1–4)	5
Anxiety (NMSQuest item 17, yes), $n$ (%)	65 (27.0%)	–
Orthostatic hypotension (NMSQuest item 20, yes), $n$ (%)	131 (53.9%)	–
Fatigue (NHP-EN, dichotomized, yes), $n$ (%)	137 (56.4%)	–
Cognitive function (MoCA) <sup>h</sup> , median (q1–q3)	26 (22–28)	5
Pain (yes), $n$ (%)	163 (67.1%)	–

SD, standard deviation; q1–q3, first-third quartile; Walk-12G = Generic Walk-12; GSE = General Self-Efficacy Scale; PD = Parkinson's disease; H&Y = Hoehn & Yahr; UPDRS = Unified Parkinson's Disease Rating Scale (part III = motor examination); FOGQsa = self-administered version of the Freezing of Gait Questionnaire; GDS-15 = the 15-item Geriatric Depression Scale; NMSQuest = Nonmotor Symptoms Questionnaire; NHP-EN = Energy subscale of the Nottingham Health Profile; MoCA = Montreal Cognitive Assessment. Possible scoring range, scoring direction: <sup>a</sup>0–42, higher = worse; <sup>b</sup>10–40, higher = better; <sup>c</sup>1–5, higher = worse; <sup>d–f</sup>0–4, higher = worse; <sup>g</sup>0–15, higher = worse; <sup>h</sup>0–30, higher = better. <sup>i</sup>Missing data due to they were unable to perform or complete the timed Chair Stand Test. Those who declined to participate ( $n = 157$ ) had a mean (SD) age of 72 (9.8) years, PD duration ( $n = 129$ ) of 9.2 (6.4) years, and were 52 % men.





\*Total number of invited participants were recruited from three hospitals: N= 35, N= 128, and N= 274

Fig. 1. Flow diagram: the recruitment process of participants.

#### *Personal and social environmental factors*

Data on personal factors included age (years), sex (man/woman) and general self-efficacy. The General Self-Efficacy Scale (GSE) was used, which is scored 10–40 (higher = better/stronger general self-efficacy) [28]. Data on social environmental factors were collected with structured questions on social support and

living situation. Social support was addressed by the question: “Is there someone around, who could assist you in case you would need some help and support?” If responding yes, the relationship to the assisting person/s was specified. The three response categories were recoded as social support from partner, other than partner or none. A dichotomous ques-

tion targeted the living situation (living alone/not alone).

#### *Disease related factors- severity, motor and non-motor symptoms*

Disease severity was assessed according to Hoehn and Yahr (HY) [29], which ranges from stage I (unilateral involvement) to stage V (confinement to bed or wheelchair unless aided). The postural response in relation to an external perturbation (postural instability, item 30) as well as bradykinesia (item 31) were assessed according to the motor examination (part III) of the Unified PD Rating Scale (UPDRS) [30]. These two items (scored 1–4, higher = worse) were dichotomized; those with scores  $\geq 1$  on item 30 were categorized as having postural instability whereas those with scores  $\geq 1$  on item 31 were categorized as having bradykinesia. FOG was assessed according to item 3 (scored 0–4, higher = worse) of the self-administered version [31] of the FOG questionnaire [32], i.e. FOGQsa. Those scoring  $\geq 1$  were categorized as “freezers” [33]. Lower extremity function was assessed with the timed Chair-Stand Test [34, 35]; the time (seconds) for completing five repetitions as fast as possible was registered.

Non-motor symptoms included depressive symptoms, anxiety, symptoms of orthostatic hypotension, fatigue, cognitive function and pain. Depressive symptoms were assessed with the 15-item Geriatric Depression Scale (GDS-15, interview-administered), scored 0–15 (higher = worse) [36]. Anxiety and orthostatic hypotension were assessed with two dichotomous (No/Yes) items (nos. 17 and 20) of the self-administered Nonmotor Symptoms Questionnaire (NMSQuest) [37]. Fatigue was assessed with the self-administered Energy subscale of the Nottingham Health Profile (NHP-EN) [38]; those who affirmed at least one out of three dichotomous (Yes/No) questions (tired all the time, everything is an effort, soon out of energy) were classified as having fatigue [39]. Cognitive functioning was assessed by using the Montreal Cognitive Assessment (MoCA), scored 0–30 (higher = better) [40]. Pain was assessed by the dichotomous (No/Yes) question “Are you bothered by pain?”

#### *Statistical analyses*

Categorical variables are described by number of participants (percentage), while ordinal and continuous variables are expressed by medians (first and third quartiles, q1-q3), or means (SD). Pearson ( $r$ )

or Spearman ( $r_s$ ) correlations were used to assess relationships among independent variables (i.e., personal, social environmental, PD-related factors) in order to identify any multi-collinearity. Because the results from both correlation matrices were almost the same, we have used Pearson ( $r$ ) correlations throughout. There was a sign of multi-collinearity ( $r > 0.7$ ) between ‘Postural response (item 30, UPDRS)’ and ‘Disease severity’ as well as between ‘Social support’ and ‘Living alone’. Disease severity (HY) was omitted since it is not a modifiable factor, whereas social support was omitted due to a skewed distribution of data (only two participants did not receive any social support).

Univariable linear regression analyses were used to investigate the unadjusted relationship of each independent variable and the dependent variable (Walk-12G scores). In order to avoid leaving out a confounding variable, we decided to include all variables with a  $p$ -value  $< 0.3$  in the multivariable analysis. Probability values ( $P$ ) for all independent variables were inspected and the variable with the highest  $p$ -value was manually removed. This procedure continued until all independent variables in the final model had  $p$ -values  $< 0.1$ , which became the final model. The strength of the relationship between each independent variable and the dependent variable was assessed by the standardized regression coefficient ( $\beta$ ).

In a second multivariable model, the timed Chair Stand Test was excluded. This since 31 participants were unable to perform or complete the test. That is, the second model was computed due to the concern that the results might not be possible to generalize to people with poor lower extremity function.

The significance level applied was  $< 0.05$ . All statistical analyses were performed using SPSS Windows 23.0 (IBM SPSS Inc., Chicago, IL, USA, Released 2015).

## RESULTS

The mean (SD) Walk-12G score was 15.8 (11.0). The results from the univariable analyses are presented in Table 2. A total of 15 variables of interest were included in univariable analyses and all these variables turned out as significant ( $p < 0.05$ ). Of all 15 variables, FOG explained the largest amount of variability ( $\beta = 0.505$ ,  $p < 0.001$ ) of perceived walking difficulties, whereas sex (women) explained the least ( $\beta = 0.157$ ,  $p = 0.014$ ). All these 15 variables

were entered into the multivariable linear regression model.

The multivariable linear regression analysis resulted in eight statistically significant independent variables that explained 56.3% of the variance in perceived walking difficulties (Table 3). The strongest independent variable was FOG ( $\beta = 0.265$ ,  $p < 0.001$ ). It was followed by general self-efficacy ( $\beta = -0.242$ ,  $p < 0.001$ ), fatigue ( $\beta = 0.204$ ,  $p < 0.001$ ), PD duration, ( $\beta = 0.178$ ,  $p < 0.001$ ), lower extremity function ( $\beta = 0.130$ ,  $p = 0.013$ ), ortho-

static hypotension ( $\beta = 0.126$ ,  $p = 0.014$ ), bradykinesia ( $\beta = 0.120$ ,  $p < 0.017$ ), and postural instability ( $\beta = 0.112$ ,  $p = 0.024$ ) (Table 3).

After excluding the chair-stand test and rerunning the analysis, seven statistically significant independent variables explained 53.4% of the variance in perceived walking difficulties. The strongest independent variable was FOG ( $\beta = 0.275$ ,  $p < 0.001$ ). It was followed by fatigue ( $\beta = 0.236$ ,  $p < 0.001$ ), general self-efficacy ( $\beta = -0.225$ ,  $p < 0.001$ ), PD duration, ( $\beta = 0.173$ ,  $p < 0.001$ ), bradykinesia ( $\beta = 0.164$ ,

Table 2

Simple linear regression analyses with Generic Walk-12 scores as the dependent variable in people with Parkinson's disease,  $n = 243$

Independent variables	Unstandardized Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value
Sex (women)	3.56 (0.72, 6.39)	0.157	0.014
Age (year)	0.38 (0.24, 0.53)	0.321	<0.001
Living alone (dichotomized, yes)	4.50 (1.35, 7.64)	0.178	0.005
General self-efficacy (GSE) <sup>1</sup>	-0.72 (-0.90, -0.54)	-0.455	<0.001
PD duration (years)	0.63 (0.43-0.83)	0.367	<0.001
Postural instability (UPDRS III item 30, scores $\geq 1$ = yes)	8.06 (4.98-11.13)	0.316	<0.001
Bradykinesia (UPDRS III item 31, scores $\geq 1$ = yes)	7.44 (4.71, 10.16)	0.327	<0.001
Freezing of gait (FOGQsa item 3, scores $\geq 1$ = yes)	11.22 (8.79-13.65)	0.505	<0.001
Lower extremity function (Chair-Stand Test, seconds)	0.44 (0.29-58)	0.370	<0.001
Depressive symptoms (GDS-15) <sup>2</sup>	1.63 (1.19, 2.07)	0.428	<0.001
Anxiety (NMSQuest item 17, yes)	6.66 (3.64, 9.69)	0.270	<0.001
Orthostatic hypotension (NMSQuest item 20, yes)	7.64 (5.01, 10.26)	0.346	<0.001
Fatigue (NHP-EN, dichotomized, yes)	10.99 (8.55, 13.43)	0.496	<0.001
Cognitive function (MoCA) <sup>1</sup>	-0.87 (-1.18, -0.55)	-0.330	<0.001
Pain (yes)	6.16 (3.29, 9.01)	0.263	<0.001

GSE = General Self-Efficacy Scale; PD = Parkinson's disease; UPDRS = Unified Parkinson's Disease Rating Scale (part III = motor examination), FOGQsa = self-administered version of the Freezing of Gait Questionnaire; GDS-15 = the 15-item Geriatric Depression Scale; NMSQuest = Nonmotor Symptoms Questionnaire; NHP-EN = Energy subscale of the Nottingham Health Profile; MoCA = Montreal Cognitive Assessment. <sup>1</sup>Higher scores = better, <sup>2</sup>Higher scores = worse. Missing data is described in Table 1.

Table 3

Multiple linear regression analysis with Generic Walk-12 scores as the dependent variable in people with Parkinson's disease,  $n = 212^a$

Independent variables <sup>1</sup>	Unstandardized Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value	R square <sup>b</sup> %	Adjusted R square <sup>b</sup>
Freezing of gait (FOGQsa item 3, scores $\geq 1$ = yes)	5.39 (3.31-7.47)	0.265	<0.001	56.3	54.5
General self-efficacy (GSE, higher scores = "better")	-0.35 (-0.50, -0.20)	-0.242	<0.001	25.1	24.7
Fatigue (NHP-EN, dichotomized, yes)	4.14 (2.05, 6.24)	0.204	<0.001	14.0	13.8
PD duration (years)	0.30 (0.14-0.47)	0.178	<0.001	6.6	6.4
Lower extremity function (Chair-Stand Test, sec)	0.15 (0.03, 0.27)	0.130	0.013	3.7	3.5
Orthostatic hypotension (NMSQuest item 20, yes)	2.56 (0.51, 4.61)	0.126	0.014	3.2	3.0
Bradykinesia (UPDRS III item 31, scores $\geq 1$ = yes)	2.46 (0.45, 4.48)	0.120	0.017	1.2	1.0
Postural instability (UPDRS III item 30, scores $\geq 1$ = yes)	2.59 (0.34-4.84)	0.112	0.024	1.3	1.1

FOGQsa = self-administered version of the Freezing of Gait Questionnaire; GSE = General Self-Efficacy Scale; NHP-EN = Energy subscale of the Nottingham Health Profile; PD = Parkinson's disease; NMSQuest = Nonmotor Symptoms Questionnaire; UPDRS = Unified Parkinson's Disease Rating Scale (part III = motor examination); <sup>1</sup>The following 15 independent variables were included: Sex, age, living alone, general self-efficacy, PD duration, postural instability, bradykinesia, freezing of gait, lower extremity function, depressive symptoms, anxiety, orthostatic hypotension, fatigue, cognitive function, pain. <sup>2</sup>The final model included the participants who had data for lower extremity function (whereof 36 participants in HY stage IV and none in stage V). <sup>b</sup>Stepwise linear regression was conducted with all the independent variables included in the final model to get the change in  $R^2$  values.

$p=0.001$ ), postural instability ( $\beta=0.107$ ,  $p=0.025$ ) and orthostatic hypotension ( $\beta=0.103$ ,  $p=0.036$ ) (Table 4) None of the final multivariable models included any participant in HY stage V.

## DISCUSSION

Our study aimed to identify factors that independently contribute to perceived walking difficulties in people with PD. We identified FOG as the strongest independent variable in relation to perceived walking difficulties in people with PD, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability. To the best of our knowledge, this is the first study that investigated factors that independently contribute to perceived walking difficulties in people with PD.

The findings indicate that FOG should be the primary target when addressing perceived walking difficulties in people with PD. That FOG is of importance for walking difficulties corroborates previous research [6, 10, 19–23]. For example, persons with PD have described that FOG negatively influences community walking and perceived participation [22, 23]. Our findings further underline the importance of addressing FOG to improve walking in people with PD. For example, cueing strategies may facilitate walking if the person has FOG episodes [41, 42].

General self-efficacy was the second strongest contributing factor to perceived walking difficulties in people with PD, which to the best of our knowledge

is a novel finding in PD-research. Based on data from the larger project [26] that this study is part of, general self-efficacy has been shown to independently contribute to life satisfaction [43], but not to concerns about falling [44] in people with PD. Other PD-studies have reported that self-efficacy is of importance for engagement in exercise [45] and self-management [46]. Moreover, support by family, healthcare professionals and others has been reported as important for both self-efficacy and self-management in PD [41, 46]. One PD intervention study that included a self-management approach, reported no statistically significant improvements in walking activity and endurance [47]. Further studies are needed to investigate whether a self-management approach is beneficial for walking ability among people with PD. A narrative literature review [48] described that the Chronic Disease Self-Management Program developed by Lorig et al., [49] has a positive impact on self-efficacy. According to Bandura self-efficacy is “the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations” [50, p. 2] and is a predictor of behavior that influences the choice of activities and motivation. Persons with high self-efficacy are more likely to pursue an active role in goal setting and coping as well as adhere to prescribed regimens [51]. All considered, our findings add to the current body of literature and suggest that general self-efficacy is an important aspect to consider in PD care and rehabilitation.

In the present study, fatigue was the third strongest contributing factors to perceived walking difficulties. Previous PD-studies have shown that fatigue is asso-

Table 4  
Multiple linear regression analysis with Generic Walk-12 scores as the dependent variable in people with Parkinson’s disease after excluding the variable chair stand test,  $n=243$

Independent variables <sup>1</sup>	Unstandardized Coefficients B (95% CI)	Standardized Coefficients $\beta$	P-value	R square <sup>a</sup> %	Adjusted R square <sup>a</sup>
Freezing of gait (FOGQsa item 3, scores $\geq 1$ = yes)	6.02 (3.85–8.19)	0.275	<0.001	53.4	51.9
Fatigue (NHP-EN, dichotomized, yes)	5.17 (2.97, 7.38)	0.236	<0.001	25.4	25.1
General self-efficacy (GSE, higher scores = “better”)	–0.35 (–0.51, –0.20)	–0.225	<0.001	13.6	13.4
PD duration (years)	0.29 (0.13–0.45)	0.173	<0.001	6.2	6.0
Bradykinesia (UPDRS III item 31, scores $\geq 1$ = yes)	3.66 (1.58, 5.74)	0.164	0.001	3.5	3.3
Postural instability (UPDRS III item 30, scores $\geq 1$ = yes)	2.70 (0.34–5.06)	0.107	0.025	2.6	2.4
Orthostatic hypotension (NMSQuest item 20, yes)	2.25 (0.15, 4.35)	0.103	0.036	1.2	1.0
				0.9	0.7

FOGQsa = self-administered version of the Freezing of Gait Questionnaire; NHP-EN = Energy subscale of the Nottingham Health Profile; GSE = General Self-Efficacy Scale; PD = Parkinson’s disease; UPDRS = Unified Parkinson’s Disease Rating Scale (part III = motor examination); NMSQuest = Nonmotor Symptoms Questionnaire; <sup>1</sup>The following 14 independent variables were included: Sex, age, living alone, general self-efficacy, PD duration, postural instability, bradykinesia, freezing of gait, depressive symptoms, anxiety, orthostatic hypotension, fatigue, cognitive function, pain. <sup>a</sup>Stepwise linear regression was conducted with all the independent variables included in the final model to get the change in  $R^2$  values.

ciated with walking economy [52], and with lower levels of self-reported [53, 54] as well as objectively measured [55] physical activity. Moreover, lower limb muscle fatigue (i.e., physical fatigue) is associated with objectively measured gait parameters in people with PD [9]. Although further studies are needed to understand the association between fatigue and walking difficulties, one explanation may be that fatigue induces difficulties in maintaining attention [56]. This as attention has been shown to be of importance for walking in people with PD [57, 58]. Although attention is a cognitive function, global cognitive functioning (as assessed with MOCA) did not contribute to perceived walking difficulties in this study. Rerunning the analyses and substituting the MOCA total score by its domain scores (results not shown but available on request) yielded largely similar results. This applied for both models and when using the original domain scores [59] (i.e. Visuospatial/Executive, Naming, Attention, Concentration and Calculation, Language, Abstraction, Delayed recall and Orientation) as well as when using more recent suggested domain scores [60].

One factor that independently contributed to perceived walking difficulties needs specific attention, that is, lower extremity function as assessed with the chair stand test [34, 35]. It should be noted that 31 participants (whereof 19 in HY stage IV and 3 in stage V) were unable to complete this test. After excluding this variable in the multivariable analysis, the results remained largely similar. This consistency indicates that all the identified factors independently contribute to perceived walking difficulties regardless of their interaction with lower extremity function. That lower extremity function turned out as a significant contributing factor highlights the need of promoting lower extremity strength [61, 62]. According to recommendations [63, 64], strength training should be combined with training that includes other components such as balance. This is further underlined by the fact that postural instability contributed independently to perceived walking difficulties in this study.

The postural response was assessed in relation to an external perturbation. Several studies showed that training in responding to external perturbations [65–67] has some effect on gait, balance and balance-related activity performance. Balance training should challenge the person with PD [68] and home based training on postural instability seems to have no beneficial effect in people with PD [63].

### *Strengths, limitations and future perspectives*

We consider it a strength that we included the full spectrum of PD severity although some readers might argue that we should have excluded those in HY stage V. It should be noted that none of those in HY stage V ( $n=3$ ) were included in any of the two final models since they had missing data on some of the independent variables. To clarify, the final model of any regression analysis includes only those that have complete data on all the included independent variables.

Another strength is that we used multivariable analyses and that the sample size allowed us to consider a broad variety of explanatory factors. Even if the regression model explained 56.3% of the variance in the dependent variable, there are additional independent variables of interest for perceived walking difficulties in people with PD. For example, the social environmental factors included represent a limited portion of the wide range of possible environmental factors that might be of importance for perceived walking difficulties, for example, crowds, inclement weather and uneven/slippery surfaces [19, 22, 24]. In addition, although balance problems are complex in people with PD and may incorporate several aspects, the present study only addressed the ability to counteract an external perturbation. Future studies should preferably also incorporate additional aspects of balance control. We used a rather coarse indicator of fatigue and it might be of interest to incorporate assessments of different types (i.e., mental and physical) of fatigue in future studies [69, 70].

The Walk 12-G is a PRO instrument. According to the Food and Drug Administration (FDA), “use of a PRO instrument is advised when measuring a concept best known by the patient or best measured from the patient perspective” [71]. The responses may vary due to cultural differences in relation to the targeted construct [72] and using a PRO instrument may be disadvantageous for people with disabilities and low literacy [73]. A previous psychometric study of Walk-12G did, however, report satisfactory data completeness in PD as well as multiple sclerosis samples [27].

The cross-sectional design makes it impossible to infer any causal relations. Longitudinal studies are needed to identify predictive factors but also to gain an increased understanding of how perceived walking difficulties evolve over time. Since this is the first study that used multivariable analysis to identify contributing factors to perceived walking difficulties in

people with PD, the findings need to be replicated in other PD-samples as well as in different national contexts.

## CONCLUSIONS

This study identified eight contributing factors for perceived walking difficulties in people with PD. FOG was the most important factor, followed by general self-efficacy, fatigue, PD duration, lower extremity function, orthostatic hypotension, bradykinesia and postural instability. That is, motor and non-motor symptoms as well as personal factors (i.e., general self-efficacy) seem to be of importance when addressing perceived walking difficulties among people with PD. Longitudinal studies are needed to identify predictive factors and understand how perceived walking difficulties evolve over time. With such knowledge at hand, interventions addressing modifiable factors could be developed, ultimately enhancing walking ability in people with PD.

## ACKNOWLEDGMENTS

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## CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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## Study IV







## ORIGINAL ARTICLE

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# Mobility device use in people with Parkinson's disease: A 3-year follow-up study

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The Swedish Research Council; Strategic Research Area in neuroscience (MultiPark); NEURO Sweden; Norrbacka-Eugeniastiftelsen; Ribbingska Foundation in Lund; Greta och Johan Kocks stiftelser; Swedish Parkinson Foundation; The Swedish Association of Persons with Neurological Disabilities (NHR)

**Objectives:** This study aimed to investigate how the use and perceived unmet need of mobility devices (MD) in people with Parkinson's disease (PD) evolve over a 3-year period.

**Methods:** The study reports baseline assessments ( $n = 255$ ) and comparisons for participants with complete data at baseline and the 3-year follow-up ( $n = 165$ ). Structured questions addressed the use and perceived unmet need of various MDs indoor and outdoor (eg, canes, wheeled walkers, and manual and powered wheelchairs). McNemar tests were used to investigate differences over time.

**Results:** In the total sample at baseline, 30% and 52% of the participants reported using MDs indoors and outdoors, respectively. Among those with complete data also at the 3-year follow-up, the proportion of participants using MDs increased significantly ( $P < .001$ ) from 22% to 40% for indoors and from 48% to 66% for outdoors, with transition of MD toward more assistive potential (ie, wheeled walker and manual wheelchair). Wheeled walkers were the most commonly used MD indoors as well as outdoors on both occasions. Among the users of multiple MDs, the most common combination was cane and wheeled walker on both occasions. The proportion of participants who reported a perceived unmet need of MDs was 5% at baseline, whereas it was 21%, 3 years later.

**Conclusions:** The use and perceived unmet need of MDs in people with PD increase over time. There is a need for addressing MDs at clinical follow-ups of people with PD, with continuous attention in primary health care and municipality contexts.

**KEY WORDS**

assistive devices, canes, mobility, Parkinson's disease, walking aids, wheelchairs, wheeled walkers

## 1 | INTRODUCTION

Parkinson's disease (PD) is a chronic progressive neurodegenerative disease, which results in functional loss and disability due to motor symptoms (eg, bradykinesia, tremor, postural instability) and non-motor symptoms (eg, fatigue, depression, cognitive dysfunction).<sup>1,2</sup> As PD progresses, gait and balance problems become more prevalent.<sup>1</sup> Mobility devices (MDs) can compensate for such problems and facilitate activity performance.<sup>3</sup> This implies that it is important to increase the understanding of how the use and perceived unmet

need of MDs evolve over time. To the best of our knowledge, no study has yet addressed such matters in people with PD.

According to the International Classification of Functioning, Disability and Health (ICF), MDs are part of environmental factors,<sup>4</sup> which can act as a facilitator or a barrier for activity performance.<sup>5</sup> Various types of MDs with different levels of support may be required depending on the person's functioning, level of independence in activities of daily living (ADL), his/her activity repertoire, and environmental settings.<sup>3</sup> Commonly used MDs in people with PD include canes (ie, walking sticks), wheeled walkers (ie, rollators) as well as manual and

powered wheelchairs.<sup>3,6</sup> Canes are usually suitable for those with milder disability, wheeled walkers for those with moderate disability, and motorized devices for those with severe disability.<sup>3</sup> Although MDs are used to better cope with walking difficulties and promote safety, there is research indicating that MD use in people with PD is associated with an increased number of falls<sup>7,8</sup> and more freezing episodes.<sup>6,9</sup>

Overall in PD research, studies targeting MD use are scarce. One of the few studies targeting such issues, based on a sample of very old community-living people in five European countries, described that persons with self-reported PD had a higher use of MDs (55%) than matched controls (30%), but no statistically significant difference regarding the perceived unmet need of MDs.<sup>10</sup> The actual use as well as the perceived unmet need of MDs most likely reflects the systems of provision and funding.<sup>11</sup> In Sweden, the provision of MDs is regulated in the Health Care Act. All municipalities as well as the county councils must see to that people in need of such equipment get access to it, while applying local regulations for the actual provision. MDs are free of charge for the individual through the national provision system,<sup>11</sup> but fees for the consultations with healthcare professionals are becoming common. Overall, the MD provision system in Sweden is considered to work well, but it might nevertheless be challenging for the individual to overview and retrieve the information needed. Therefore, a delay in obtaining MD is probably not seldom. There is also a growing private market, where people can buy their MDs without any involvement from the public authorities. People with PD have a higher use of MDs (indoors and outdoors) than those with essential tremor or dystonia.<sup>12</sup>

To gain an increased knowledge about MD use in people with PD, this study aimed to investigate how the use and perceived unmet need of MDs in people with PD evolve over a 3-year period.

## 2 | METHODS

We utilized data collected within the project "Home and Health in People Ageing with PD, (HHPD)".<sup>13</sup> Details regarding the project design and methods have been published elsewhere.<sup>13</sup> The study has a cross-sectional as well as a follow-up design. We used data collected at baseline (completed in 2013,  $n = 255$ ) and at a 3-year follow-up (completed in 2016,  $n = 165$ ). The project was conducted in accordance with the Helsinki Declaration and was approved by the Regional Ethical Review Board in Lund, Sweden (Nos. 2012/558; 2015/611). All participants gave their written informed consent.

### 2.1 | Participants and recruitment

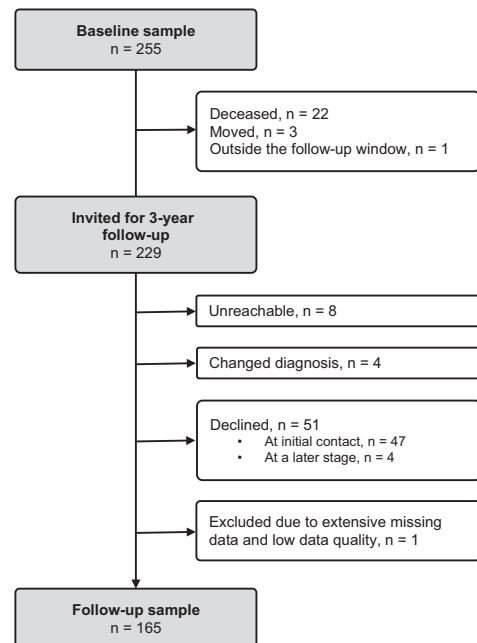
Participants were recruited from three hospitals in Skåne County, Sweden. A flowchart of the recruitment procedure has been published previously.<sup>14</sup> At baseline, 653 persons met the inclusion criterion of a PD diagnosis (ICD-10: G20.9) since at least 1 year. Of those, 216 were not eligible due to difficulties in understanding or speaking Swedish ( $n = 10$ ), severe cognitive difficulties ( $n = 91$ ), living outside Skåne County ( $n = 58$ ), or other reasons that made them unable to give

informed consent or take part in the majority of the data collection (eg, hallucinations, a recent stroke;  $n = 57$ ). The remaining 437 persons were invited to participate. Of these, 22 were unreachable, two had a revised diagnosis, and 157 declined. One person was excluded due to extensive missing data, resulting in a sample of 255 participants at baseline. Their mean (min-max) age was 70 (45-93) years, and median (min-max) PD duration was 8 (1-43) years (40% women).

All those who completed baseline assessments and had agreed to be contacted again ( $n = 255$ ) were considered eligible for the 3-year follow-up. At that time, 22 participants were deceased, three had moved, and one ended up outside the follow-up window (3 years  $\pm$  3 months). Thus, 229 persons were invited to participate. Of these, eight were unreachable, four had a revised diagnosis, and 51 declined. A flowchart of the recruitment process at the 3-year follow-up is presented in Figure 1. One person was excluded due to extensive missing data and low data quality. The final sample included 165 persons. Their mean (min-max) age was 72 (48-94) years, whereas their median (min-max) PD duration was 11 (5-46) years (for details, see Table 1).

### 2.2 | Procedure

Data collection was administered by experienced registered occupational therapists who had undergone project-specific training. Both



**FIGURE 1** Flow diagram: the recruitment process of participants for the three-year follow-up

**TABLE 1** Participant characteristics for total sample at baseline and for those included in the 3-year follow-up

Variables	Cross-sectional sample N = 255 Baseline	Follow-up sample n = 165	
		Baseline <sup>a</sup>	3-year follow-up
Sex (women), n (%)	102 (40)	59 (35.5)	59 (35.5)
Age (year), mean (SD)	70.0 (9.2)	68.6 (8.8)	71.6 (8.8)
Living alone (dichotomous, yes), n %	68 (26.7)	36 (21.8)	40 (24.2)
Education (elementary/higher secondary/university), n (%)	86 (33.7)/83 (32.5)/86 (33.7)	48 (29.1)/56 (33.9)/61 (37.0)	56 (33.9)/48 (29.1)/61 (37.0)
Satisfaction with economic situation, median (q1-q3) <sup>b</sup>	7.0 (5.0-9.0)	7.0 (5.0-9.0)	7.0 (5.0-9.0)
Residential area (rural/urban/metropolitan), n (%)	84 (32.9)/68 (26.7)/103(40.4)	58 (35.2)/38 (23.0)/69 (41.8)	62 (37.6)/34 (20.6)/69 (41.8)
Need help from others in daily activities (PADLS, scores $\geq 3$ = yes), n %	68 (26.9)	39 (23.6)	59 (36.0)
Fear of falling (dichotomous, yes), n (%)	123 (48.8)	70 (42.7)	93 (57.1)
Falls past 6 months (yes), n (%)	113 (44.3)	70 (42.4)	82 (49.7)
PD duration (years), median (q1-q3)	8.0 (5.0-13.0)	8.0 (5.0-12.0)	11 (8.0-15.0)
PD severity (H&Y), median (q1-q3)	3.0 (2.0-4.0)	2.0 (2.0-3.0)	3.0 (2.0-4.0)
Motor symptoms (UPDRS, part III), median (q1-q3)	30.0 (22.0-39.2)	29.0 (21.0-37.0)	27.0 (21.0-40.0)
Perceived walking difficulties (Walk-12G), mean, (SD)	16.0 (11.1)	15.1 (10.8)	18.4 (12.1)
Freezing of gait (FOGQsa item 3, scores $\geq 1$ = yes), n (%)	142 (56.6)	89 (54.3)	95 (58.6)
Cognitive function (MoCA), median (q1-q3)	26.0 (22.0-28.0)	26.0 (23.0-28.0)	26.0 (23.0-28.0)
Depressive symptoms (GDS-15), median (q1-q3)	2.0 (1.0-4.0)	2.0 (1.0-4.0)	3.0 (1.0-5.0)
Fatigue (NHP-EN, yes), n %	144 (56.9)	86 (52.1)	96 (58.9)

q1-q3, first-third quartile; SD, standard deviation; PADLS, Parkinson's disease Activities of Daily Living Scale (1-5, higher=worse); H&Y, Hoehn & Yahr (stage I-V, higher=worse); UPDRS, Unified Parkinson's Disease Rating Scale (part III=motor examination, 0-108, higher=worse); Walk-12G, Generic Walk-12 (0-42, higher=worse); FOGQsa, self-administered version of the Freezing of Gait Questionnaire (item 3: 0-4, higher=worse); MoCA, Montreal Cognitive Assessment (0-30, higher=better); GDS-15, the 15-item Geriatric Depression Scale (0-15, higher=worse); NHP-EN, Energy subscale of the Nottingham Health Profile, those who affirmed at least one of its three dichotomous (yes/no) questions were classified as having fatigue. Internal missing data: n = 0-10 for the total sample at baseline, and n = 0-14 for the 3-year follow-up sample.

<sup>a</sup>Data for those who were included in the 3-year follow-up

<sup>b</sup>Scored from 0 (very unsatisfied) to 10 (very satisfied).

data collection waves (baseline and 3-year follow-up) included a self-administered postal survey and a subsequent home visit. The home visit included interview-administered questions and questionnaires as well as clinical assessments. Further details regarding the procedure have been described and published elsewhere.<sup>15</sup>

## 2.3 | Assessments

### 2.3.1 | Use and perceived unmet need of mobility devices

Structured questions addressed the use and perceived unmet need of various MDs indoors and outdoors. For each device, participants were asked to state whether they had the device or not, whether they used it, or whether they perceived an unmet need of that particular device. The MDs listed (for indoor as well as outdoor use) were as follows: canes (ie, walking sticks), crutches, other walking

devices without wheels (quadropods, walking frames, etc.), wheeled walkers (ie, rollators), and manual and powered wheelchairs, respectively. Two additional devices (Nordic walking sticks, tricycles) were listed for outdoor use only.

### 2.3.2 | Descriptive variables

Data on age and sex were retrieved using the participants' social security numbers. Residential areas were categorized into rural, urban, or metropolitan based on postal code.

The self-administered postal survey included several rating scales and questions. Perceived difficulties and dependence in ADL were assessed according to the Parkinson's disease Activities of Daily Living Scale.<sup>16</sup> Perceived walking difficulties in everyday life were assessed with the Generic Walk-12.<sup>17</sup> Freezing of gait was assessed with item 3 of the self-administered version<sup>18</sup> of the Freezing of Gait Questionnaire.<sup>19</sup> Fatigue was assessed according to the

Energy subscale of the Nottingham Health Profile.<sup>20</sup> A dichotomous (Yes/No) question targeted fear of falling: "Are you afraid of falling?" For details regarding scoring and interpretation of scores, see footnotes in Table 1.

Interview-administered questions during the home visit addressed living situation (alone/not alone), educational level (elementary/higher secondary/university), satisfaction with economic situation, and PD duration. A dichotomous (Yes/No) question concerned history of falls during the past 6 months. Depressive symptoms were assessed according to the Geriatric Depression Scale.<sup>21</sup>

Clinical assessments addressed PD severity according to the Hoehn and Yahr staging,<sup>22</sup> motor symptoms according to the motor examination (part III) of the Unified Parkinson's Disease Rating Scale,<sup>23</sup> and global cognitive functioning according to the Montreal Cognitive Assessment.<sup>24</sup>

## 2.4 | Data analyses

MD users were defined as those who reported using at least one MD. Those who reported having an MD without using it were categorized as non-users. At baseline ( $n = 255$ ), 26 persons reported that they had at least one MD which was not used indoors; the corresponding value was 50 in relation to outdoor use. For those with complete data at both follow-ups ( $n = 165$ ), 16 reported at baseline that they had at least one MD which was not used indoors; this was reported by 56 persons 3 years later. In relation to outdoor use, this was reported by 30 participants at baseline as compared to 90 participants 3 years later.

Ordinal and continuous variables were described by medians (first-third quartiles) or means (SD), depending on the distribution

of the data (ie, normality was checked). Categorical variables were described by number of participants, including proportion (%). McNemar tests were used to test for differences over time.

The significance level applied was  $P < .05$ . Statistical analyses were performed in IBM SPSS Statistics, version 24 for Windows (Armonk, NY: IBM Corp., Released 2016).

## 3 | RESULTS

### 3.1 | Use and perceived unmet need of mobility devices in the total sample at baseline

At baseline, 75 of 253 participants (30%) reported that they used some kind of MD indoors (Table 2), whereas 133 of 254 participants (52%) reported using some kind of MD outdoors (Table 3). Wheeled walkers were the most commonly used MD indoors as well as outdoors, followed by canes (indoors), and Nordic walking sticks (outdoors). Eleven participants (4%) expressed a perceived unmet need of one or more MD (indoors,  $n = 2$ ; outdoors,  $n = 8$ ; both indoors and outdoors,  $n = 1$ ).

### 3.2 | Comparisons for those with complete data at baseline and the 3-year follow-up

The follow-up sample included 165 participants, but there were some internal missing data.

The overall use of MDs increased significantly ( $P < .001$ ) indoors as well as outdoors over the 3-year period (Tables 2-3).

Indoor use of some kind of MD was reported by 36 of 164 participants (22%) at baseline as compared to 66 (40%) 3 years later

Mobility device	Cross-sectional sample N = 255 Baseline n (%)	3-year follow-up sample n = 165		P-value <sup>b</sup>
		Baseline <sup>a</sup> n (%)	3-year follow-up n (%)	
Any mobility device	75 (30)	36 (22)	66 (40)	<.001
Cane	24 (9)	12 (7)	20 (12)	.152
Crutches	12 (5)	11 (7)	10 (6)	1.000
Other walking device without wheels (quadropod, walking frame, etc.)	8 (3)	3 (2)	9 (5)	.070
Wheeled walker	54 (21)	22 (13)	41 (25)	.002
Wheelchair, manual	8 (3)	5 (3)	19 (12)	.001
Powered wheelchair	1 (0.4)	1 (1)	3 (2)	.500

As participants commonly reported using multiple mobility devices, numbers and percentages cannot be added up.

Internal missing data:  $n = 0-2$  for total sample at baseline, and  $n = 0-4$  for the 3-year follow-up sample.

<sup>a</sup>Data for those included in the 3-year follow-up.

<sup>b</sup>McNemar test for difference over 3-year follow-up.

**TABLE 2** Use of mobility devices indoors in people with Parkinson's disease

**TABLE 3** Use of mobility devices outdoors in people with Parkinson's disease

Mobility device	Cross-sectional sample N = 255 Baseline n (%)	3-year follow-up sample n = 165		P-value <sup>b</sup>
		Baseline <sup>a</sup> n (%)	3-year follow-up n (%)	
Any mobility device	133 (52)	79 (48)	108 (66)	<.001
Nordic walking sticks	43 (17) <sup>c</sup>	31 (20) <sup>d</sup>	38 (23) <sup>e</sup>	.265
Cane	28 (11)	19 (12)	27 (16)	.201
Crutches	14 (6)	9 (5)	15 (9)	.180
Other walking device without wheels (quadropod, walking frame, etc.)	0 (0)	0 (0)	0 (0)	-
Wheeled walker	70 (28)	36 (22)	41 (25)	.458
Tricycle	2 (1)	1 (1)	3 (2)	.625
Wheelchair, manual	21 (8)	10 (6)	28 (17)	<.001
Powered wheelchair	14 (6)	9 (5)	13 (8)	.219

As participants commonly reported using multiple mobility devices, numbers and percentages cannot be added up.

Internal missing data: n = 0-2 for total sample at baseline, and n = 0-3 for the 3-year follow-up sample.

<sup>a</sup>Data for those included in the 3-year follow-up.

<sup>b</sup>McNemar test for difference over 3-year follow-up.

<sup>c</sup>35 participants reported Nordic walking sticks as their only mobility device outdoors.

<sup>d</sup>25 participants reported Nordic walking sticks as their only mobility device outdoors.

<sup>e</sup>23 participants reported Nordic walking sticks as their only mobility device outdoors.

( $P < .001$ ). As to specific MDs, wheeled walkers and manual wheelchairs were the only types for which the indoor use increased significantly ( $P = .002$  and  $.001$ , respectively). At both time points, wheeled walkers were the most commonly used MD indoors, followed by canes (Table 2).

Outdoor use of some kind of MD was reported by 79 of 165 participants (48%) at baseline as compared to 108 of 163 (66%) 3 years later ( $P < .001$ ). Manual wheelchairs were the only MD for which the outdoor use increased significantly ( $P < .001$ ). At both time points, wheeled walkers were the most commonly used MD outdoors, followed by Nordic walking sticks (Table 3).

At baseline, as well as 3 years later, most participants did not use any MDs indoors, followed using a single MD, two MDs, and three or more MDs. The same pattern applied for outdoor MD use at baseline, whereas at the 3-year follow-up, most participants used a single MD outdoors, followed by no MD, two MDs, and three or more MDs (Figures S1A-B). If using more than one MD, the most common combination was using a cane and a wheeled walker; this applied for both indoors and outdoors and at both time points.

Of 161 participants, 82 participants (51%) reported using MDs indoors and/or outdoors at baseline as compared to 109 participants (68%) 3 years later (Table 4). Among the new users of MDs at the 3-year follow-up, 18 participants used MDs outdoors only and 13 used MDs both indoors and outdoors, whereas two used MDs indoors only. A more detailed description of the transitions from non-users, indoor users only, outdoor users only, and using MDs both indoors and outdoors is presented in Table 4.

Eight participants (5%) expressed a perceived unmet need of one or more MDs at baseline (indoors,  $n = 2$ ; outdoors,  $n = 5$ ; both

indoors and outdoors,  $n = 1$ ). Thirty-four participants (21%) expressed a perceived unmet need 3 years later (indoors,  $n = 8$ ; outdoors,  $n = 20$ ; both indoors and outdoors,  $n = 6$ ).

## 4 | DISCUSSION

To the best of our knowledge, this is the first study that provides detailed information on how the use and perceived unmet need of MDs in people with PD evolve over time. As could be expected among persons with a chronic progressive disease that affects gait and balance, the results show an increased use as well as an increased perceived unmet need of MDs over a 3-year period.

Wheeled walkers were the most commonly used MD indoors as well as outdoors, which was the case at baseline as well as 3 years later. This finding is in agreement with another Swedish PD study,<sup>25</sup> but contradicts a study based on a European sample (ie, Sweden, Germany, the United Kingdom, Hungary, and Latvia) where cane was the most commonly used MD.<sup>10</sup> It should be noted that the latter study included a small sample of very old people ( $n = 20$ ) with self-reported PD (75-89 years) who were single living in urban areas during 2003-2004.<sup>26</sup> Canes (ie, walking sticks) have been reported as the most commonly used MD among people with a first-ever stroke,<sup>27</sup> middle-aged, and older adults with multiple sclerosis,<sup>28</sup> as well as among older adults in the United States<sup>29</sup> and Europeans.<sup>30</sup> These discrepancies suggest that people with PD require MDs with more support than other populations, but might also reflect that using a wheeled walker may be more advantageous than a cane for persons with PD. For example, wheeled walkers have been



**TABLE 4** Cross-tabulation of numbers of users and non-users of any mobility device indoors and outdoors at baseline and the 3-year follow-up,  $n = 161^a$ 

3-year follow-up, $n$	Baseline <sup>b</sup> , $n$				Total
	Non-user	User indoors only	User outdoors only	User both indoors and outdoors	
Non-user	46	1	4	1	52
User indoors only	2	0	0	0	2
User outdoors only	18	0	21	4	43
User both indoors and outdoors	13	3	21	27	64
Total	79	4	46	32	161

<sup>a</sup> $n = 161$  due to internal missing data.<sup>b</sup>Data for those included in the 3-year follow-up.

associated with fewer freezing episodes, improved safety and gait speed,<sup>6,9</sup> whereas canes induced more freezing episodes.<sup>6</sup> Although most of our participants used a single MD, several did in fact use multiple MDs. The latter might be due to a variability in symptoms (eg, "on" versus "off" periods), environmental circumstances, or activity characteristics (eg, walking at home versus traveling longer distances out of home). Further studies are needed to explore whether using multiple MDs facilitate activity performance and perceived participation in people with PD.

The present study shows a higher use as well as a higher perceived unmet need of MDs outdoors than indoors. The higher use of MDs outdoors is in agreement with previous studies in people with PD<sup>7,25</sup> and among single-living older people.<sup>30</sup> Using MDs outdoors can be a strategy for necessary and valued activities such as shopping.<sup>31</sup> Moreover, outdoor walking poses greater challenges than walking indoors due to more complex and demanding environments, such as traffic, other pedestrians and bicyclists, uneven surfaces, wind, and rain.<sup>32</sup>

In the present study, some participants (about 15%, see footnotes in Table 3) reported Nordic walking sticks as their only MD outdoors. Walking with Nordic walking sticks is becoming increasingly popular as a form of everyday physical activity.<sup>33</sup> A recent systematic review suggested that it positively affects motor (eg, freezing of gait) and non-motor symptoms (eg, pain) in people with PD, although the authors highlighted the need for further well-designed and larger studies.<sup>34</sup> Readers might question whether our participants reported using Nordic walking sticks as an exercise tool or as an MD. However, the included question specifically addressed the use of Nordic walking sticks as an MD. All considered, it seems important to consider Nordic walking sticks when asking people with PD about MD use outdoors.

At the 3-year follow-up, the majority of novel users of MDs used MDs only outdoors, followed using MDs both indoors and outdoors. The present study showed also that an increased proportion of participants used MDs with more assistive potential (ie, wheeled walker and manual wheelchair) over time. These results are in line with previous findings in a study of single-living older adults.<sup>30</sup> However, further research is needed to understand predictive factors of MD use in people with PD.

At baseline, the perceived unmet need of MDs (5%) was only minor. Similar proportions have been reported among persons with self-reported PD and their matched controls in a European context.<sup>10</sup> A plausible explanation for the low proportion of perceived unmet need of MDs in this study is the well working publicly funded MD provision system in Sweden. The need of MDs is assessed by qualified healthcare professionals (ie, occupational therapists, physiotherapists), equal for all without any influence of the patient's socioeconomic situation.<sup>11</sup> The need assessment is usually done in close consultation with the user, his/her family members, taking the physical environment in housing, and the close neighborhood into account. A study among very old people in five European countries showed differences in the levels of unmet needs among the countries, with more unmet needs in countries in Eastern Europe.<sup>35</sup> For example, the lowest proportion of perceived unmet need of MDs was reported in the Swedish sample (2%) as compared to the Latvian sample (7%).<sup>35</sup> The provision systems for assistive technology are markedly different in these two countries, and older people in Sweden seem to be better informed about the possibilities to get this kind of support.<sup>11</sup> Consequently, assessment of unmet need of MDs is a delicate matter, most likely dependent on national policies and services as well as the information provided on how to access such support.

On the other hand, the finding might reflect a lack of awareness of different MDs and their potential benefits. That is, people with PD and their family members might need increased information about MDs to express their needs. The perceived unmet need of MDs did, however, increase from 5% to 21% over a 3-year period. This increase probably reflects the progression of gait and balance problems in PD, as demonstrated by the descriptive data in our sample (eg, increased Generic Walk-12 scores, number of fallers, see Table 1). Importantly, a perceived unmet need of MDs might not be equivalent to a need as assessed by healthcare personnel. Thus, the evaluation should include both the person's perceived needs and an assessment by health care personnel. It needs also to be underlined that MD use may be associated with an increased number of falls,<sup>7,8</sup> reduced walking speed,<sup>9</sup> and more freezing episodes while using a cane<sup>6</sup> or a standard walker (ie, non-wheeled

walking device).<sup>9</sup> That is, an MD might not always act as a facilitator but might become a barrier for safe activity performance. The latter might explain the proportion of participants that had an MD that they did not use (see method section, data analyses). These findings highlight the complexity inherent in MD provision for people with PD, requiring specific competence and efficient follow-up routines.

#### 4.1 | Strengths and limitations

The follow-up design of the HHPD project allowed us to investigate changes in use and perceived unmet need of MDs in people with PD over a 3-year period. Our sample was considerably larger than in previous experimental or cross-sectional studies addressing MD use in PD, where sample sizes ranged from  $n = 19$ –77.<sup>6,9,10,12</sup> PD studies have been criticized for being based on samples characterized by selectivity,<sup>36</sup> and we therefore consider it a strength that we included participants who represented the full spectrum of PD severity (ie, Hoehn and Yahr stages I–V) and a wide age range (45–91 years).

As to limitations, the results refer to a Swedish context and might not apply for other national contexts, not the least as MD provision systems vary considerably across countries.<sup>11,35</sup> Moreover, we did not consider any socio-demographic factors. Large differences in MD use in terms of age, education, income, ethnicity, and multimorbidity have been reported in previous studies involving older people.<sup>29</sup> Accordingly, such factors deserve attention in future studies on MD use in people with PD.

## 5 | CONCLUSIONS

The use of MDs increases significantly among people with PD over a 3-year period, and the types of MDs used shift toward those with more assistive potential, that is, to a higher use of wheeled walkers and manual wheelchairs. The perceived unmet need of MDs is low but increases over time. There is a need for addressing MDs at clinical follow-ups of people with PD, with continuous attention in primary health care and municipality contexts.

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## CONFLICT OF INTEREST

No conflict of interest is reported.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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I was born in Habiganj, Bangladesh. I am a registered physiotherapist with a Bachelor's degree in Physiotherapy from Bangladesh. I further deepened my knowledge in relation to Public Health Sciences by studying a Master's degree in Public Health Nutrition, and a Master's degree in International Health in Sweden. I then worked as a research officer at the Dept. of Public Health Sciences at Karolinska Institute in Stockholm. Moreover, I have a long experience of working as a physiotherapist.

My PhD specialises in Physiotherapy within Health Sciences, and was conducted in the research group Active and Healthy Ageing, affiliated with the Center for Ageing and Supportive Environments (CASE) and the Strategic Research Area in Neuroscience (MultiPark) at Lund University, Sweden. Furthermore, my learning process was supported by the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH).

I was accepted as a PhD student in June 2014. My PhD thesis focuses on activity avoidance due to perceived risk of falling, perceived walking difficulties, and the use and perceived need of mobility devices in people with Parkinson's disease (PD). This is a part of a longitudinal project "Home and Health in People Ageing with PD", which was conceived and designed by my main supervisor M. H. Nilsson and my co-supervisor S. Iwarsson. The baseline data collection for the project was completed in 2013, which was followed by an equivalent 3-year follow-up, completed in 2016. The data collection included a self-administered postal survey followed by a subsequent home visit, which involved interview-administered questions and questionnaires, observations and clinical assessments.