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Fear of falling in persons with Parkinson's disease

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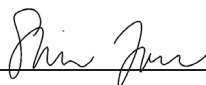November 4, 2016 at 9 am

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Abstract:

Fear of falling (FOF) is common in persons with Parkinson's disease (PD) and may have large consequences in daily life, causing a sedentary lifestyle, social isolation and reduced quality of life. FOF is therefore an important aspect to consider for researchers as well as clinicians and the rehabilitation team. Adequate and high quality rating scales are needed to be able to accurately assess FOF and thereby monitor how it changes over time. To facilitate the process of choosing a suitable rating scale, the conceptual understanding of commonly used FOF rating scales needs to be improved and further knowledge of their psychometric properties is needed. In order to provide optimal treatment, care and rehabilitation for people with PD, comprehensive studies that explore explanatory factors of FOF are needed. Moreover, there is a need for a deeper and richer understanding of FOF as a phenomenon. As yet, no study has explored how persons with PD experience FOF.

The overarching aim of this thesis was to increase the knowledge of how FOF can be assessed in persons with PD, as well as to expand and deepen the understanding of FOF in persons with PD in relation to explanatory factors and the persons' own experiences.

Four different FOF rating scales were analyzed in the first two studies. These were the Swedish version of the Falls Efficacy Scale (FES(S)), Falls Efficacy Scale-International (FES-I), Activities-specific Balance Confidence scale (ABC) and modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE). The first study was a linking study in which the four FOF rating scales were linked to the International Classification of Functioning, Disability and Health (ICF). This study did not include any empirical data. The second study was a psychometric study, in which the four FOF rating scales were administered twice (test and retest) as a postal survey. This study included 102 participants (median age 74 years, median PD duration 5 years). The third study was a multivariable regression study, in which explanatory factors of FOF (conceptualized as concerns about falling) were explored, taking both PD-related disabilities, personal and environmental factors into consideration. This study included 241 participants (median age 70 years, median PD duration 8 years). The fourth study was a qualitative interview study which explored how persons with PD and FOF experienced their FOF. Interviews were conducted with twelve persons with PD (median age 70 years, median PD duration 9 years).

The linking study revealed that the vast majority of the items in the four FOF rating scales emphasized the ICF component of activities and participation. All four scales predominately focused on the chapter of mobility, in particular the ABC, whereas the other scales were more diverse. The psychometric comparison revealed that ABC had markedly worse data completeness than the other scales, and FES(S) and ABC had more outliers when comparing the two test occasions. All four scales showed acceptable reliability, but FES-I was the only scale with a test-retest reliability that reached the suggested level for usage in individual comparisons. Several factors were significant ($p < 0.05$) explanatory factors of concerns about falling. Walking difficulties in everyday life were the strongest explanatory factor, followed by orthostatism, motor symptoms, age and fatigue. FOF affected the lives of the persons with PD and FOF in several ways. It was experienced as a disturbance in everyday life. FOF was a varying experience and different strategies were adopted to handle FOF.

In conclusion, FES-I or mSAFFE are suggested for assessing FOF in people with PD. However, scale selection should consider the aspects of FOF that one wishes to address. Moreover, the results indicate that interventions targeting FOF need to be individually tailored for persons with PD and focus on several aspects, e.g., PD-related symptoms and disabilities, activities and environmental factors.

Key words: Activity avoidance; Balance confidence; Concerns about falling; Fall-related self-efficacy; International Classification of Functioning, Disability and Health (ICF); Linking study; Psychometrics; Qualitative research; Regression analysis; Reliability; Self-reported rating scale

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Fear of falling in persons with Parkinson's disease

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LUND UNIVERSITY

The red tulip is a worldwide symbol of Parkinson's disease. In 1980, a Dutch horticulturalist with Parkinson's disease, developed a red and white tulip. He named it "Dr. James Parkinson's tulip" to honor James Parkinson, who was the first person to describe the disease in 1817.

Till mamma

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Abstract

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List of publications

This thesis is based on the following papers:

I.   **Bladh S**, Nilsson MH, Carlsson G, Lexell J. Content analysis of 4 fear of falling rating scales by linking to the International Classification of Functioning, disability and health. PM & R. 2013 Jul; 5(7):573-582 e1.

II.   **Jonasson SB**, Nilsson MH, Lexell J. Psychometric properties of four fear of falling rating scales in people with Parkinson's disease. BMC Geriatrics. 2014 May 21; 14:66.

III.   **Jonasson SB**, Ullén S, Iwarsson S, Lexell J, Nilsson MH. Concerns about falling in Parkinson's disease: Associations with disabilities and personal and environmental factors. Journal of Parkinson's disease. 2015; 5(2):341-349.

IV.   **Jonasson SB**, Nilsson MH, Lexell J, Carlsson G. Experiences of fear of falling in persons with Parkinson's disease − a qualitative study. *Submitted for publication.*

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Abbreviations

ABC	Activities-specific Balance Confidence scale
FES	Falls Efficacy Scale
FES-I	Falls Efficacy Scale-International
FES(S)	Swedish version of the Falls Efficacy Scale
FOF	Fear of falling
FOGQsa	Self-administered version of the Freezing of Gait Questionnaire
GDS-15	Geriatric Depression Scale
GSE	General Self-Efficacy Scale
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disability and Health
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
ProFaNE	Prevention of Falls Network Europe
r_s	Spearman's correlation coefficient
SD	Standard Deviation
SDD	Smallest Detectable Difference
SEM	Standard Error of Measurement
UPDRS III	Part three of the Unified Parkinson's Disease Rating Scale
Walk-12G	Generic Walk-12

Definitions

Bandwidth of content coverage	percentage of used ICF categories of the total number of ICF categories [1]
Content density	the number of identified meaningful concepts divided by the number of items in a rating scale [1]
Content diversity	the number of unique ICF categories linked divided by the number of identified meaningful concepts [1]
Falls	an unexpected event, in which the person comes to rest on the ground, floor or lower level [2]
Fear of falling	used in this thesis as an umbrella term for several conceptualizations of fear of falling: concerns about falling [3, 4], low fall-related self-efficacy [5], decreased balance confidence [6] and activity avoidance due to the risk of falling [7]
Near falls	a fall initiated but arrested by support from a wall, railing, other person, etc. [8]
Outlier	an individual with a difference in scale scores between two test occasions (test and retest) outside the first or third quartile $\pm 1.5 \times$ interquartile range of the mean difference in scale scores between test and retest [9]
Rehabilitation	a process aimed at enabling people with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels [10]
SDD	calculated as $SEM \times 1.96 \times \sqrt{2}$ [11]
SEM	calculated as $SD_{baseline} \times \sqrt{1 - ICC}$ [12]

Preface

When a person is afflicted with a chronic disease, there are often physical as well as psychological consequences that may affect activities and the person's existence as a whole. The role of the health care system and rehabilitation team is to help and support individuals to find ways of doing what they want in life, despite chronic diseases. To enable help and support in the most optimal way, it is essential that we understand the factors that may constitute hindrance in everyday life for these individuals. Knowledge is needed regarding how the hindering factors can be assessed, their explanatory factors, and how individuals with chronic diseases experience the hindering factors.

Fear of falling (FOF) is frequently experienced in the aging population and is even more common in people with certain chronic diseases, such as Parkinson's disease (PD). FOF is one factor that may prevent individuals from conducting the activities that they treasure and may contribute to a life of inactivity and social isolation, with a reduced quality of life. This thesis will focus on FOF in persons with PD. I will present my doctoral studies where I have explored how FOF can be assessed, its explanatory factors, and how persons with PD experience their FOF.

Introduction

Parkinson's disease

Parkinson's disease (PD) is a progressive, neurodegenerative disease leading to degeneration of dopamine producing cells in the deep parts of the brain. However, several brain areas, circuits and transmitter substances are involved, as well as the brain stem and the peripheral autonomic nervous system [13, 14]. The cause of PD is unknown, but genetic as well as environmental factors are hypothesized to be involved [15].

The worldwide prevalence of PD is 0.3% and increases with age. It varies from 0.04% in the ages 40 to 49 years up to 2% in the ages above 80 years [16]. In Europe, 1.2 million people are estimated to have PD [17]. The corresponding number for Sweden is about 22 000 people [18]. The incidence of PD is higher in men than in women (ratio 1.5:1) [15]. The mean age of symptom onset is 62 to 70 years, and symptoms before 50 years of age are rare [19]. Due to an aging population, the prevalence of PD is estimated to double between year 2005 and 2030 [20].

The PD diagnosis is based on clinical observations and assessments [21]. According to the United Kingdom PD Society Brain Bank clinical diagnostic criteria, a diagnosis of PD requires presence of bradykinesia and at least one of the other cardinal signs (described below, i.e., tremor at rest, rigidity and postural instability that is not caused by primary visual, vestibular, cerebellar or proprioceptive dysfunction) [22]. Moreover, there are a number of exclusion criteria (e.g., history of repeated head injuries and sustained remission) and supportive criteria (e.g., unilateral onset, progressive disorder and positive response to medication with levodopa) [22].

Parkinson-related symptoms and disabilities

Cardinal signs
Cardinal signs of PD include bradykinesia, tremor at rest, rigidity, and postural instability [22, 23]. These are described below.

Bradykinesia means slowness of movements, and implies difficulties in planning, initiating and executing movements, difficulties with sequential movements and to perform multiple tasks simultaneously [23]. The onset of bradykinesia is often seen as slowness in conducting activities of daily living and prolonged reaction times. There is a loss of spontaneous movements and gestures, arm swing while walking is reduced, and tasks that require fine motor control become difficult [23]. Furthermore, drooling (due to impaired swallowing) and dysarthria are common [23, 24].

Tremor is an involuntary rhythmic movement of a body part [13]. Tremor in people with PD is typically present at rest and ceases with action or during sleep. It occurs typically at a frequency of 4 to 6 Hertz and is often most pronounced in the distal part of a limb [23].

Rigidity means an involuntary increase in muscle tone and implies a resistance to passive movement of a limb, often together with the cogwheel phenomenon [13, 23]. The rigidity is often increased if there is simultaneous movement in the contralateral limb and can be associated with pain [23].

Postural instability means a lack of postural control, i.e., difficulties in maintaining balance in static and dynamic situations. Postural instability, or balance impairment, is common in people with PD [25] and has been reported as one of the most distressing symptoms [26]. About every fourth person who is subsequently diagnosed with PD has been reported to have balance impairments already at their first visit to a neurological clinic, i.e., prior to PD diagnosis [27]. Two years after diagnosis, balance impairment can be found in 34% of persons with PD. Ten and 15 years after the diagnosis, the corresponding proportions are 71% and 92%, respectively [25]. One study showed that already five years before the PD diagnosis, balance impairments were more frequent in persons who later developed PD than in controls [28].

Persons with PD fall more often than age-matched healthy controls [29]. A meta-analysis showed that 57% of the persons with PD reported at least one fall, and 40% reported repeated falls during one year. Moreover, 21% of those without falls during the previous year reported falling at least once during a three months prospective follow-up period [30]. Falls are often experienced within the home or a familiar environment [31, 32], particularly among recurrent fallers [29]. Most falls occur while walking [29, 31]. Moreover, near falls are common [33].

Walking difficulties
Walking difficulties are common in people with PD already early on during the course of disease. A previous study found that 61% of persons with a PD duration of less than five years reported gait disturbances. The corresponding number for those with a PD duration for more than five years was 75% [34]. Walking

difficulties in people with PD are characterized by reduced step length, gait speed and arm swing, as well as having a stooped posture [35]. Their walking difficulties worsen as the disease progresses with a further reduction of gait speed, shuffling and shortened steps, and increased double support phase, i.e., time with both feet on the ground [35, 36]. Turning difficulties while walking are an early symptom [37] and are characterized by taking many and short steps [38]. Dual tasking, i.e., to conduct an additional (e.g., cognitive) task while walking, is often difficult and may result from a reduced walking automaticity [35].

Freezing of gait is common in people with advanced PD [39]. It is often described by the person with PD as if their feet were "glued to the ground" [39]. Freezing episodes are commonly experienced when they start to walk (start hesitation), make a turn (turning hesitation) or approach a destination such as a chair (destination hesitation) [40, 41]. Moreover, freezing of gait can be triggered by stress, dual-tasking, crowded places and narrow passages (e.g., doorways) [41].

Non-motor symptoms

Although PD is considered a motor disorder, almost all persons with PD report multiple non-motor symptoms [24]. Non-motor symptoms include, e.g., fatigue, anxiety, pain, sleep disturbances, depression, cognitive dysfunction and autonomic dysfunction, such as constipation and orthostatic hypotension [24, 42]. Several non-motor symptoms are negatively associated with quality of life [24]. One study found that already five years prior to PD diagnosis, the prevalence of several non-motor symptoms were significantly higher in those who went on to develop PD than in controls [28]. The number of non-motor symptoms increases with PD duration and severity [24].

Treatment, care and rehabilitation

There is no cure for PD, but medication with levodopa is often effective in the early years of the disease. As PD progresses, the effect of levodopa is often reduced and "on and off fluctuations" become usual. 'On' represents periods of the day when medication is effective and PD-related symptoms are somewhat limited, whereas 'off' represents periods with increased motor and/or non-motor symptoms [43, 44]. Persons with severe PD might benefit from advanced treatment methods, such as deep brain stimulation [43] or continuous subcutaneous administration of medication through a pump [44].

According to the World Health Organization (WHO), rehabilitation of people with disabilities, regardless of the origin, is a "process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social

functional levels". WHO further states that rehabilitation "provides disabled people with the tools they need to attain independence and self-determination" [10].

As of today, rehabilitation of persons with PD is often based on clinical experiences rather than empirical evidence, as there are few randomized controlled trials targeting rehabilitation. The Swedish National Board of Health and Welfare (Socialstyrelsen) is currently working on national guidelines, aiming to support county councils and municipalities in the treatment, care and rehabilitation of persons with PD. According to the upcoming guidelines, the health care system ought to offer persons with PD regular (at least twice a year) check-ups by a physician with extensive experiences of PD [45]. It is furthermore suggested that persons with PD should be offered comprehensive interdisciplinary team rehabilitation. The goal is to optimize functioning, reduce disability and teach the individuals with PD to cope with their disease [45].

A rehabilitation team may comprise of, e.g., a physician, nurse, physiotherapist, occupational therapist and a social worker. The team members provide different interventions through a rehabilitation process. For example, a physician can follow the PD progress and adjust medication when necessary. A PD specialized nurse can offer the person with PD continuity and availability, and thereby increase the quality of life for persons with PD as well as their families [45]. Physiotherapy is proven effective for, e.g., improving walking speed, muscle strength and movement functions in persons with PD [35]. An occupational therapist can be helpful in finding ways to facilitate activities of daily living by introducing various assistive devices and compensatory strategies. A social worker can offer counseling and thereby provide valuable support in dealing with the disease, both emotionally and in the contact with various authorities regarding, e.g., the social insurance system.

In Sweden, PD health care is most commonly provided at specialized outpatient neurology or geriatrics clinics. However, some persons with PD receive their care through the primary health care. Moreover, nurses and rehabilitation staff, employed by the municipalities, can visit severely disabled persons in their homes and support them with, e.g., smaller medical issues, home adjustments and physical exercises. As of today, interdisciplinary team rehabilitation is scarce and many persons with PD are commonly offered single interventions from different health care professions [45].

Fear of falling

The focus of this thesis is fear of falling (FOF) in persons with PD, which is a common phenomenon. The following section presents various conceptualizations of FOF, specific information of FOF in persons with PD, various rating scales for assessing FOF, as well as methods for evaluating such rating scales.

Conceptualizing fear of falling

FOF can be conceptualized as low fall-related self-efficacy [5], decreased balance confidence [6], a lasting concern about falling [3], or as activity avoidance due to the risk of falling [7]. Studies have shown that these conceptualizations are closely related but not interchangeable [46, 47]. In this thesis, the term FOF is used as an umbrella term for concerns about falling, decreased balance confidence, low fall-related self-efficacy, and activity avoidance due to the risk of falling.

Much of the literature on FOF is based on Bandura's model of self-efficacy [48]. Bandura states that functioning is dependent not only on actual skills, but also on a person's self-beliefs of efficacy. Someone with high self-efficacy will expect positive outcomes, while a person with low self-efficacy will expect negative outcomes in social, intellectual, as well as physical pursuits [48]. Bandura defines perceived self-efficacy as "people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances. It is concerned not with the skills that one has but with judgments of what one can do with whatever skills one possesses" (page 94) [48].

Fear of falling in persons with Parkinson's disease

FOF is a common and non-negligible problem in PD with a prevalence ranging from 35 to 59% [49-53]. FOF is more common and pronounced among those who have experienced previous falls and among those who have a more severe PD, but occurs also among those without a history of falls [53, 54] and throughout the course of the disease [54]. It is more common and pronounced in people with PD than in aged matched healthy controls [29, 55-58].

In a previous study of persons with PD, 11% of the participants described FOF as their most stressful physical symptom [59]. FOF is a predictor of future falls and near falls already in mild PD [33]. Moreover, FOF is a predictor of reduced walking in the community [60], a barrier for ambulatory persons to engage in physical exercise [61] and expressed as restricting participation in meaningful activities [62]. FOF is associated with activity limitations [54, 63] and physical inactivity [63]. It

is negatively associated with quality of life [64] and a more important determinant of health-related quality of life than balance impairments and actual falling [65]. FOF is therefore suggested to be routinely evaluated in clinical practice [63].

Activities in FOF rating scales that are commonly scored as inducing high levels of FOF are, for example, walking on slippery surfaces, simple shopping, standing on a chair and reaching for something, walking a kilometer and going to a place with crowds [46, 54, 56, 64, 66-68].

Explanatory factors of fear of falling in Parkinson's disease

There is increasing knowledge of explanatory factors of FOF in PD, which may be important in order to provide optimal treatment, care and rehabilitation for people with PD and FOF. Several studies have investigated factors associated to FOF in persons with PD by using multivariable regression analyses [49, 51, 64, 69-71]. Walking difficulties, impaired balance, difficulties in activities of daily living and fatigue were all found to be explanatory factors of FOF in people with PD in at least two studies each [49, 51, 64, 69, 71]. Knee muscle strength [69] and motor fluctuations [51] have been studied in one multivariable study each and were found to be explanatory factors of FOF. Turning hesitations, anxiety, motor symptoms, cognitive impairment, depression, PD duration, and PD severity were found to be explanatory factors of FOF in some multivariable studies [51, 64, 70, 71] but not in others [49, 51, 64, 69, 71]. Female gender and a history of falls do not significantly explain FOF in people with PD [49, 51, 69, 71], which is in contrast to FOF in elderly persons without PD [72].

Taken together, there is a handful of studies that have identified explanatory factors of FOF in people with PD, but the results are sometimes inconclusive. Moreover, two of the studies collected data by using postal surveys and lacked clinical data [51, 64]. Three of the studies included only a small number ($n = 4$ to 6) of potential independent variables [64, 69, 70], resulting in non-comprehensive analyses of explanatory factors of FOF. Furthermore, prior multivariable PD studies have mainly focused on the associations between FOF and PD-related disabilities, such as difficulties in walking and activities of daily living [49, 51, 64, 69, 70]. Less is known about the associations between FOF and personal and environmental factors [49, 51].

At the time of the Explanatory study that is included in this thesis (study III), most previous studies that explored explanatory factors of FOF had conceptualized it as fall-related self-efficacy [49, 51, 64, 70]. Only one study had explored explanatory factors of FOF, conceptualized as balance confidence [69] and activity avoidance due to the risk of falling [64], respectively. It was only recently that a study was published (other than the Explanatory study in this thesis) that explored explanatory factors of FOF conceptualized as concerns about falling [71].

Experiences of fear of falling in Parkinson's disease

Although FOF is a subjective emotion, to the best of my knowledge, no study has focused on exploring how persons with PD experience FOF. Previous qualitative PD studies that focused on other concepts than FOF have described that it impacts activities and perceived participation [62, 73] and is seen as a great loss of freedom [74]. There are qualitative studies on FOF in elderly persons without PD [75-79]. However, since many explanatory factors of FOF are PD-related, it is plausible that the experience of FOF in persons with and without PD differ. Therefore, there is a need for studies that focus on the experiences of FOF in persons with PD.

Assessing fear of falling

There is a wide range of methods for assessing FOF, from simple one-item questions to various self-reported rating scales that assess different aspects of FOF [47]. The dichotomous question "Are you afraid of falling" (yes/no) is commonly used, e.g., [50, 52, 53]. However, it is limited by its simple nature and makes it difficult to capture variations in the phenomenon between individuals and over time. Others have used the same question but formulated the response options as a Likert scale, e.g., "Not at all, A little, Somewhat, or Very much" [80] or "Never, Almost never, Sometimes, Often, or Very often" [81].

The first continuous rating scale for assessing FOF was the Falls Efficacy Scale (FES), developed by Tinetti and colleagues in 1990 [5]. FES assesses fall-related self-efficacy and is based on a definition of FOF as "low perceived self-efficacy at avoiding falls during essential, nonhazardous activities of daily living" [5]. The activities that are included as items in FES were chosen based on the thoughts and opinions of physiotherapists, occupational therapists, rehabilitation nurses and physicians [5]. Although widely used, FES has been criticized for having too many response categories, containing imprecise items that assess FOF in activities that are too basic, and that the items do not cover exercise or social activities [4, 6, 82]. As a result, the FES has been modified several times and many other FOF rating scales have been developed that assess different aspects of FOF [47].

Four different rating scales targeting various aspects of FOF were used in this thesis. These are described below.

Swedish version of the Falls Efficacy Scale

The Swedish version of FES (FES(S)) assesses FOF conceptualized as fall-related self-efficacy [83]. In FES(S), respondents answer the overall question how confident they are in conducting 13 different activities (items) without falling, e.g., go to the toilet, get dressed and undressed, and clean the apartment. Response categories range from 0 (Not confident at all) to 10 (Completely confident) and the

total score ranges from 0 to 130 (higher = better) [83]. The activities that are included as items in FES(S) were selected based on the items in the original FES and "the authors' clinical reasoning" [83]. One study has assessed the psychometric properties of FES(S) in persons with PD with satisfying results [46] but the findings need to be confirmed.

Activities-specific Balance Confidence scale

The Activities-specific Balance Confidence scale (ABC) assesses balance confidence [6]. Respondents answer the overall question how confident they are that they would not lose their balance or become unsteady when conducting 16 different activities (items), e.g., walk around the house, stand on a chair and reach for something, and walk in a crowded mall where people rapidly walk past you. The activities that are included as items in ABC are selected based on suggestions from clinicians as well as from community-living seniors [6].

In this thesis, a Swedish translated and culturally adapted version of the ABC was used. The cultural adaptation implies that items related to stepping onto or off escalators are changed to traveling by bus (L. Lundin-Olsson, unpublished material, written personal communication, June 20, 2012). Response categories range from 0 (No confidence) to 10 (Completely confident). The total score is the mean value of the 16 items, transformed into percentage, i.e., it ranges from 0 to 100% (higher = better). Five studies have assessed the psychometric properties of ABC in people with PD [66-68, 84, 85]. However, three of these studies had small sample sizes (*n* = 19 to 37) [67, 68, 84] and three included a limited set of psychometric analyses of validity and reliability [66, 67, 84]. One study, which was published after the Psychometric study that is included in this thesis (study II), criticized ABC for having too many response categories but otherwise showed satisfying results [85].

Modified Survey of Activities and Fear of Falling in the Elderly

The modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE) assesses activity avoidance due to the risk of falling [7]. Respondents answer the overall question whether they avoid doing 17 different activities (items) because of a risk of falling, e.g., go for a walk, go up and down stairs, and go out to a social event. The response options are: Would never avoid, Sometimes avoid, or Always avoid (scored 1 to 3, respectively). The total score ranges from 17 to 51 (higher = worse) [7].

The mSAFFE is a modified and simplified version of Survey of Activities and Fear of Falling in the Elderly (SAFE) that assesses both activity level, FOF, and activity restriction [82]. The activities that are included as items in mSAFFE are the 17 activities that were most commonly avoided by residents in public senior housings out of the 22 activities that are included in SAFE [7]. These were in turn chosen

from "existing disability instruments" based on "judgements made by three experts" [82].

In this thesis, the Swedish translated mSAFFE was used (L. Lundin-Olsson, unpublished material, written personal communication, June 20, 2012). One previous study assessed the psychometric properties of mSAFFE in persons with PD with satisfying results [46] but the findings need to be confirmed.

The mSAFFE was originally referred to as "SAFFE" by its developers [7]. Thereby, the name SAFFE was used in the published version of the ICF Linking study that is included in this thesis (study I). However, there has been some confusion in the literature concerning the original rating scale (SAFE) and the modified version (SAFFE) [86, 87]. The modified version has also been referred to as "mSAFFE" [47, 88]. In order to avoid further confusion, the name "mSAFFE" was used in the Psychometric study that is included in this thesis (study II), as well as in this thesis.

Falls Efficacy Scale-International

The Falls Efficacy Scale-International (FES-I) assesses concerns about falling [4]. In FES-I, the respondents answer the overall question how concerned they are about the possibility of falling in 16 different activities (items), e.g., taking a bath or shower, visiting a friend or relative, and walking up or down a slope. The response options are: Not at all concerned, Somewhat concerned, Fairly concerned, or Very concerned (scored 1 to 4, respectively). The total score ranges from 16 to 64 (higher = worse) [4] and can be categorized into groups describing low (16-19 points), moderate (20-27 points) and high concerns about falling (28-64 points) [89].

FES-I is developed by the Prevention of Falls Network Europe (ProFaNE) and the activities that are included as items are selected based on items from the original FES, ABC and SAFE as well as the "professional experience of ProFaNE members". In this thesis, the Swedish translated FES-I was used [90]. To the best of my knowledge, no study has assessed the psychometric properties of FES-I in people with PD.

Evaluating rating scales of fear of falling

When choosing a FOF rating scale for clinical use or research purposes, there are some aspects that need to be considered, such as if the rating scale captures the aspects of interest and whether the scale provides assessments of high quality with little measurement error. The following sections will deal with ways of studying the validity, i.e., that a scale assesses what it is intended to assess, and other psychometric properties, i.e., data completeness, scaling assumptions, targeting and reliability.

Content validity by linking rating scales to the International Classification of Functioning, Disability and Health

An increased conceptual understanding of FOF rating scales might facilitate the process of choosing a suitable scale. One way of increasing the conceptual understanding is by linking the rating scales to the International Classification of Functioning, Disability and Health (ICF) [91-93]. Linking is a way of mapping the content covered by a scale (overall question, response options and items) and results in a structured description of the scale. It provides a way of exploring the content validity [93] and should be considered a complement to traditional psychometric evaluations.

The ICF was developed by the World Health Organization in 2001. It is a hierarchically structured classification of health outcomes, developed with the intention to form a common language for health across cultures and disciplines [91].

The ICF embodies aspects of health and some aspects of health-related well-being (e.g., education and labor). It is divided in two parts: the first part covers functioning and disability while the second part covers contextual factors. Each of the two parts has two components. Functioning and disability contain the components "body functions and structures" and "activities and participation". Contextual factors contain the components of "environmental factors" and "personal factors" [91].

Body functions are defined as "the physiological functions of body systems (including psychological functions)". Body structures are defined as "anatomical parts of the body such as organs, limbs and their components". Activity is defined as "the execution of a task or action by an individual", whereas participation is defined as "involvement in a life situation". Environmental factors are defined as the "physical, social and attitudinal environment in which people live and conduct their lives", while personal factors are the "particular background of an individual's life and living" [91].

Problems with body functions or structures are described as impairments. Difficulties within the component of activities and participation are described as activity limitations or participation restrictions. "Functioning" is an umbrella term for all body functions, activities and participation, whereas "disability" serves as an umbrella term which covers impairments, activity limitations and participation restrictions [91].

The various components contain a large number of hierarchically organized categories, each assigned a unique code. The following example illustrates the structure of ICF:

> "d Activities and participation" (component level)
>
> "d4 Mobility" (chapter/first level category)

"d450 Walking" (second level category)

"d4502 Walking on different surfaces" (third level category)

Evaluating psychometric properties of rating scales

To evaluate whether a rating scale is of high quality and suitable for the sample in question, one needs to study its psychometric properties, such as data completeness, scaling assumptions, targeting, and reliability. These issues are sample dependent [94] and need to be evaluated when a rating scale is used in a new population, e.g., people with PD. Moreover, psychometric properties, as well as other research findings, needs to be confirmed in separate studies in the same population. Psychometric properties can be evaluated in various ways. In this thesis, classical test theory is applied.

Data completeness is a measure of the degree to which a rating scale is completed. If many respondents fail to complete or choose not to complete a rating scale, it could be a sign that the rating scale is difficult to understand or is irrelevant to the respondents [94]. Data completeness can be determined by calculating the percentage of missing data for items and total scores [94, 95].

Scaling assumptions refer to the legitimacy of summing items into a total score. Items should be roughly parallel and have similar variance, which can be explored by studying item means, standard deviations (SDs) and distribution of item response option frequency. Moreover, items should measure the same underlying construct and contribute with enough information to the total score, which is said to be fulfilled if the corrected item-total correlations exceed 0.4 [94, 95].

Targeting refers to whether the rating scale's score distribution can adequately represent the true level of e.g., FOF in the study sample [94]. This can be evaluated by studying the rating scale's score distribution, skewness, floor and ceiling effects. Mean total score should be close to the scale's midpoint, total scores should range the full span, skewness should be less than ± 1 [94, 96], and floor and ceiling effects (i.e., the percentage respondents receiving the minimum and maximum possible score, respectively) should not exceed 15 to 20% [94, 97].

Reliability refers to the random error associated with scale scores and the reproducibility of scores [94]. Reliability can be assessed in several ways. Internal consistency can be assessed with Cronbach's alpha and relates to whether several items that propose to assess the same construct produce similar scores [98]. Test-retest reliability, i.e., a rating scale's ability to produce stable scale scores over a time period when a respondent's condition is unchanged, can be assessed with Intraclass Correlation Coefficient (ICC) [94]. Cronbach's alpha and ICC values above 0.75 or 0.80 are considered acceptable for group level [99, 100], while an ICC value above 0.90 has been suggested as a minimum when using scales for

individual comparisons [100, 101]. To further explore the reliability between two test occasions, the number of outliers for a rating scale can be calculated, i.e., individuals with large differences in scale scores between test and retest [9]. Moreover, Standard Error of Measurement (SEM) is an expression of the measurement error, which indicates the smallest change that can be interpreted as a "real" change (i.e., above measurement error) in a group of people [11]. SEM can be converted into the Smallest Detectable Difference (SDD), which indicates the smallest change that can be interpreted as a real change (i.e., above measurement error) for an individual [11].

Rationale

FOF is common in people with PD and may have large consequences in daily life, causing a sedentary lifestyle, social isolation and reduced quality of life. FOF is therefore an important aspect to consider for researchers as well as clinicians and the rehabilitation team.

Adequate and high quality outcome assessments are needed to be able to accurately assess FOF and monitor how it changes over time. There are several rating scales for assessing various conceptualizations of FOF. To be able to distinguish between them and to facilitate the process of choosing a suitable rating scale, the conceptual understanding of the scales needs to be improved. Moreover, knowledge of the scales' psychometric properties (i.e., data completeness, scaling assumptions, targeting and reliability) is essential for picking an appropriate rating scale and will facilitate the interpretation of data obtained from the scales. As of today, there is limited knowledge of the psychometric properties of FOF rating scales in people with PD. The FES-I has, for example, never been tested in people with PD. Furthermore, simultaneous head-to-head comparisons of several FOF rating scales are lacking.

In order to provide optimal treatment, care and rehabilitation for people with PD and FOF, there is a need for a better understanding of FOF among researchers as well as clinicians. Knowledge about contributing factors to FOF is crucial. Comprehensive studies are needed that explore explanatory factors of FOF, taking both PD-related disabilities, personal and environmental factors into consideration. Although FOF is a subjective emotion, no study has yet explored how persons with PD experience FOF. To be able to meet and treat persons with PD and FOF in the best way possible, there is a need for a deeper and richer understanding of FOF as a phenomenon. This implies that qualitative studies that explore how persons with PD experience FOF are needed.

Aim

The overarching aim of this thesis was to increase the knowledge of how FOF can be assessed in persons with PD, as well as to expand and deepen the understanding of FOF in persons with PD in relation to explanatory factors and the persons' own experiences.

Specific aims

Study I: To gain a deeper understanding of the content of four FOF rating scales (FES-I, FES(S), ABC and mSAFFE) by linking them to the ICF.

Study II: To evaluate the psychometric properties of four FOF rating scales (FES-I, FES(S), ABC and mSAFFE) in persons with PD. More specifically, to investigate and compare the scales' data completeness, scaling assumptions, targeting, and reliability.

Study III: To identify explanatory factors of FOF (conceptualized as concerns about falling) in persons with PD by focusing on both personal, and environmental factors, as well as PD-related disabilities.

Study IV: To explore the experiences of FOF in persons with PD who have reported FOF.

Methods

Overall study designs

This thesis builds upon four separate studies: the ICF Linking study (I), the Psychometric study (II), the Explanatory study (III) and the Interview study (IV). An overview of the main outcome assessments and main analyses is outlined in Table 1.

Table 1.

Overview of main outcome assessments and main analyses in the four studies

	Study I	Study II	Study III	Study IV
Name of study	ICF Linking study	Psychometric study	Explanatory study	Interview study
Main outcome assessments	Not applicable	FES-I, FES(S), ABC, mSAFFE	FES-I	Not applicable
Main analyses	Content density, content diversity, bandwidth of content coverage	Basic descriptive statistics, corrected item-total correlation, Cronbach's alpha, ICC, SEM, SDD	Multivariable ordinal regression	Qualitative content analysis

ICF = International Classification of Functioning, Disability and Health; FES-I = Falls Efficacy Scale-International; FES(S) = Swedish version of Falls Efficacy Scale; ABC = Activities-specific Balance Confidence scale; mSAFFE = modified Survey of Activities and Fear of Falling in the Elderly; ICC = Intraclass Correlation Coefficient; SEM = Standard Error of Measurement; SDD = Smallest Detectable Difference.

Recruitment of participants

The ICF Linking study did not include any empirical data. The recruitment processes for the Psychometric study, the Explanatory study and the Interview study are presented below.

Psychometric study

The Psychometric study was a postal survey study sent out on two occasions (test and retest). Data were collected from March to June, 2013. Participants were recruited from two outpatient clinics in southern Sweden. Inclusion criterion was a PD diagnosis (ICD-10: G 20.9) since at least one year. Exclusion criteria were difficulties reading and writing Swedish, clinically confirmed dementia, or cognitive or medical problems of a severity that were assumed to restrict giving informed consent or participating in the study. Moreover, individuals who were completely bedridden or wheelchair bound were excluded.

To reach a "good sample size" according to recommendations for methodological quality and test-retest reliability analysis [102], a target was set to 50 to 99 participants with total scores on the FOF rating scales at both test and retest. Based on previous postal surveys in people with PD [103, 104], a response rate of approximately 65%, some additional drop outs at retest as well as some internal missing responses on the FOF rating scales were anticipated.

The author of this thesis (i.e., SBJ) and a PD specialized nurse at each outpatient clinic screened the medical records for all PD patients that had visited the two clinics during the past 14 months ($n = 275$). After applying the inclusion and exclusion criteria, 174 potential participants remained, of whom 102 were finally included in the study. A flow chart of the recruitment process for the Psychometric study is presented in Figure 1.
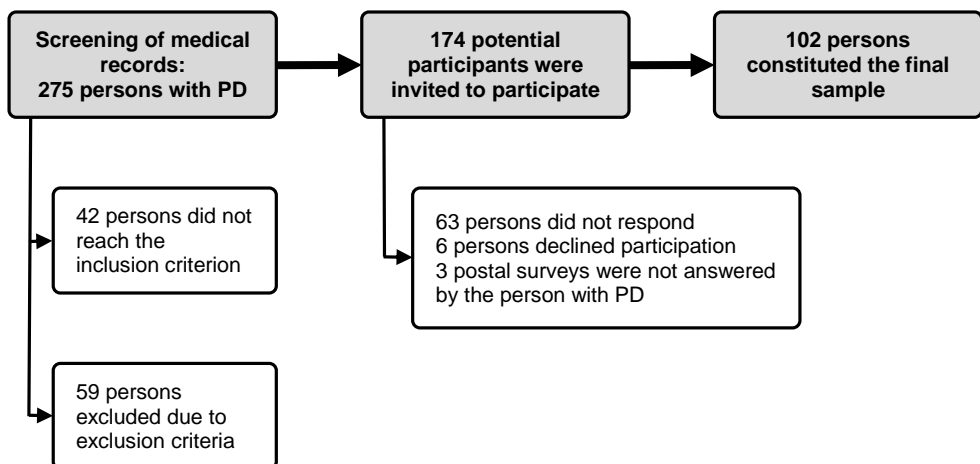
Figure 1.
Flow chart of the recruitment process for the Psychometric study. PD = Parkinson's disease.

Explanatory study

The Explanatory study was based on data collected through a postal survey and during a subsequent home visit within the larger project "Home and health in people ageing with PD" [105]. Data were collected from November 2012 to November 2013. Participants were recruited from three hospitals in southern Sweden (other hospitals than in the Psychometric study). Inclusion criterion was a PD diagnosis (ICD-10: G 20.9) since at least one year. Exclusion criteria were difficulties in understanding and speaking Swedish and/or pronounced cognitive difficulties or other reasons that rendered the individual unable to give informed consent or take part in the majority of the data collection (e.g., hallucinations or a recent stroke). Living outside the region of Skåne was an additional exclusion criterion, applied only for those who were recruited from the largest hospital. Moreover, this study excluded those who did not respond to all items of the FES-I (the dependent variable in the Explanatory study) within two months from the home visit.

PD specialized nurses at each hospital screened the medical records for all PD patients ($n = 717$) at the three hospitals. After applying the inclusion and exclusion criteria, 437 potential participants remained, of whom 241 were finally included in this study. A flow chart of the recruitment process for the Explanatory study is presented in Figure 2.
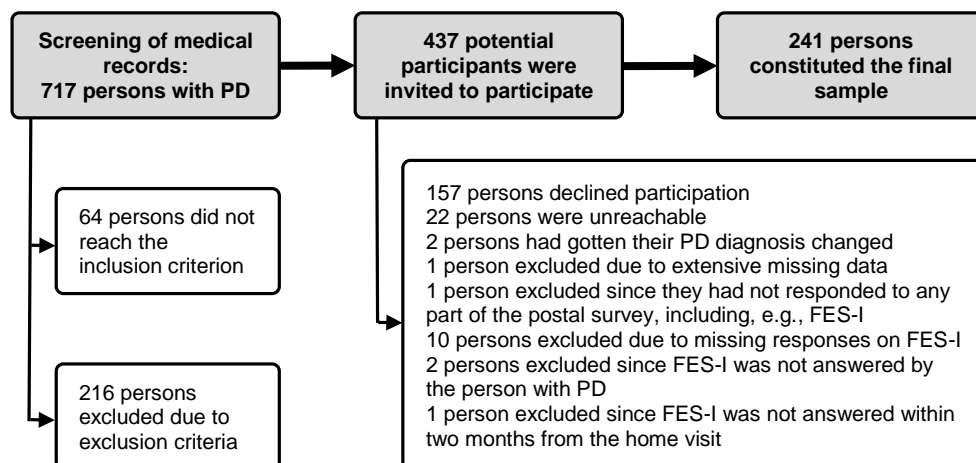

Figure 2.
Flow chart of the recruitment process for the Explanatory study. PD = Parkinson's disease; FES-I = Falls Efficacy Scale-International.

Interview study

In the Interview study, data were collected from July to October, 2014. The recruitment process was conducted in several steps, in order to ensure the inclusion of information rich cases in relation to the experiences of FOF. Participants were recruited among the 56 persons who stated that they were afraid of falling (affirmed the dichotomous question "Are you afraid of falling?") in the Psychometric study. For further inclusion and exclusion criteria, see Psychometric study. An initial, strategic selection was conducted based on data from the Psychometric study, striving for heterogeneity regarding age, gender, PD severity, degree of FOF (assessed by the FES-I), living circumstances, previous falls and the use of mobility devices.

The potential participants were invited in two steps: first 25 and then an additional six potential participants, since the quantitative data collection (described below) revealed a lack of persons with a high level of FOF in the first sample. Those who wanted to participate were asked questions regarding their PD duration, self-rated PD severity (mild/moderate/severe), intensity of FOF (Are you afraid of falling: not at all/a little/somewhat/very much [80]), frequency of FOF (Are you afraid of falling: never/almost never/sometimes/often/very often [81]), living circumstances (alone/not alone), occurrence of falls during the past six months and the use of mobility devices.

The final selection of participants was based on the updated data on the variables mentioned above, in order to get a heterogenic sample with various experiences of FOF. The final sample contained twelve participants. A flow chart of the recruitment process for the Interview study is presented in Figure 3.
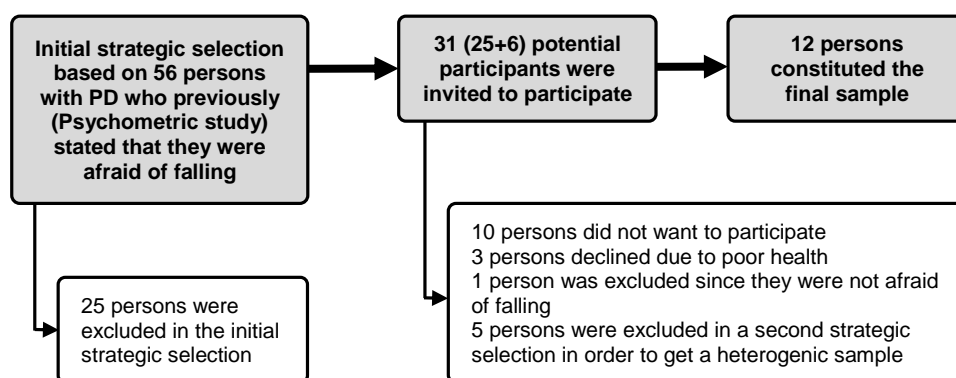
Figure 3.
Flow chart of the recruitment process for the Interview study. PD = Parkinson's disease.

Procedures

ICF Linking study

In the ICF Linking study, the overall questions, items and response categories in four FOF rating scales (FES-I, FES(S), ABC and mSAFFE, described in the introduction) were linked to the ICF. The linking process followed the updated linking rules [93]. According to the linking rules, one item may consist of multiple meaningful concepts, and all concepts are to be linked to the most precise ICF category. The same ICF category may be used several times for linking multiple meaningful concepts within an item. Content of a meaningful concept that is not explicitly named in the corresponding ICF category is documented as "additional information" [93].

Initially, all meaningful concepts of the overall questions, items and response categories in the four FOF rating scales were identified and linked to the most precise ICF categories [93]. This task was conducted individually and independently by the three linkers (the author, Maria H Nilsson; MHN, and Gunilla Carlsson; GC, who thereafter discussed their results to reach a consensus. In cases where consensus was not easily reached, a fourth person (Jan Lexell; JL) was involved to further deepen the discussions and decide on the appropriate corresponding ICF category. This process was in agreement with previous linking studies [1, 106].

Psychometric study

The participants in the Psychometric study received a postal survey containing information about the study, a written informed consent form, socio-demographic and disease-related questions, the four FOF rating scales (FES-I, FES(S), ABC and mSAFFE) and a pre-stamped return envelope. The FOF rating scales were administered twice (test and retest), two weeks apart. A reminder was sent after two weeks to non-responders on the first survey, and after one week on the retest survey. The internal order of the four FOF rating scales was altered to minimize the risk that the ordering affected data completeness. Four different arrangements were used so that the scales appeared an equal number of times as the first, second, third and fourth rating scale.

Explanatory study

Data for the Explanatory study were collected by means of a self-administered postal survey and a subsequent home visit that contained both structured interviews and clinical assessments. All participants provided their written informed consent during the home visit. The data collection was administered and conducted by two project administrators that underwent project-specific training. Potential participants received information about the study by mail and were then contacted by telephone and asked if they wanted to participate. For those who wanted to participate, a date for the home visit was scheduled. A postal survey with self-administered questions and rating scales (e.g., FES-I) was sent to the participants ten days in advance of the home visit. During the home visit, the project administrator screened the questionnaire to avoid any missing responses. Since the Explanatory study utilized data collected within a larger project, the data collection was extensive and covered more than the data that were included in this thesis. The mean time for the home visits was 2 hours and 20 minutes (SD 27 minutes; minimum 1 hour and 15 minutes; maximum 4 hours and 5 minutes).

Interview study

Data for the Interview study were collected by means of qualitative interviews, conducted by the author in the participants' homes. All participants provided their written informed consent during the home visit. Potential participants received information about the study by mail and were then contacted by telephone and asked if they wanted to participate. Those who wanted to participate and were chosen in the strategic selection (described in the previous section) were telephoned anew to schedule a date for the qualitative interview. Those who wanted to participate but were excluded in the strategic selection were contacted and informed about the decision of not including them in the study.

The qualitative interviews were semi-structured and followed a study-specific interview guide. The interview guide contained open-ended questions that enabled the participant to talk freely about, for example, the importance and meaning of FOF, activities and situations when FOF was experienced, variations in FOF due to external and internal factors, and the perceived consequences of FOF (see Appendix 1). Follow-up questions and probes were used to deepen the participants' answers.

At the end of each interview, the interviewer/author summarized the main points of the interview and gave the participant the opportunity to add comments and clarifications. The interviews were audio recorded and lasted from 25 to 78 (median 40) minutes. After the interviews, the participants responded to FES-I, socio-demographic and disease-related questions.

Each interview was transcribed verbatim by the author. After four interviews were conducted, the author and a senior researcher (GC, experienced in qualitative studies) read the transcripts and discussed the interviews in order to ensure that no important areas were missed. Another six interviews were then conducted, and the transcripts were read and discussed by all four researchers that were involved in the study (the author, GC, MHN, and JL). After two additional interviews were conducted, the author and one of the senior researchers (GC) discussed all twelve interviews and found that no new data of interest to the study aim was added, and thus decided to terminate the data collection.

Outcome assessments

All participants responded to questions on age, gender, PD duration, self-rated PD severity (mild/moderate/severe), falls during the past six months (yes/no), use of mobility devices outdoors (yes/no), living circumstances (alone/not alone), and difficulties in activities of daily living (Parkinson's disease Activities of Daily Living Scale; PADLS, possible response categories: no/mild/moderate/high levels of/extreme difficulties with day-to-day activities [107]).

Several assessments of FOF were used in the thesis. All participants responded to a dichotomous question addressing FOF ("Are you afraid of falling: yes/no") and FES-I. The ICF Linking study and the Psychometric study also included FES(S), ABC and mSAFFE [4, 6, 7, 83]. These rating scales are described in the introduction. Furthermore, the Interview study included questions on the intensity (Are you afraid of falling: not at all/a little/somewhat/very much [80]) and frequency of FOF (Are you afraid of falling: never/almost never/sometimes/often/very often [81]).

In the Psychometric study, all data were collected through a postal survey. In the Explanatory study, most data were collected through a structured interview during a home visit. Exceptions were data on PD severity (which were collected during the initial phone call), difficulties in activities of daily living and FOF (which were collected through a postal survey). The Explanatory study included additional outcome assessments, which are described in the next section.

Participants in the Interview study responded to the above mentioned questions during the initial phone call (to enable the strategic selection of participants) and again after the qualitative interview (in order to receive updated data, for descriptive purposes). Exceptions were data on difficulties in activities of daily living and FES-I, which were collected after the qualitative interview only.

There were several reasons for choosing the four FOF rating scales that were included in the ICF Linking study and the Psychometric study. FES-I was included because it is developed and recommended by the ProFaNE [4]. FES-I was developed by combining and modifying items from FES, ABC and SAFE, and these scales were therefore considered for inclusion. However, FES [5] and SAFE [82] are not available in Swedish, while the adapted versions FES(S) and mSAFFE are. Moreover, SAFE is extensive and complicated whereas the modified and simplified mSAFFE might be more suitable for frail people, such as persons with PD. Finally, the inclusion of rating scales that assess various conceptualizations of FOF were warranted. FES-I and FES(S) relate to concern and confidence in relation to falls, respectively, whereas ABC relates to losing balance and becoming unsteady, and mSAFFE relates to activity avoidance due to the risk of falling.

The reason for choosing FES-I as the dependent variable in the Explanatory study was partly due to the results of the Psychometric study, partly due to the lack of previous studies that explored explanatory factors of FOF conceptualized as concerns about falling.

For each of the four FOF rating scales, Swedish-translated and Swedish-adapted versions were used. Because of linguistic and cultural differences between the English and Swedish language, the versions used are not literal translations and have minor differences.

Additional outcome assessments in the Explanatory study

The Explanatory study included several additional outcome assessments that were not included in the other studies. These are described below.

The postal survey included several patient-reported outcomes. Dichotomous (yes/no) questions addressed near falls during the past six months, perceived balance problems while dual tasking and fluctuations with increasing PD symptoms. Three self-administered rating scales in addition to FES-I were included: Generic Walk-12 (Walk-12G), General Self-Efficacy Scale (GSE) and the Energy subscale of the Nottingham Health Profile (NHP-EN). Walk-12G addresses walking difficulties in everyday life (possible scoring range 0-42; higher = worse) [103], GSE addresses general self-efficacy (possible scoring range 10-40; higher = better) [108, 109], whereas NHP-EN addresses fatigue and contains three dichotomous (yes/no) questions [110]. Moreover, the Explanatory study included individual items from two self-administered rating scales. Those were item 6 (i.e., turning hesitations) of the self-administered version of Freezing of Gait Questionnaire [111] (FOGQsa, possible item scoring range 0-4; higher = worse) [112] and two dichotomous (yes/no) items of the Nonmotor Symptoms Questionnaire (NMSQuest): anxiety (item no. 17) and orthostatism (no. 20) [113].

During the home visit, a structured interview included questions on social support and possession of a security alarm connected to home care services, as well as the Geriatric Depression Scale (GDS-15, possible scoring range 0-15; higher = worse) [114]. Clinician-reported outcomes were used during the home visit and included assessments of motor symptoms (part three of the Unified Parkinson's Disease Rating Scale; UPDRS III, possible scoring range 0-108; higher = worse [115]) and cognitive function (Montreal Cognitive Assessment; MoCA, possible scoring range 0-30; higher = better [116]). Moreover, a performance outcome of lower-extremity function (timed Chair-Stand Test [117, 118]) was included.

Finally, the type of housing was categorized into apartment or single-family housing by the project administrators and residential area was categorized into rural, urban or metropolitan based on postal code according to the Swedish Board of Agriculture [119].

Data analyses

The four studies build upon completely separate analyses that are described below.

ICF Linking study

Following the example of Geyh et al. [1], content density, content diversity and bandwidth of content coverage for each linked FOF rating scale were calculated and reported to enable a quantitative comparison of the rating scales. Content density is the number of identified meaningful concepts divided by the number of items in the rating scale. Content diversity is the number of unique ICF categories linked divided by the number of identified meaningful concepts. A value of 1 means that each meaningful concept is linked to different categories, which implies that the content of the rating scale is highly diverse. Bandwidth of content coverage is the percentage used ICF categories of the total number of ICF categories, i.e., 1454 [1].

Psychometric study

Data completeness, scaling assumptions, targeting and reliability were studied and compared for each of the four FOF rating scales according to the analyses that are described in the introduction under the subheading "Evaluating psychometric properties of rating scales".

Imputation was not used, i.e., a total score required absence of any missing item responses. One-way random, single measures ICC with absolute agreement definition of concordance was used for studying the test-retest reliability [120]. SEM was calculated using the formula $SD_{baseline} \times \sqrt{1 - ICC}$ [12]. SDD was calculated using the formula $SEM \times 1.96 \times \sqrt{2}$ [11]. Due to differences in scoring ranges between the FOF rating scales, SEM and SDD values were also expressed as percentages of the possible scoring ranges, to facilitate comparisons. These were calculated as $SEM\% \text{ or } SDD\% = SEM \text{ or } SDD \div number \text{ } of \text{ } possible \text{ } scoring \text{ } options \times 100$. For example, possible total score for mSAFFE ranges from 17 to 51, which means that there are 35 possible scoring options. This implies that for mSAFFE, $SEM\% = SEM \div 35 \times 100$.

An outlier was defined as a participant with a difference in scale scores between test and retest outside the first or third quartile $\pm 1.5 \times$ interquartile range of the mean difference in scale scores between test and retest [9].

All analyses were based on data from the first postal survey, except ICC, SEM and SDD values, which utilized data from the first as well as the second (retest) postal survey in the Psychometric study.

Explanatory study

Concerns about falling, assessed with FES-I, constituted the dependent variable in the Explanatory study. FES-I total scores were categorized into three groups: low (16-19 points), moderate (20-27 points) and high (28-64 points) concerns about falling, according to previous work by Delbaere et al. [89]. Data on personal factors, environmental factors and PD-related disabilities constituted the independent variables ($n = 22$).

Personal factors included: age, gender and general self-efficacy (GSE). Environmental factors included: use of mobility devices outdoors, social support, living circumstances, possession of a security alarm, housing type and residential area. PD-related disabilities included: motor symptoms (UPDRS III), walking difficulties (Walk-12G), turning hesitations (FOGQsa item 6), balance problems while dual tasking, falls and/or near falls during the past six months, lower extremity function (Chair-Stand Test), difficulties in activities of daily living (PADLS), fluctuations with increasing PD symptoms, cognitive function (MoCA), depression (GDS-15), fatigue (NHP-EN), anxiety (NMSQuest item 17) and orthostatism (NMSQuest item 20).

FOGQsa item 6, PADLS and NHP-EN were dichotomized. Those who scored ≥ 1 in FOGQsa item 6 were classified as having turning hesitations [51]. In PADLS, those who responded "no" or "mild difficulties with day-to-day activities" were

recorded as not needing help from others, whereas those who responded "moderate", "high levels of" or "extreme difficulties with day-to-day activities" were recorded as needing help from others. Those who affirmed at least one of the three dichotomous questions in NHP-EN were classified as having fatigue [121].

Spearman's correlation coefficient (r_s) was used to study relationships among independent variables in order to detect any multicollinearity. Due to a skewed distribution of data in the variable 'Social support' (only two persons did not receive any social support) and signs of multicollinearity between the variables 'Social support' and 'Living circumstances' ($r_s > 0.7$), 'Social support' was omitted from further analyses.

Associations between the dependent variable and the remaining 21 independent variables were then analyzed in a series of univariable ordinal regression models (data not shown). In order to avoid leaving out a confounding variable, it was decided to include all variables with a p-value below 0.3 in the multivariable regression model. All associations fulfilled this criterion and the variables were entered into a multivariable ordinal regression model (cumulative odds model, link function: logit) with the categorized FES-I as the dependent variable.

Ordinal regression analysis is suitable when the dependent variable is of ordinal nature. It estimates the average odds ratios of all possible dichotomizations of the response variable, which are assumed to be equal [122]. That is, the odds ratio for having low or moderate compared to high concerns about falling were assumed to be equal to the odds ratio of having low compared to moderate or high concerns. This assumption can be checked by using the test of parallel lines, where a non-significant Chi-square is desirable and indicates that the model is well fitted [122].

The first step of the modelling included 21 dichotomous, categorical or continuous/ordinal independent variables. The estimates and p-values for all independent variables in the multivariable model were inspected, and the variable with the highest p-value was manually removed. This step continued until all independent variables in the model had p-values below 0.1. The limit $p < 0.1$ was decided in order to ensure that no confounding variable was left out of the final model. Odds ratios with 95% confidence intervals for the independent variables that remained in the final model are reported. Nagelkerke's pseudo R^2 for the final model is presented as a measure of the models' explanatory capacity [123]. The test of parallel lines revealed a highly insignificant Chi-square ($p = 0.811$), which indicated that the model was well fitted [122].

The level of statistical significance was set to $p < 0.05$.

Interview study

The qualitative interviews were analyzed using manifest and latent content analysis, as described by Graneheim and Lundman [124]. Content analysis was considered to be a suitable method as it focuses on identifying similarities, differences and patterns in texts and enables a fairly structured work method [125].

The twelve transcribed interviews constituted the units of analysis and were thus the material that was coded, categorized and interpreted. The interviews were read through several times to obtain a sense of the whole. The text was divided into meaning units, which were then condensed and assigned various codes, describing the content. The codes were grouped into categories, which constituted descriptions of the manifest content of the interviews. After the process of categorization, the analysis continued through interpretation of the categories into themes, representing the latent, underlying meaning of the interviews.

In the process of categorization and interpretation, the researchers alternated between looking at the codes and the interviews in order to maintain a sense of the context. The author conducted and transcribed the interviews and performed the initial analysis. Subsequently, all four researchers discussed the interviews, codes, categories and themes on several occasions, which resulted in repeated adjustments and restructuring of categories and themes. These discussions mainly involved the author and GC, but all four researchers (the author, GC, MHN and JL) were involved throughout the analytical phase, in order to ensure that categories and themes fitted the data, and that the analysis addressed the intended focus of the study [124].

Ethical considerations

Ethical aspects have been addressed and reflected upon throughout the studies that are included in this thesis. The overall ethical principle for all scientific work should always be that a study must not cause the participants any unnecessary harm or discomfort. Most empirical research is, however, associated with some level of discomfort for its participants; if nothing else, it may be time consuming. The foreseeable benefits of the studies included in this thesis were considered to outweigh any foreseeable discomfort experienced by the participants.

The ICF Linking study did not include any participants. All potential participants in the other studies received written information that clearly stated that participation was voluntary, that they could withdraw from the study at any time, and that participation would not have any effect on their ongoing or future health care. Participation was not associated with rewards or compensations of any kind. Written informed consent was obtained from all participants. Collected data were treated confidentially and results are presented in such a way that individuals can not be identified.

The Psychometric study, the Explanatory study and the Interview study were conducted in accordance with the Helsinki Declaration and were approved by the Regional Ethics Review Board in Lund, Sweden (Dnr 2013/118, 2012/558 and 2014/412, respectively).

In the Psychometric study, potential participants were contacted by mail. Information about the study was received together with the postal survey. Non-responders received a new letter as a reminder. If they still did not respond, no further contact was made.

In the Explanatory study and the Interview study, potential participants received information about the study by mail. They were subsequently contacted by telephone and then got the opportunity to pose questions and were asked if they wanted to participate. If they declined participation, no further contact was made.

The Explanatory study included rather time consuming home visits that may have been strenuous for the participants. However, participants were offered the possibility to divide the home visit into two occasions. Moreover, one part of the home visit constituted objective assessments of the home and exterior surroundings

(part of a larger project, not included in this thesis), which did not require any active involvement of the participant.

If the home visits in the Explanatory study revealed that a participant was in need of help from e.g., physiotherapists, home help services or needed additional assistive devices, the project administrators had a brochure with relevant contact information that was offered to the participant.

In the Interview study, the sampling of participants was strategic and conducted in several steps. This implied that all persons who were initially contacted were not finally included as participants. Five persons agreed to participate but were later excluded in the strategic selection. All potential participants were informed about the strategic sampling method at the initial telephone contact. The five excluded persons were contacted again and informed about the decision of not including them in the study.

The individual interviews in the Interview study were conducted at a location of the participants' choice. All participants choose to be interviewed in their own home. On the day of the interview, the author arrived at the participant's home on the scheduled time but had set aside extra time to allow time for coffee, if offered by the participant. This was done to show respect for the participant and create a relaxed atmosphere that enabled them to open up during the interview.

The interviews in the Interview study included several questions on FOF that had obvious emotional consequences for some of the participants. The participants decided which information to share and were informed that they did not have to answer all questions if they did not want to. Transcripts were depersonalized before being shared with the co-researchers involved in the study.

Results

The results start with a description of the participants. Thereafter, the results of the four studies are presented under the headings Assessing FOF (covers the ICF Linking study and the Psychometric study) and Understanding FOF (covers the Explanatory study and the Interview study).

Participants

The Psychometric study, the Explanatory study and the Interview study included participants aged 45 to 93 years, with a PD duration ranging from 1 to 43 years. Roughly half of the participants were afraid of falling: 55% in the Psychometric study and 46% in the Explanatory study. FOF was an inclusion criterion for participation in the Interview study, which explains why all of its participants were afraid of falling. An overview of basic participant characteristics is presented in Table 2 (see next page). The ICF Linking study did not include any empirical data and is therefore not included in the table.

Assessing fear of falling

This section covers the results from the ICF Linking study (i.e., ICF linking of FES-I, FES(S), ABC and mSAFFE) and the Psychometric study (i.e., Psychometric properties of FES-I, FES(S), ABC and mSAFFE). The results from the two studies are presented separately.

ICF linking of FES-I, FES(S), ABC and mSAFFE

A total of 13 meaningful concepts from the overall questions and response categories, and 101 meaningful concepts from the 62 items of the four FOF rating scales (FES-I, FES(S), ABC, mSAFFE) were identified. All but three of the total number of meaningful concepts could be linked to the ICF.

Table 2.

Overview of participants' characteristic

	Psychometric study (II), $n = 102$	Explanatory study (III), $n = 241$	Interview study (IV), $n = 12$
Women, n (%)	43 (42%)	93 (39%)	6 (50%)
Age (years)	74 (68-78)	70 (64-77)	70 (66-75)
PD duration (years)	5 (3-11)[a]	8 (5-13)	9 (5-12)
Self-rated PD severity, n (%)			
Mild	24 (24%)[a]	82 (34%)[b]	3 (25%)
Moderate	61 (62%)[a]	112 (47%)[b]	9 (75%)
Severe	13 (13%)[a]	46 (19%)[b]	0 (0%)
Fear of falling (yes), n (%)	56 (55%)	112 (46%)	12 (100%)
Concerns about falling, n (%)[1]			
Low	23 (25%)[c]	69 (29%)	0 (0%)
Moderate	27 (29%)[c]	58 (24%)	6 (50%)
High	42 (46%)[c]	114 (47%)	6 (50%)
Falls past 6 months (yes), n (%)	36 (35%)	104 (43%)[b]	9 (75%)
Use of mobility devices outdoors (yes), n (%)	43 (44%)[d]	123 (51%)	9 (75%)
Need help from others in daily activities (yes), n (%)[2]	19 (21%)[c]	60 (25%)	5 (42%)
Living alone (yes), n (%)	28 (28%)[b]	61 (25%)	4 (33%)

Data are median (first-third quartile) unless otherwise stated. PD = Parkinson's disease.
[1] Falls Efficacy Scale-International. Total score was categorized: 16-19 = low; 20-27 = moderate; 28-64 = high concerns about falling.
[2] Parkinson's disease Activities of Daily Living Scale. Dichotomized: "No" and "Mild difficulties with day-to-day activities" are recorded as not needing help from others. "Moderate", "High levels of" and "Extreme difficulties with day-to-day activities" are recorded as needing help from others.
[a] 4 missing responses; [b] 1 missing response; [c] 10 missing responses; [d] 5 missing responses

The overall questions and response categories of the FES-I, FES(S) and ABC were linked to the ICF component of body functions, while the overall question and response categories of mSAFFE were linked to the component of activities and participation. These differences are due to that FES-I, FES(S) and ABC ask about concerns, confidence or losing balance/becoming unsteady, while mSAFFE asks about activity avoidance. The overall questions in FES-I, FES(S) and mSAFFE contained the meaningful concept "falling". Because falling cannot be linked to an ICF category, these three meaningful concepts were assigned the code "nd", i.e., not definable. More specific details of the linking of overall questions and response categories are presented in Appendix 2.

Table 3 illustrates the spread of item contents of the four FOF rating scales. The table reveals that the items emphasize the component of activities and participation; a vast majority of the meaningful concepts identified within the 62 items were linked

to this component and only one single meaningful concept (from ABC) was linked to the environmental component. Although several items relate to the surrounding environment, these did not constitute meaningful concepts by themselves. Thus, most environmental factors ended up as "additional information". Detailed results of the linking of the 62 items of the four rating scales are presented in Appendix 3-6.

Table 3.

Content comparison of the 62 items of four fear of falling rating scales, using the ICF as a reference

ICF category	FES-I	FES(S)	ABC	mSAFFE
b Body functions	–	–	–	–
s Body structures	–	–	–	–
d Activities and participation	–	–	–	–
d1 Learning and applying knowledge	–	–	–	–
d2 General tasks and demands	–	1	–	–
d3 Communication	1	1	–	–
d4 Mobility	15	9	21	11
d5 Self-care	4	6	–	4
d6 Domestic life	6	5	2	3
d7 Interpersonal interactions and relationships	–	–	–	–
d8 Major life areas	–	–	–	–
d9 Community, social and civic life	7	–	–	4
e Environmental factors	–	–	1	–

The values represent the number of linkages of meaningful concepts from items, presented on ICF component and chapter levels.
ICF = International Classification of Functioning, Disability and Health; FES-I = Falls Efficacy Scale-International; FES(S) = Swedish version of the Falls Efficacy Scale; ABC = Activities-specific Balance Confidence scale; mSAFFE = modified Survey of Activities and Fear of Falling in the Elderly.

Together, the four rating scales covered six out of nine chapters of the component of activity and participation. Two chapters were covered by all four rating scales: the chapters of mobility and domestic life, which indicate that all rating scales include mobility-related activities and household activities. All four rating scales, particularly ABC, were most strongly linked to the chapter of mobility.

Table 4 presents the quantitative summary of the linking of items and reveals general similarities between the four rating scales. Content density was somewhat higher for FES-I (2.1 compared with 1.3 to 1.7 for the other rating scales). This implies that FES-I contained the most meaningful concepts per item. Content diversity was equally low (0.5) for FES-I and ABC, although for different reasons. In FES-I, multiple meaningful concepts *within* items were often (in 50% of items) linked to the same ICF category. This was the case for 19% of items in ABC.

However, meaningful concepts in *different* ABC items were often linked to the same ICF category; e.g., four items were linked to the category "Reaching" (see Appendix 3-6). Table 4 further reveals that mSAFFE had the lowest content density (1.3) but the greatest content diversity (0.8). This finding mirrors its shortly phrased items that cover diverse aspects of activities and participation. Bandwidth of content coverage was roughly the same for all four scales (0.9 to 1.2%), which means that about 1% of all ICF categories were used to link the items in each FOF rating scale.

Table 4.

Quantitative summary of the linking of the 62 items of four fear of falling rating scales to the ICF

	FES-I	FES(S)	ABC	mSAFFE
No. of items	16	13	16	17
No. of meaningful concepts				
Total	33	22	24	22
Per item (content density)	2.1	1.7	1.5	1.3
Unique ICF categories used for linkage				
Total, *n*	18	15	13	17
Per meaningful concept (content diversity)	0.5	0.7	0.5	0.8
Bandwidth of content coverage, %[1]	1.2	1.0	0.9	1.2

ICF = International Classification of Functioning, Disability and Health; FES-I = Falls Efficacy Scale-International; FES(S) = Swedish version of the Falls Efficacy Scale; ABC = Activities-specific Balance Confidence scale; mSAFFE = modified Survey of Activities and Fear of Falling in the Elderly.
[1] % used ICF categories of the total number of ICF categories, i.e., 1454.

Psychometric properties of FES-I, FES(S), ABC and mSAFFE

One of the 102 participants left FES-I completely blank and another person left both FES(S) and ABC blank. These were excluded from further analyses. The results showed that FES-I, FES(S) and mSAFFE had roughly equal data completeness with 0.9% (FES-I) to 1.3% (mSAFFE) missing responses on items, whereas ABC had substantially more missing responses (6.9%). ABC items 14 and 15 (Travel by bus without/with a bag of groceries, respectively) had the most missing responses (13 each) followed by ABC item 6 (Stand on chair to reach; 9 missing responses). Four persons had misunderstood the response format in ABC (three persons wrote "X" instead of specifying a digit after the items, and one person supplied double digits on each item), resulting in uninterpretable responses on all items. The numbers of participants that obtained total scores on the FOF rating scales are presented in Table 5. Data completeness for individual items are presented in Tables 6-9.

Item means and SDs, respectively, were roughly parallel for all FES(S) items and for most items in each of the FES-I, ABC and mSAFFE. However, some items were scored as more difficult than others (i.e., a larger proportion of participants chose

the worse response options). These were: FES-I items 11 (Walking on slippery surface), 14 (Walking on uneven surface) and 15 (Walking up or down a slope), ABC items 6 (Stand on chair to reach) and 16 (Walk on icy sidewalks), and mSAFFE item 8 (Go out when it is slippery). Some items were scored as easier than others (i.e., a larger proportion of participants chose the best response options). These were FES-I item 3 (Preparing simple meals) and mSAFFE items 4 (Go to the doctor or dentist) and 12 (Walk around indoors) (data available on request). Scoring distributions on item levels are presented in Tables 6-9. All four scales had corrected item-total correlations exceeding 0.4 (see Table 5).

Table 5.

Psychometric comparison of the four fear of falling rating scales

	FES-I	FES(S)	ABC	mSAFFE
Missing item responses[1]	0.9%	1.0%	6.9%	1.3%
Corrected item-total correlation, min-max	0.59 (item 6) – 0.85 (items 1 and 7)	0.79 (item 3) – 0.94 (item 2)	0.75 (item 16) – 0.91 (item 12)	0.54 (item 6) – 0.87 (item 1)
Total scores, n	92	90	82	86
Mean (SD)	30 (12.0)	93 (36.4)	62 (29.6)	26 (7.9)
Min-Max	16-59	11-130	1-100	17-47
Skewness	0.72	-0.64	-0.45	0.80
Floor/ceiling effects	9.8 / 0	0 / 17.8	0 / 4.9	10.5 / 0
Cronbach's alpha	0.96	0.98	0.98	0.94
ICC (95% CI)	0.92 (0.88-0.95) $n = 81$	0.82 (0.73-0.88) $n = 76$	0.86 (0.79-0.91) $n = 68$	0.85 (0.78-0.90) $n = 76$
SEM (% of possible scoring range)[2]	3.4 (7)	15.4 (12)	11.0 (11)	3.0 (9)
SDD (% of possible scoring range)[3]	9.6 (20)	42.7 (33)	30.5 (30)	8.4 (24)

Possible scoringe ranges: FES-I: 16-64, higher = worse; FES(S): 0-130, higher = better; ABC: 0-100, higher = better; mSAFFE: 17-51, higher = worse.
FES-I = Falls Efficacy Scale-International; FES(S) = Swedish version of the Falls Efficacy Scale; ABC = Activities-specific Balance Confidence scale; mSAFFE = modified Survey of Activities and Fear of Falling in the Elderly; ICC = Intraclass Correlation Coefficient; CI = Confidence Interval; SEM = Standard Error of Measurement; SDD = Smallest Detectable Difference.
[1]One person left the FES-I blank and another left FES(S) and ABC blank. Those are not included.
[2]SEM calculated as $SD_{baseline} \times \sqrt{1 - ICC}$.
[3]SDD calculated as $SEM \times 1.96 \times \sqrt{2}$.

All four scales spanned almost the full range of possible scale scores and mean scores were somewhat close to the scales' midpoints (i.e., FES-I: 40; FES(S): 65;

ABC: 50; mSAFFE: 34). Skewness was $< \pm 1$, and floor and ceiling effects were < 20% for all four rating scales (Table 5).

All four FOF rating scales had Cronbach's alphas > 0.90 and ICC > 0.80. The FES-I had ICC > 0.90. SEM% varied from 7 to 12%. This implies that changes in mean scores greater than 7 to 12% of the possible scoring ranges indicate "real" changes (above measurement error), when assessing FOF for a group of people with PD. SDD% were 20 to 33%, indicating that the smallest changes in an individual's FOF scores that can be interpreted as a "real" change (above measurement error) should exceed 20 to 33% of the possible scoring ranges. FES-I obtained the lowest SEM% and SDD%, where a difference of at least 4 and 10 points between the two test occasions indicated a "real" change in a group and individual level, respectively. Reliability coefficients, SEM and SDD values for the four rating scales are presented in Table 5. When comparing the two test occasions, three outliers were identified in mSAFFE, four in FES-I, 10 in ABC and 15 in FES(S).

Table 6.

Scoring distribution and data completeness of Activities-specific Balance Confidence scale (ABC)

Item	Activity	Mean (SD) $n = 97$[1]	Missing responses
1.	Walk around the house	7.2 (2.7)	5
2.	Walk up or down stairs	6.0 (3.4)	6
3.	Bend over and pick up a shoe from the floor	6.4 (3.0)	5
4.	Reach for a small can off a shelf at eye level	7.5 (2.8)	6
5.	Stand on your tiptoes and reach for something above your head	6.1 (3.3)	6
6.	Stand on a chair and reach for something	4.4 (3.8)	9
7.	Sweep or vacuum the floor	6.3 (3.7)	7
8.	Walk to a taxi that is waiting by the sidewalk	6.9 (3.3)	6
9.	Get into or out of a car	6.7 (3.0)	5
10.	Cross a street	6.6 (3.5)	8
11.	Step onto or off a curb	6.8 (3.3)	5
12.	Walk on a street where people are rapidly passing	6.8 (3.2)	6
13.	Others bump into you as you walk on the street	5.9 (3.5)	5
14.	Travel by bus *without* a bag of groceries	6.6 (3.8)	13
15.	Travel by bus *with* a bag of groceries	6.1 (3.8)	13
16.	Walk on icy sidewalks	3.7 (3.5)	6

Possible item score range 0-100, higher = better.
[1]One person left the rating scale blank and four persons misunderstood the entire scale, resulting in invalid responses. Missing data includes the four persons who misunderstood the scale, but not the person who left it blank.

Table 7.

Scoring distribution and data completeness of Falls Efficacy Scale-International (FES-I)

Item	Activity	Mean (SD) $n = 101$[1]	Missing responses
1.	Cleaning the house	2.0 (1.1)	2
2.	Getting dressed or undressed	1.5 (0.8)	1
3.	Preparing simple meals	1.4 (0.8)	2
4.	Taking a bath or shower	1.6 (1.0)	-
5.	Buying some groceries	1.7 (1.1)	1
6.	Getting in or out of a chair	1.7 (0.8)	2
7.	Climbing stairs	2.0 (1.0)	1
8.	Walking around in the neighbourhood	1.7 (0.9)	-
9.	Reaching for something above your head or on the ground	2.0 (1.0)	1
10.	Answering the telephone before it stops ringing	1.7 (0.9)	2
11.	Walking on a slippery surface	2.7 (1.0)	-
12.	Visiting acquaintances, friends or relatives	1.7 (0.9)	1
13.	Walking in crowds	1.9 (1.0)	-
14.	Walking on an uneven surface	2.3 (1.1)	1
15.	Walking up or down a slope	2.3 (1.1)	-
16.	Participating in a social event	1.7 (0.9)	-

Possible item score range 1-4, higher = worse.
[1]One person left the rating scale blank. This person is not included in the missing data.

Table 8.

Scoring distribution and data completeness of the Swedish Falls Efficacy Scale (FES(S))

Item	Activity	Mean (SD) $n = 101$[1]	Missing responses
1.	Get in and out of bed	7.2 (2.7)	1
2.	Go to the toilet	7.5 (2.7)	1
3.	Wash yourself	8.0 (2.6)	1
4.	Get in and out of a chair	7.2 (2.7)	-
5.	Get dressed and undressed	7.3 (2.9)	1
6.	Take a bath or a shower	7.1 (3.3)	-
7.	Go up and down stairs	6.4 (3.4)	4
8.	Walk around the neighbourhood	6.9 (3.4)	3
9.	Reach into cupboards/closets	6.9 (3.4)	-
10.	Clean the apartment	6.6 (3.6)	-
11.	Prepare a meal that does not require carrying hot or heavy objects	6.9 (3.4)	1
12.	Hurrying up to answer the telephone	6.5 (3.4)	-
13.	Simple shopping	6.7 (3.6)	1

Possible item score range 0-10, higher = better.
[1]One person left the rating scale blank. This person is not included in the missing data.

Table 9.

Scoring distribution and data completeness of modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE)

Item	Activity	Mean (SD) $n = 102$	Missing responses
1.	Walk to the store and shop	1.7 (0.8)	3
2.	Clean your house	1.6 (0.7)	1
3.	Prepare simple meals	1.3 (0.5)	1
4.	Go to the doctor or dentist	1.2 (0.4)	1
5.	Take a bath	1.5 (0.7)	7
6.	Take a shower	1.3 (0.5)	-
7.	Go for a walk	1.5 (0.6)	-
8.	Go out when it is slippery	2.2 (0.7)	-
9.	Visit a friend or relative	1.4 (0.6)	3
10.	Walk to a place with crowds	1.8 (0.7)	1
11.	Climb stairs	1.6 (0.7)	-
12.	Walk around indoors	1.1 (0.3)	1
13.	Walk a kilometer	1.8 (0.8)	1
14.	Bend down to pick up something	1.6 (0.6)	-
15.	Travel by public transport	1.7 (0.8)	3
16.	Attend a social event or party	1.5 (0.6)	-
17.	Reach for something above your head	1.7 (0.7)	-

Possible item score range 1-3, higher = worse.

Understanding fear of falling

This section covers the results from the Explanatory study (i.e., Explanatory factors of concerns about falling) and the Interview study (i.e., Experiences of FOF). The results from the two studies are presented separately.

Explanatory factors of concerns about falling

The multivariable ordinal regression model revealed that six of the 21 studied independent variables were associated ($p < 0.1$) with concerns about falling. These were: walking difficulties in everyday life, orthostatism, motor symptoms, age, fatigue and depressive symptoms (presented in order of importance). All but depressive symptoms were significant ($p < 0.05$) explanatory factors of concerns about falling (see Table 10). The model's explanatory capacity was 73.4% (Nagelkerke's pseudo $R^2 = 0.734$).

Table 10.

Multivariable ordinal regression with concerns about falling (Falls Efficacy Scale-International; FES-I) as the dependent variable, *n* = 229

Independent variable	OR (95% CI)	Wald	*p*-value
Walking difficulties (Generic Walk-12)[1]	1.27 (1.19-1.35)	60.33	<0.001
Orthostatism (Nonmotor Symptoms Questionnaire item 20, no = reference category)	2.57 (1.30-5.07)	7.40	0.007
Motor symptoms (UPDRS III)[1]	1.04 (1.00-1.07)	6.27	0.012
Age (years)	1.05 (1.01-1.10)	6.21	0.013
Fatigue (dichotomized Energy subscale of the Nottingham Health Profile, no = reference category)	2.13 (1.02-4.41)	4.14	0.042
Depression (Geriatric Depression Scale)[1]	1.18 (0.99-1.40)	3.68	0.055

Test of parallel lines: Chi-square *p* = 0.811. Nagelkerke's pseudo R^2 = 0.734.
OR = Odds Ratio; CI = Confidence Interval; UPDRS III = Unified Parkinson's Disease Rating Scale, motor examination.
[1]Higher total score = worse.

Walking difficulties in everyday life were the strongest individual explanatory factor of concerns about falling (indicated by the considerably higher Wald than the other factors). The obtained odds ratio of 1.27 means that a one point higher Walk-12G score (i.e., more walking difficulties) would increase the odds of belonging to a higher concern category with 27% (i.e., having moderate or high instead of low concerns, or having high instead of moderate or low concerns about falling). If the Walk-12G total score would instead increase by three points, the odds of belonging to a higher concern category would double (odds ratio 1.27^3 = 2.05).
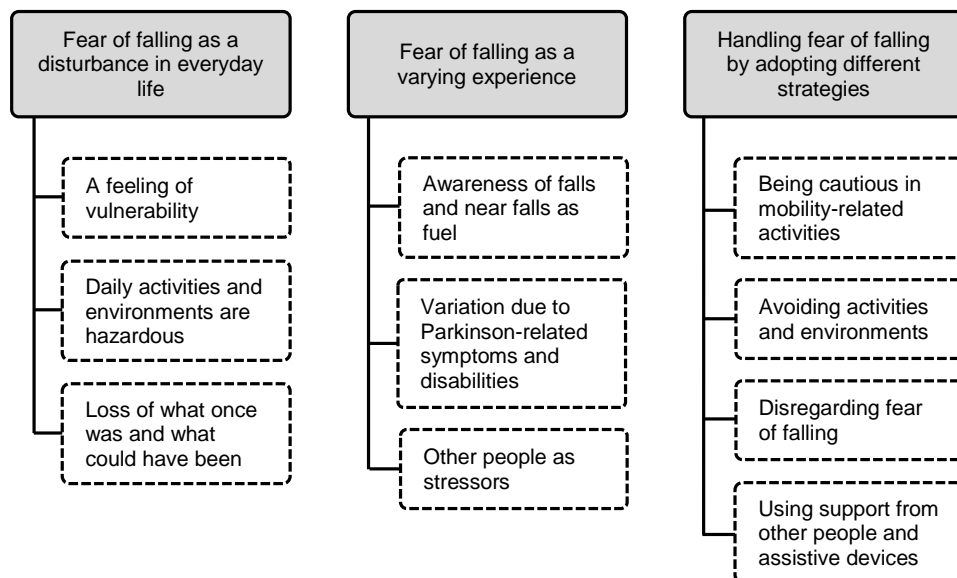
Experiences of fear of falling

The qualitative analysis revealed that FOF affected everyday life in several ways. The participants' experiences were diverse and expressed in many ways. Three themes emerged from the data, covering the experiences of FOF in persons with PD: (i) FOF as a disturbance in everyday life, (ii) FOF as a varying experience, and (iii) Handling FOF by adopting different strategies. These themes are outlined below, and the structure of the themes and categories is described in Figure 4.

Fear of falling as a disturbance in everyday life
FOF was described as making everyday life frightening and less joyful. The participants expressed that their FOF made them feel nervous, insecure and vulnerable. They were afraid of not being able to get up after a fall. Many participants described that FOF was always at the back of their minds. It was common to feel insecure in crowds and among people in a hurry. Many described

that FOF increased when being alone and that they preferred being accompanied by someone when leaving their house.

Figure 4.
Overview of themes (grey boxes) and underlying categories (white boxes) of experiences of fear of falling in persons with Parkinson's disease.

FOF made a variety of activities and environments seem hazardous and frightening. Some mentioned FOF in regular activities, such as reaching, turning while standing and getting up from lying or sitting. The design of the physical environment was expressed to induce specific challenges, e.g., tactile paving (designed for visually impaired people) were perceived as hazardous by some participants. Slippery and uneven surfaces were frequently mentioned, sometimes using words as "being terrified" in the shower because of the slippery floor. Some described the home as a comfort zone with less FOF, even though many had experienced most falls at home. Stairs (especially walking downstairs) were brought up as a source for FOF by a majority of the participants.

Many participants expressed how their FOF restricted everyday life and sometimes took the joy out of previously appreciated activities. The participants believed that they would have been more free, active and out in public if they had not experienced FOF. Some stated that their FOF interfered with social life and made them isolated. For some, it was evident that even though they could still take part in many activities, their FOF restricted them from fully participating.

"Yes, I think it [life without FOF] would have been different. I think it would. (…) Yes, it would have been much easier to live then. If you didn't have to think about it." (#12)

Fear of falling as a varying experience

The participants' experiences of FOF were not constant. They were aware of the increased risk of falling when having PD, which increased their FOF; they knew that falls can occur suddenly and at all times. They were afraid of the consequences of falls and many were afraid of potential injuries. Their own, as well as others', experiences of falls fed into their fear. FOF was also expressed in relation to near falls, i.e., situations where they almost fell but managed to regain balance. These situations were described as unpleasant and even shocking, and it made them shaky and insecure.

The participants expressed that their FOF was aggravated as their PD progressed, as a result of increased walking difficulties, hyperkinesia, rigidity, off episodes, freezing of gait and impaired balance. Many participants described that their FOF increased at times when they were feeling low, tired or stressed, while they had less or no FOF at times when they were in good spirits.

"I would guess that when you are in good spirits, then the concerns about falling are reduced, or gone. And if you are feeling down then, then all the… dark thoughts will appear and then you notice both this and that, that is hazardous." (#7)

The participants expressed that their FOF sometimes increased due to the attitudes and treatment from other people. They described that people wanted to help, but the help could be "too much". There was a need to manage by oneself and the FOF increased if someone tried to help but did it in a "wrong way". The participants thought that people had certain expectations and they felt obliged to do things faster than they had preferred, which negatively affected their FOF.

Handling fear of falling by adopting different strategies

All participants used strategies in one way or another to handle their FOF. Activities were performed with more caution than before; FOF made the participants alert and attentive at all times, looking for and registering risks in the environment. The participants thought actively about how they walked and moved around. Many described how activities and motions were performed at a slower pace and with more caution due to their FOF. It was commonly expressed to be very attentive when climbing stairs, especially if carrying something at the same time. Some said that they used tricks to avoid or overcome freezing episodes and that this reduced their FOF.

Some activities and environments were avoided altogether since the FOF was too intense in those situations. Some participants mentioned that they rarely visited

stores and shops due to an increased FOF in these environments. Inclement weather, such as snow, ice and slippery walkways were often avoided since this increased FOF considerably.

> "You try to live as before but, you… notice, quite a lot, there are things that you can't do. To fix something on the roof of the house for example. Afraid of, if you fall there, then you injure yourself really badly, right. You avoid those situations, where a fall could cause real injuries." (#2)

Other activities were performed despite FOF, e.g., because the participants thought that they "had to" do certain things, despite experiencing FOF in those situations (e.g., leaving the home or climbing stairs).

> "Well it's rare [that I climb stairs]. It's difficult. When I do I'm really worried. (…) Sometimes you have to go up to the attic. And that, then I'm really scared." (#8)

The desire to do something was sometimes prioritized above the FOF, which meant that some activities were performed despite an ongoing FOF, simply because the participant wanted to. Some stated that their FOF could be distracted by having other things to concentrate on, or by doing something that was perceived as enjoyable; at such times they did not think about their fear. Some performed activities as a practice, despite their FOF. One man mentioned positive thinking and self-efficacy – that you can do more than you think.

Other ways to handle FOF was by obtaining help from other people or by using assistive devices. Most participants expressed that company and support from people reduced FOF if it was provided according to their needs and wishes. A variety of assistive devices were described as reducing FOF, but the participants also identified shortcomings that increased their fear. For example, walking devices were used by many participants and perceived as reducing FOF, but they were not considered to be entirely safe; several participants expressed that rollators can tip over or roll away when least expected.

Discussion

The overarching aim of this thesis was to increase the knowledge of how FOF can be assessed in persons with PD, as well as to expand and deepen the understanding of FOF in persons with PD in relation to explanatory factors and the persons' own experiences. The following sections discuss and intertwine the results from the four studies in light of previous research, with the intention to integrate the results and arrive at relevant clinical implications that are closely connected to the results.

Assessing fear of falling

The results from the ICF Linking study and the Psychometric study add new knowledge regarding the content of commonly used FOF rating scales (FES-I, FES(S), ABC and mSAFFE) and their psychometric properties in persons with PD. In the following section, the four FOF rating scales are discussed, mainly from the perspectives of the above mentioned studies. However, the results of the Explanatory study and the Interview study are incorporated when appropriate.

Focus and content of the rating scales

The ICF Linking study revealed that the most meaningful concepts of FES-I, FES(S), ABC and mSAFFE items were associated with the ICF chapter of mobility from the component of activities and participation. The ABC had a particularly strong mobility focus, while the content of FES-I, FES(S) and mSAFFE were more diverse with linkages to four or five ICF chapters each. One previous study has linked FES(S) and ABC to the ICF [126] and another study linked only the ABC [127]. These studies were not conducted entirely according to the linking rules [92, 93]. One study did not link meaningful concepts to the most precise ICF category [127]. The other study did not link the overall questions although these contain meaningful concepts [126]. Items in the latter study were moreover linked to one single ICF category each, even though many items contain multiple meaningful concepts that should be linked separately [92, 93]. Despite not conducted entirely

as proposed, these studies support the strong mobility focus found in ABC and the more diverse content of FES(S) [126, 127].

ABC, mSAFFE and FES-I contain several walking-related items, i.e., items that contain the word "walk/walking" and/or were linked to the ICF category "d450 Walking" or any of its subcategories. Seven out of 16 items in ABC, 6 out of 17 items in mSAFFE and 5 out of 16 items in FES-I are walking-related, while in FES(S), only 1 out of 13 items is walking-related. In the Explanatory study, walking difficulties in everyday life were found to be the strongest explanatory factor of FOF, conceptualized as concerns about falling, which is in agreement with previous studies of persons with PD [49, 51]. Moreover, previous studies have shown that most falls among persons with PD occur while walking [29, 31]. A strong emphasis on walking might therefore be warranted when assessing FOF in people with PD, which favors ABC, mSAFFE and FES-I rather than FES(S).

Some of the activities that the participants brought up in relation to FOF during the qualitative interviews were stair climbing, walking in crowds, walking on slippery surfaces and grocery shopping. These activities are included as items in FES-I and mSAFFE, and some are included also in FES(S) and ABC. However, other aspects highlighted by the participants are not considered in the rating scales, e.g., strategies beside activity avoidance for handling FOF, and the impact of PD-related symptoms and disabilities, such as walking difficulties, tiredness and stress. FOF rating scales are valuable in research as well as in clinical practice, as they can present a quick overview of FOF. However, rating scales cannot replace a thorough medical history in clinical practice, where a more comprehensive understanding of FOF can be obtained. If a more complete understanding of FOF is warranted, rating scales should be used in combination with a thorough medical history taking.

Content density versus clarity of items

Guidelines for interpretation of the quantitative measures of the linking analysis (e.g., content density) are lacking. The understanding is that the interpretation depends on the nature of the rating scale, e.g., a high content density can be both positive as well as negative [128]. Content density refers to the number of meaningful concepts per item. Scales with low content density are suggested to be suitable for clinical settings because their items are assumed to be less complex [128], as they contain few activities per item. However, combining the results from the ICF Linking study and the Psychometric study contradict this assumption. That is, while FES-I and FES(S) were the two scales with the highest content density, these scales had the highest level of data completeness. This is supported by a previous study in persons with PD, which also reported high data completeness of FES(S) [46]. ABC was the scale with the second lowest content density but had

substantially more missing data than the other scales (6.9% vs. 0.9-1.3%). Thus, it seems as if low content density does not always imply low complexity of items.

High content density indicates that single items contain multiple meaningful concepts (e.g., activities). This could cause difficulties when interpreting a response, as it is unknown whether it refers to one or all activities within an item. For example, both FES(S) and ABC contain the item "Go/Walk up or down stairs". In the Psychometric study, this was scored as the most difficult FES(S) item and the fourth most difficult ABC item. In the Interview study, a majority of the participants expressed that stairs increased their FOF, but several emphasized that walking downstairs was worse than upstairs, which is in agreement with previous studies [129, 130]. It is unknown how the stair items would have been responded to if they included only walking downstairs or upstairs. On the other hand, low content density is no guarantee for a clear and simple item. For example, FES-I and mSAFFE also contain a stair item, phrased as "Climb stairs". Although it has only one meaningful concept, it is not clearer than the stair item that contains two meaningful concepts, since the direction is not specified.

Multiple meaningful concepts within an item (i.e., high content density) might, however, be valuable as it could provide a more detailed and precise instruction to the respondent. For example, the ABC item "Stand on a chair and reach for something" includes two meaningful concepts and illustrates a well-defined activity. However, nine participants in the Psychometric study did not respond or provided an invalid response to this item. This might indicate that the participants did not conduct the activity. Indeed, ABC is recommended for use in higher-functioning persons with PD, whereas FES-I is suggested for the less ambulant [35].

Wording and scale instructions

A reasonable assumption is that a person's response to a rating scale is a function of the overall question, the item and the response categories. This implies that there may be a difference in a person's responses to two identical items if the overall questions differ. While both FES(S) and ABC relate to Bandura's theory of self-efficacy [48], their overall questions are rather disparate. In FES(S), the overall question relates to performing activities without falling, whereas ABC relates to performing activities without losing balance or becoming unsteady. The scales have similar response categories that address confidence and contain similar items targeting cleaning and walking up or down stairs. Surprisingly, when reviewing the results from the Psychometric study, it seems as if the overall questions do not largely affect the responses to these items, as their mean scores are similar (mean scores for item on cleaning: FES(S) 6.6, ABC 6.3; stair climbing: FES(S) 6.4, ABC 6.0). That is, although the overall questions refer to rather diverse outcomes,

participants may disregard (or have forgotten about) these aspects when responding to these two items.

The high proportion of missing data found in ABC might imply that the scale's instructions or response format need to be clarified. It should be noted that a Swedish translated and adapted version of ABC (L. Lundin-Olsson, unpublished material, written personal communication, June 20, 2012) was used in this thesis and the English original ABC [6] might be perceived as more clear. The high proportion of missing data on individual ABC items suggests that these items were difficult to understand or perceived as irrelevant by the participants [95]; these items might address activities that persons with PD do not conduct. FES-I, FES(S), mSAFFE as well as the English original ABC include instructions on how to respond to activities that the respondent does not engage in. However, these instructions are not included in the Swedish ABC. The two bus items (added in the Swedish cultural adaptation of ABC) were the two items with the most missing responses (13 each). Indeed, 22 participants stated that they always avoided traveling by public transport (mSAFFE item 15), which could explain the high number of missing responses to these items in ABC. However, the item with the fourth most missing responses ($n = 8$) was "Cross a street" (ABC item 10). This activity is likely conducted by all participants, which means that activity avoidance cannot solely explain the poor data completeness of ABC. To the best of my knowledge, no other study has examined the data completeness of ABC in persons with PD or other samples.

During the qualitative interviews, the participants expressed that their FOF increased when being alone, whereas various assistive devices were sometimes expressed as reducing FOF. None of the Swedish translations of the four FOF rating scales include instructions on how to respond to the items in terms of having company or usage of assistive devices. That is, are respondents supposed to answer how afraid of falling they are while engaging in an activity alone, with company of e.g., a spouse, while receiving eventual usual help from home care personnel, with or without the use of assistive devices? Since the instructions are not clear, various respondents might respond to items differently. As opposed to the Swedish translations, the English original FES-I does include the statement "Please reply thinking about how you usually do the activity" [4], and the English original ABC include the sentence "If you normally use a walking aid to do the activity or hold onto someone, rate your confidence as if you were using these supports". Adding these clarifications is worth considering in future adaptations of the FES(S) and mSAFFE, as well as in the Swedish translations of FES-I and ABC.

Scaling assumptions and reliability of the rating scales

The Psychometric study revealed that FES(S) items were roughly parallel. However, FES-I, ABC and mSAFFE contained items with difficulty levels of greater variability. Although classical test theory states that items within a scale should be "roughly parallel" [94, 95], there are no guidelines describing how strict this judgement should be. Indeed, while FES(S) was intentionally developed to include items that cover basic activities [83], FES-I, ABC and SAFE (i.e., the forerunner of mSAFFE) were developed with the intention to include items with a wider continuum of difficulties [4, 6, 82]. One could argue that the latter is preferable, as it results in scales that are able to assess FOF in individuals with both low and high levels of FOF.

All four FOF rating scales had high Cronbach's alpha values (0.94-0.98). These indicate that the scales are internally consistent and, thus, that items within a scale produce similar scores [131]. However, Cronbach's alpha is strongly affected by the length of a rating scale. It increases with the number of items and a too high alpha (> 0.90) could be a sign of item redundancy [131]. Previous studies in persons with PD have reported Cronbach's alphas for FES(S) [46], ABC [66-68, 84, 85] and mSAFFE [46], which were all > 0.90. There is at least one abbreviated version of FES-I [132] and three abbreviated versions of ABC [66, 67, 133] that contain five to seven items each. Interestingly, also these have fairly high Cronbach's alphas when studied in persons with PD. One study explored the internal consistency of the shortened FES-I, which had a Cronbach's alpha of 0.89 [134]. Three studies have reported in total six assessments of the internal consistency of the various short versions of ABC in persons with PD, whereof all but one assessment revealed Cronbach's alphas ≥ 0.90 [66, 67, 133]. This could imply that the high Cronbach's alphas are not merely a sign of item redundancy, but indicate that the scales truly are internally consistent.

SEM% for the four rating scales varied from 7 to 12% and SDD% varied from 20 to 33%. It should be noted that calculations of SEM and SDD were based on ICC values; i.e., ICC was used as the reliability coefficient in the formula $SEM = SD_{baseline} \times \sqrt{1 - reliability}$ [12]. There is no consensus on whether SEM should be based on ICC [12] or Cronbach's alpha [101]. Calculations based on Cronbach's alpha instead of ICC would result in substantially lower SEM. This would affect also SDD values, since calculation of SDD is based on SEM ($SDD = SEM \times 1.96 \times \sqrt{2}$) [11].

Choosing a fear of falling rating scale

The findings in the Psychometric study favored FES-I or mSAFFE when assessing FOF in people with PD. All four scales showed acceptable internal consistency and

test-retest reliability, but FES-I was the only scale with satisfactory test-retest reliability for use in individual comparisons (ICC > 0.90) [100, 101]. However, it should be noted that this is the first study of the psychometric properties of FES-I in people with PD. Additional studies are needed to confirm the findings and to explore psychometric aspects that are not covered within this thesis, e.g., responsiveness and limits for clinically meaningful change. ABC revealed insufficiencies in terms of data completeness, and ABC and FES(S) had many outliers when comparing the two test occasions. A recent review listed ABC, mSAFFE and FES as recommended to assess FOF in people with PD, primarily based on their psychometric properties [135]. Unfortunately, this review did not take the psychometric results of ABC from this thesis into consideration, nor did the review include FES-I.

When choosing a FOF rating scale, it is important to consider not only the psychometric properties but also what aspect one wishes to address. All four rating scales that are included in this thesis predominately focused on the ICF chapter of mobility and included linkages to domestic life. FES-I and mSAFFE were the only scales that covered the chapter of community, social and civic life. FES-I, mSAFFE and ABC contained 5 to 7 walking-related items each, which might be warranted since walking difficulties in everyday life were the strongest explanatory factor of FOF, conceptualized as concerns about falling.

During the qualitative interviews, many participants expressed that their FOF increased outdoors, while home was sometimes described as a comfort zone with less FOF. This speaks in favor of either FES-I, ABC or mSAFFE, since they all include several items that refer to outdoor activities, while FES(S) contains mainly indoor activities at home. Thus, although the Psychometric study, as well as a previous study of persons with PD [46], revealed acceptable reliability for FES(S), the scale might underestimate the true level of FOF in people with PD.

FES-I includes several items that contain multiple activities, which could cause problems when interpreting the respondents' answers. The mSAFFE offers items with a good range of diverse content but contains less detailed descriptions of the activities than ABC. Moreover, it should be noted that the overall question of mSAFFE asks about activity avoidance rather than concerns or confidence. Furthermore, ABC refers to losing balance or becoming unsteady, while FES-I, FES(S) and mSAFFE all refer to actual falling.

Consequently, there is no simple answer to which FOF rating scale to choose. Several aspects should be taken into consideration, such as the psychometric properties, warranted conceptualization of FOF and appropriate scale content for the research study or clinical situation in question.

Understanding fear of falling

The results from the Explanatory study and the Interview study contribute to the understanding of FOF in persons with PD by adding new knowledge regarding explanatory factors of concerns about falling and experiences of FOF. In the following section, the results from these two studies are discussed, and the ICF Linking study and the Psychometric study are incorporated when appropriate.

FOF in relation to walking difficulties

The results of the Explanatory study revealed a well-fitted multivariable model with a high (73.4%) explanatory capacity (i.e., much of the variance in concerns about falling could be explained by the independent variables in the final regression model). Walking difficulties in everyday life were by far the strongest explanatory factor of concerns about falling, followed by orthostatism, motor symptoms, age and fatigue. The importance of walking difficulties is shown also in the Interview study, where the participants expressed an increased FOF as a result of their walking difficulties. These findings support previous studies that targeted explanatory factors of FOF, conceptualized as fall-related self-efficacy [49, 51] and balance confidence [69]. In this thesis, as well as in two of the previous studies [49, 51], walking difficulties were assessed with the self-rating scale Walk-12G that addresses walking difficulties in everyday life [103]. It encompasses a variety of walking aspects, such as smoothness of walking, balancing while walking, stair climbing and walking distance. One of the previous studies [49] included both Walk-12G and gait speed as independent variables in their regression model. However, while Walk-12G was an independent explanatory factor of FOF, gait speed was not. Taken together, this suggests that interventions aiming at preventing or reducing FOF in people with PD might benefit from focusing on various aspects of gait (e.g., walking on various surfaces and in various environments) rather than focusing on speed or walking distance alone.

FOF in relation to orthostatism

The importance of orthostatism as an explanatory factor of FOF is a novel finding. Orthostatism is a common [136] and known risk factor for falls in people with PD [137], but no previous study has explored its explanatory capacity in relation to FOF. A feeling of not being in control of yourself was expressed as increasing FOF by the participants during the qualitative interviews. Indeed, orthostatic episodes might imply a temporal loss of control. However, a previous study reported no

difference in prevalence of FOF among those with and without orthostatic hypotension [138]. This discrepancy between studies might be explained by methodological differences. In this thesis, orthostatism was self-rated in relation to the past month, whereas Matinolli et al. [138] assessed blood pressure during three minutes on a single occasion. In that study, orthostatism was defined as at least 20 mm Hg fall in systolic, or 10 mm Hg fall in diastolic blood pressure, with or without symptoms [138]. One could hypothesize that self-ratings of orthostatism capture persons' experiences better than a clinical measure at a single occasion. A person who experience episodes of orthostatism might be more likely to report FOF than a person who does not experience such episodes. Orthostatism may require specific attention in the clinical setting, but further studies are needed to clarify the relationship between FOF and orthostatism in people with PD.

FOF in relation to motor symptoms

Motor symptoms were found to be a significant explanatory factor of FOF conceptualized as concerns about falling. This is supported by the findings in the Interview study, where the participants expressed that their FOF increased as their PD progressed, as a result of e.g., rigidity and balance difficulties. These aspects are included in the UPDRS III [115], which was used for assessing motor symptoms in the Explanatory study. However, previous studies have shown inconsistencies regarding the explanatory capacity of motor symptoms on FOF. One study found motor symptoms to be a significant factor [69], while two studies found non-significant associations with FOF [49, 71]. One of the studies which found that motor symptoms were not an explanatory factor of FOF was based on persons with relatively mild PD [49] in comparison with the sample in this thesis. Their mean PD duration was 5 years compared to 8 years (median) in the Explanatory study, and their median UPDRS III score was 13 compared to 30 points. However, the other study that found a non-significant explanatory capacity of motor symptoms on FOF was based on persons with more severe PD (mean UPDRS III score 37) [71]. Thus, more studies are needed to clarify the possible impact of motor symptoms on FOF.

FOF in relation to age, fatigue and other PD-related symptoms

Age was a significant explanatory factor of FOF in this thesis, as well as in a previous study of persons with PD [69]. However, three previous studies have found non-significant associations between age and FOF in persons with PD [49, 51, 71]. Thus, the relationship between FOF and age is unclear.

The finding that fatigue significantly explained FOF is in line with previous studies of persons with PD [49, 51]. Moreover, participants in the Interview study expressed

that their FOF increased when they were tired. Impaired walking economy may cause fatigue in people with PD [139], which might potentially explain the association between fatigue and FOF, since walking and FOF are closely related.

The participants in the Interview study expressed that several additional PD-related symptoms and disabilities increased their FOF, such as balance problems, freezing of gait and off-episodes. The importance of balance problems in relation to FOF is supported by previous studies of persons with PD [49, 69, 71]. The same applies to the importance of freezing of gait [140] and motor fluctuations [51]. Yet, neither balance problems while dual tasking, turning hesitations, nor fluctuations with increasing PD symptoms were significant explanatory factors of concerns about falling in the Explanatory study. However, one aspect of balance problems (postural stability) is assessed in item 30 of UPDRS III (i.e., motor symptoms), which was a significant explanatory factor.

FOF in relation to self-efficacy

General self-efficacy (i.e., people's judgments of their capabilities [48]) was not a significant explanatory factor of FOF, conceptualized as concerns about falling. This is surprising, as FES-I (i.e., the dependent variable) was developed by combining and modifying FES, ABC and SAFE [4], of which two [5, 6] are based on Bandura's theory of self-efficacy. During the qualitative interviews, participants expressed that they sometimes conducted activities despite an ongoing FOF. Indeed, positive thinking and self-efficacy were mentioned as strategies to handle FOF. It is possible that self-efficacy can be helpful in handling FOF, but might not affect the intensity of FOF. That is, high self-efficacy might not imply low FOF, which could explain the non-significant results in the Explanatory study.

During the qualitative interviews, one man said that you can do more than you think. In previous studies of elderly persons without PD, one participant expressed that one should not think about FOF [76], and another that you have to go on with your life and conquer the fear [77]. Finding ways to utilize intrinsic motivation like this might be beneficial in interventions addressing FOF. To the best of my knowledge, the Explanatory study that is included in this thesis is the first to study the explanatory capacity of general self-efficacy on FOF. Further studies are needed to establish the possible association.

FOF in relation to environmental factors

None of the studied environmental factors significantly explained concerns about falling in this thesis. Recently, another study found that use of mobility devices

indoors and/or outdoors was an explanatory factor [71]. While this contradicts the findings in the Explanatory study, the Interview study does acknowledge the complexity of assistive devices. Several participants expressed that walking devices reduced their FOF. On the other hand, their walking devices were not considered as entirely safe, which could result in an increased FOF. In a previous qualitative study, caregivers of persons with PD who repeatedly fell highlighted that a walking device can be a risk factor for falls if the person with PD cannot handle it properly [141]. Another study of persons with PD revealed that many falls among repeated fallers occurred while using a walking device [29]. Taken together, this indicates that the prescription of mobility devices to persons with PD may be improved by adding more thorough practice on how to use the devices.

The participants in the Interview study also brought up other environmental challenges, which increased their FOF. Examples include narrow walkways, stairs, crowds, hard, uneven or slippery surfaces, and also surfaces that looked slippery even if they were not. In the ICF Linking study, only one single meaningful concept from the 61 items of the four FOF rating scales was linked to the environmental component of ICF. However, environmental factors were often contained as "additional information". Indeed, several environmental factors are found when studying the three items that were ranked as the most difficult (i.e., had worst item mean scores) in each FOF rating scale in the Psychometric study. Walk on slippery, or uneven surfaces, go up and down stairs, walk up or down a slope, and walk to a place with crowds were all among the most difficult items, which is in agreement with the findings in the Interview study. It should be noted that the environmental factors that were studied in the Explanatory study mainly concerned general environmental factors, such as living circumstances, housing type and residential area. Physical environmental factors, such as the condition of walking surfaces in or nearby the home, was not studied. Further research of the impact of physical environmental factors on FOF in people with PD is motivated.

Stair climbing has been considered non-problematic for people with PD, with the hypothesis that the steps act as external cues that facilitate the gait [142]. However, stair climbing was expressed as evoking FOF by most participants in the Interview study and was moreover scored as the most difficult FES(S) item in the Psychometric study. Moderate to extreme difficulties in climbing stairs has previously been shown to be an important explanatory factor of FOF [51], whereas stair climbing has been scored as one of the easiest walking-related activities by persons with PD [103]. Taken together, these findings suggest that although people with PD might be physically able to climb stairs, stair climbing can be associated with an increased FOF and might thus benefit from special attention in clinical practice.

During the qualitative interviews, the participants expressed an increased FOF when being alone. However, no significant association was found between FOF and living alone in the Explanatory study, nor in a previous multivariable study [51]. The findings in the Interview study corroborate that FOF restricts participation in meaningful activities [62] and it has previously been shown that FOF is perceived as a barrier to exercise [61]. This might result in that individual, non-supervised exercises are not performed even if they are prescribed. Activities in groups or together with others might increase the possibilities for persons with PD to participate in exercise. In fact, a previous study of persons with PD, as well as the European physiotherapy guidelines for PD, highlight the effectiveness of supervised training as compared to non-supervised home exercises as a method to deliver interventions [35, 143].

Many of the participants in the Interview study expressed a concern how to get up after a fall. This is in agreement with a previous study of persons with PD [62] and might partly explain the increased FOF when being alone. Hands-on knowledge on how to get up after a fall has been requested also by caregivers of those persons with PD who repeatedly fall [141]. This seems to be a common concern for persons with FOF, since it is expressed also in qualitative studies of FOF among stroke survivors [79] and persons that have had a hip fracture [78]. In order to reduce FOF, teaching persons with PD how to get up from the floor has previously been recommended [144]. The findings in the Interview study further emphasize that this is of importance.

Is fear of falling always negative?

Some might wonder if FOF is always negative and speculate whether FOF might be justified in persons with e.g., reduced balance. What if FOF results in avoidance of high-risk activities and thereby reduces fall risk? However, research points in another direction: FOF does not reduce the risk of falls. Instead, as previously mentioned, FOF is a predictor of future falls and near falls in persons with PD, already early on in the course of disease [33].

A previous study included elderly persons without PD who had a high physiological fall risk. The study revealed that those who had high FOF experienced more falls during a one-year follow-up period than those with low FOF [145]. The Interview study revealed that FOF affected everyday life in several ways, and it was evident that it negatively affected the participants' quality of life, which has previously been shown [64, 65]. During the qualitative interviews, the participants expressed that their FOF sometimes took the joy out of previously appreciated activities. Also, activities that were still performed were not appreciated in the same way as before,

due to the participants' FOF. As such, FOF has several negative effects for the individual.

The participants in the Interview study described that avoiding certain activities and environments was a strategy in handling FOF. While it cannot be ruled out that avoidance of high-risk activities, such as climbing ladders, might reduce fall frequency, it does not justify FOF in itself. One could therefore argue that FOF is always negative for the individual, while some activity avoidance might be justified due to various disabilities. Reducing FOF is not likely to be harmful or increase the risk of falls, but rather contribute to participation and increased quality of life.

Managing fear of falling

Already in 1980, FOF was identified as a risk factor for falls in the general older population and it was suggested that balance exercises could be used to improve their confidence [146]. However, this was written without any empirical evidence. Both persons with PD and clinicians working with PD have ranked the management of balance problems and falls as the number one priority for future PD research [147]. Yet, it is not until recently that there has been an intervention study with the primary aim to reduce FOF in persons with PD [148]. A randomized controlled trial showed that a twelve-week intervention with balance and gait training with augmented feedback led to significantly reduced FOF (assessed with ABC) in persons with PD, three and twelve months after the intervention [148]. Other intervention studies have included the reduction of FOF as a secondary aim, e.g., by exposing persons with PD to supervised slackline training [149] or other highly challenging balance exercises [150]. More studies are needed to confirm the effects and to establish the type of intervention that is the most effective, including the dosage needed.

While preventing or reducing FOF is beyond the scope of this thesis, the results still include aspects that could be worth considering in future intervention studies as well as in clinical practice. The findings suggest that interventions aiming at preventing or reducing FOF in persons with PD should be individually tailored and focus on several aspects, e.g., PD-related symptoms and disabilities, activities and environmental factors.

More specifically, interventions might benefit from including walking exercises of varying kinds and in various environments. A mix of walking exercises on various surfaces, indoors as well as outdoors, at home and out in the society may be beneficial for preventing or reducing FOF. This is suggested since walking difficulties in everyday life were the single most important explanatory factor of

FOF in this thesis as well as in previous studies [49, 51]. Also, the participants in the Interview study expressed that walking difficulties were increasing their FOF. Moreover, walking on slippery and uneven surfaces and walking in crowds were among the activities that were scored as most difficult in the Psychometric study as well as in previous studies [46, 66-68].

Furthermore, stair climbing might need some specific attention since the Psychometric study and the Interview study, as well as a previous study [51], revealed that it was associated with FOF. The findings in this thesis and previous studies [29, 71, 141] suggest that it is motivated to teach persons with PD and FOF how to use their walking devices, as well as to make sure that their devices are suitable and safe. Efforts are also needed to develop mobility devices that better address the needs of persons with PD. Moreover, specific attention on teaching persons with PD how to get up from the floor might be successful in preventing or reducing FOF [62, 144].

Activities and exercises aiming at reducing FOF in persons with PD might be best conducted in groups or with other persons nearby. This might increase the possibilities for persons with PD to participate, since FOF was said to increase when being alone.

Strengths and limitations

This thesis adds to the knowledge of FOF in persons with PD by using quantitative as well as qualitative approaches. By doing so, closed-ended data are compared and explained by using open-ended data. Combining the two research perspectives provides a better understanding of the phenomenon in question [151], i.e., FOF in persons with PD.

The studies included participants of both genders, with a wide spread in age (almost 50 years) and PD duration (more than 40 years), and various PD-related disabilities and intensities of FOF. As persons with PD typically have medical complaints other than their PD diagnosis [152], the studies did not exclude persons with comorbidities, such as e.g., osteoarthritis or a previous stroke. As such, the study samples can be considered as representative for the larger PD population.

The Interview study included twelve participants. Due to the small sample size, the results cannot be generalized to the entire PD population. However, as this was a qualitative study, generalization was not the aim, but instead an increased understanding of the phenomenon in question, i.e., FOF in persons with PD. Thus, the participants in the Interview study were not randomly included but strategically selected in a two-step procedure in order to ensure a heterogenic sample with

various experiences of FOF. The rigorous procedure for selection of participants therefore strengthens the credibility of the Interview study.

As in any research, there were persons who declined participation due to various reasons. One might speculate that they had more severe PD (and perhaps more pronounced FOF) and that the results might have differed if there were no dropouts. However, as data were collected by means of postal surveys and/or home visits, it is possible that more persons with severe disabilities chose to participate than if participation would have required them to leave their home.

Four commonly used FOF rating scales were studied together in the ICF Linking study and the Psychometric study, which enable head-to-head comparisons. Thus, psychometric properties of the four scales can be compared, as they are all based on the same study sample. However, the use of Swedish translations of the rating scales naturally implies that some linguistic and cultural adaptations have been made. Consequently, the results might have been slightly different if the English versions would have been used.

The Explanatory study is a fairly comprehensive study of explanatory factors of concerns about falling, as it took a large number of independent variables into consideration, including personal, environmental as well as PD-related factors. Data were collected by using self-rating scales as well as clinical measures. The cross-sectional study design restricted identification of predictive factors of concerns about falling. However, the study revealed a well-fitted regression model with high explanatory capacity. Although there might be other factors worth considering, the study revealed several factors that might be of importance for concerns about falling in persons with PD.

In the Interview study, the interviewer ended each interview by summarizing the main points and gave the participant the opportunity to make clarifications, but the interpreted meaning (themes and categories) was not checked with the participants. Due to the author's parental leave, a long period of time passed between the conduction of the interviews and the finalization of the analytical process. More than one and a half year passed, which could potentially restrict validation by the participants as their experiences of FOF might have changed since the interviews. However, all four researchers that were involved in the study took an active part in finalizing the themes and categories, in order to ensure that they emerged from the data. Thus, there was a validity check within the research team.

Suggestions for future research

- Methodological studies are needed that address how the quantitative measures of the ICF linking process should be interpreted.

- Additional studies are needed to confirm the psychometric properties of FES-I in persons with PD, as well as to explore psychometric aspects that were not covered within this thesis, e.g., responsiveness and limits for clinically meaningful change.

- The possibility of adding clarifications to scale instructions regarding how to respond to items, in terms of, e.g., being alone or using various assistive devices, could be considered in future adaptations of FES(S), mSAFFE and the Swedish versions of FES-I and ABC.

- Further studies are needed that consider the potential impact of physical environmental factors on FOF in persons with PD by using more detailed data on housing and exterior surroundings.

- Specific studies are needed that explore the use, benefits and potential problems with mobility devices for persons with PD in various environments.

- Longitudinal studies are needed to shed light on the cause and effects of FOF and its associated factors.

- Intervention studies with the primary aim to prevent or reduce FOF in persons with PD are highly needed to establish the type of intervention that is most effective.

Conclusions and clinical implications

FOF is an important factor to consider in the treatment, care and rehabilitation of persons with PD. An increased understanding of FOF is desirable among clinicians, researchers, as well as among people in the society at large. A dialogue with the person with PD is needed in order to provide help in a way that suits the individual. It should be noted that offering help in the "wrong way" might even increase FOF in persons with PD.

The ICF linking process revealed similarities as well as differences between FES-I, FES(S), ABC and mSAFFE. All four scales predominately focused on the ICF chapter of mobility and included linkages to domestic life. While ABC had a very large emphasis on mobility, the content of the other scales was more diverse. Based on their psychometric properties, FES-I or mSAFFE seem suitable for assessing FOF in people with PD in research and clinical practice. However, while FES-I was the only rating scale with satisfactory test-retest reliability for use in individual comparisons, its psychometric properties in people with PD need to be confirmed by additional studies. It should be noted that none of the studied rating scales assess FOF in itself, but various conceptualizations of FOF. FES-I assesses concerns about falling while mSAFFE assesses activity-avoidance due to the risk of falling. Although these conceptualizations are closely related and can be assembled under the umbrella term FOF, the constructs are not interchangeable. Selection of a FOF rating scale should be based on scale content, psychometric properties as well as the specific aspects of FOF that one wishes to address.

Several factors were significant explanatory factors of FOF, conceptualized as concerns about falling, in persons with PD. Walking difficulties in everyday life were the single most important factor, followed by orthostatism, motor symptoms, age and fatigue. Walking difficulties in everyday life, orthostatism, motor symptoms and fatigue may therefore need specific attention in the clinical setting, especially as a person ages. Minimizing the impact of, and teaching persons with PD to handle these symptoms, may contribute to a reduction of FOF. General self-efficacy and the studied environmental factors did not significantly explain concerns about falling in this thesis. However, there might be other explanatory factors worth considering, such as physical environmental factors.

The experiences of FOF were complex and multifaceted. FOF affected the lives of persons with PD and FOF in several ways. It was experienced as a disturbance in

everyday life, which caused feelings of vulnerability and loss, and made activities and environments seem hazardous. The experiences of FOF varied over time and in relation to different activities and environments. Different strategies were adopted to handle FOF, such as caution, avoidance, using support or disregarding FOF.

Means and interventions targeting FOF need to be individually tailored for persons with PD and focus on several aspects, e.g., PD-related symptoms and disabilities, activities and environmental factors. Interventions might benefit from including walking exercises of different types and in various environments in order to minimize walking difficulties in everyday life and, thereby, prevent or reduce FOF. Practicing stair climbing and teaching persons with PD how to get up from the floor might also be helpful in preventing or reducing FOF. Moreover, teaching persons with PD how to use their walking devices in an optimal way are motivated, as well as making sure that their devices are suitable and safe. Efforts are also needed to develop assistive devices that better address the needs of persons with PD.

It should be noted that FOF was experienced to increase when being alone, and activities and exercises aiming at reducing FOF in persons with PD might preferably be supervised and/or conducted in a group setting.

Svensk sammanfattning

Rädsla för att falla är vanligt förekommande bland personer med Parkinsons sjukdom. Rädslan förekommer främst hos dem som har fallit men rapporteras även bland personer som inte har råkat ut för något fall. Rädsla för att falla kan medföra stora konsekvenser i vardagen eftersom den kan leda till aktivitetsundvikande och en stillasittande livsstil, social isolering samt en försämrad livskvalitet. Dessutom utgör rädslan en riskfaktor för framtida fall. Därmed är rädsla för att falla hos personer med Parkinsons sjukdom en viktig aspekt att beakta, såväl för forskare som för kliniker och rehabiliteringsteam.

Adekvata och välfungerande skattningsskalor behövs för att kunna utvärdera rädsla för att falla på ett bra sätt, och därmed kunna följa hur rädslan förändras över tid. Idag finns många olika skattningsskalor som mäter olika aspekter av rädsla för att falla. För att underlätta valet av skattningsskala behövs en fördjupad kunskap om vad skattningsskalorna mäter och dess mätegenskaper. För att kunna erbjuda personer med Parkinsons sjukdom och en rädsla för att falla en optimal behandling, vård och rehabilitering behövs dessutom ytterligare studier för att identifiera faktorer som kan förklara denna rädsla. Det finns även ett behov av en djupare och rikare förståelse för rädslan som fenomen. Hittills har ingen studie undersökt hur personer med Parkinsons sjukdom upplever rädsla för att falla.

Det övergripande syftet med denna avhandling var att öka kunskapen om hur rädsla för att falla bland personer med Parkinsons sjukdom kan utvärderas, liksom att utöka och fördjupa förståelsen för rädsla för att falla hos personer med Parkinsons sjukdom i relation till såväl förklarande faktorer som personernas egna upplevelser.

I de första två studierna analyserades och jämfördes fyra olika skattningsskalor som mäter olika aspekter av rädsla för att falla. Skalor som innefattades var den svenska versionen av Falls Efficacy Scale (FES(S)), Falls Efficacy Scale-International (FES-I), Activities-specific Balance Confidence scale (ABC) och den modifierade Survey of Activities and Fear of Falling in the Elderly (mSAFFE). Den första studien var en så kallad länkningsstudie, där innehållet i de fyra skattningsskalorna länkades till Klassifikationen av funktionstillstånd, funktionshinder och hälsa (ICF). Denna studie innefattade inga empiriska data (dvs inkluderade inga deltagare). Den andra studien var en enkätstudie, där de fyra skattningsskalorna för rädsla för att falla skickades ut två gånger med avsikt att undersöka dess mätegenskaper. Denna studie inkluderade 102 deltagare (medianålder 74 år, medianvärde för Parkinsonduration

5 år). I den tredje studien identifierades faktorer som kan förklara en bekymran för att falla (vilket utgör en aspekt av rädsla för att falla) genom att beakta såväl Parkinsonrelaterade symtom och funktionshinder, personliga faktorer, som faktorer i omgivningen. Denna studie inkluderade 241 deltagare (medianålder 70 år, medianvärde för Parkinsonduration 8 år). Den fjärde studien var en intervjustudie som undersökte hur personer med Parkinsons sjukdom och en rädsla för att falla upplevde denna rädsla. Djupintervjuer genomfördes med tolv personer med Parkinsons sjukdom (medianålder 70 år, medianvärde för Parkinsonduration 9 år).

Länkningsstudien visade att den stora merparten av frågorna i de fyra skattningsskalorna för rädsla för att falla berörde ICF-komponenten Aktivitet och Delaktighet. Alla fyra skalorna fokuserade i huvudsak på ICF-kapitlet kring förflyttningar. Detta gällde framförallt ABC, medan innehållet i de övriga skattningsskalorna var lite mer varierat.

Jämförelsen av skattningsskalornas mätegenskaper visade att ABC hade betydligt sämre datakvalitet (dvs fler obesvarade frågor) än de övriga skalorna. Både FES(S) och ABC hade dessutom fler personer med avvikande skattningar när två olika testtillfällen jämfördes med varandra. Alla fyra skattningsskalorna uppvisade en acceptabelt låg nivå av mätfel, men FES-I var den enda skalan vars mätfel understeg den nivå som har föreslagits gälla som övre gräns när en skattningsskala ska användas på individnivå.

Flera olika faktorer visade sig kunna förklara en bekymran för att falla. Gångsvårigheter i vardagen hade det starkaste förklaringsvärdet, följt av plötsliga blodtrycksfall (ortostatism), motoriska symtom, ålder och extrem trötthet (fatigue).

Rädsla för att falla visade sig påverka det vardagliga livet för personer med Parkinsons sjukdom på flera olika sätt. Rädslan upplevdes som en störning i vardagen som ledde till känslor av sårbarhet och en saknad efter ett liv utan rädsla för att falla. Rädslan gjorde att olika vardagliga aktiviteter och omgivningar framstod som riskfyllda. Upplevelserna av rädsla för att falla varierade över tid, liksom i olika aktiviteter och omgivningar. Olika strategier användes för att hantera rädslan för att falla, så som en ökad försiktighet, undvikande av aktiviteter, användande av stöd från andra personer och hjälpmedel, eller att helt enkelt försöka bortse från rädslan för att falla.

Sammanfattningsvis tycks FES-I eller mSAFFE vara lämpliga för att mäta rädsla för att falla hos personer med Parkinsons sjukdom. Dock bör val av skattningsskala föregås av överväganingar kring vilken aspekt av rädsla för att falla som önskas mätas. Resultaten tyder på att insatser och åtgärder som syftar till att förebygga eller minska rädsla för att falla hos personer med Parkinsons sjukdom bör anpassas efter individen och fokusera på flera olika aspekter, såsom Parkinsonrelaterade symtom och funktionshinder, aktiviteter och omgivningsfaktorer.

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Appendix 1

Study specific interview guide for the Interview study

- What does it mean to you to be afraid of falling?

- When are you afraid of falling? (Activities, environments, influences from internal/external factors)

- How has your fear of falling developed over time?

- Why do you think that you are afraid of falling; what are you afraid of?

- What would make you less afraid of falling in these situations?

- Is the intensity of your fear of falling constant or does it vary (with time of day, indoors/outdoors, how you feel at the moment, whether you are alone/have company, etc.)?

- Have you made any changes or adjustments in your life due to your fear of falling?

- Do you behave differently due to your fear of falling?

- Would your life be any different if you were not afraid of falling?

Follow-up questions and probes were used to deepen the participants' answers.

Appendix 2

Detailed information of the linking of overall questions and response categories of four fear of falling rating scales to the ICF

Rating scale	Overall question and response categories	ICF category	Additional information
FES-I	Q: Now we would like to ask some questions about how concerned you are about the possibility of falling	b152 Emotional functions nd: not definable	Concerned Falling
	RC: Not at all/somewhat/fairly/very concerned	b152 Emotional functions	Not at all/somewhat/fairly/ very concerned
FES(S)	Q: How confident are you that you can … without falling?	b1266 Confidence nd: not definable	Falling
	RC: Not confident at all/fairly confident/completely confident	b1266 Confidence	Not at all/fairly/completely
ABC	Q: How confident are you that you will not lose your balance or become unsteady when you …?	b1266 Confidence b755 Involuntary movement reaction functions b755 Involuntary movement reaction functions	Lose your balance Become unsteady
	RC: No confidence/completely confident	b1266 Confidence	No/completely
mSAFFE	Q: Do you avoid doing certain things because of a risk of falling?	d Activities and participation nd: not definable	Avoid doing Falling
	RC: Would never/sometimes/always avoid	d Activities and participation	Never/sometimes/always avoid

ICF = International Classification of Functioning, Disability and Health; FES-I = Falls Efficacy Scale-International; FES(S) = Swedish version of the Falls Efficacy Scale; ABC = Activities-specific Balance Confidence scale; mSAFFE = modified Survey of Activities and Fear of Falling in the Elderly; Q = overall question; RC = response category; b = ICF component of body functions; d = ICF component of activities and participation.

Appendix 3

Detailed information of the linking of the Falls Efficacy Scale-International (FES-I) items to the International Classification of Functioning, Disability and Health (ICF)

Item	ICF category	Additional information
1. Cleaning the house (e.g., sweep the floor, vacuum or dust)	d6402 Cleaning living area (d6402) Cleaning living area (d6403) Using household appliances (d6402) Cleaning living area	
2. Getting dressed or undressed	d540 Dressing d540 Dressing	
3. Preparing simple meals	d6300 Preparing simple meals	
4. Taking a bath or shower	d5101 Washing whole body d5101 Washing whole body	
5. Buying some groceries	d6200 Shopping	Some groceries
6. Getting in or out of a chair	d4103 Sitting d4103 Sitting	In a chair Out of a chair
7. Climbing stairs	d4551 Climbing	
8. Walking around in the neighborhood	d4602 Moving around outside the home and other buildings	
9. Reaching for something above your head or on the ground	d4452 Reaching d4105 Bending	Above your head On the ground
10. Answering the telephone before it stops ringing	d3600 Using telecommunication devices	Answer the telephone
11. Walking on a slippery surface (e.g., wet or icy)	d4502 Walking on different surfaces (d4502) Walking on different surfaces (d4502) Walking on different surfaces	Slippery Wet
12. Visiting acquaintances, friends or relatives	d9205 Socializing d9205 Socializing d9205 Socializing	Acquaintances
13. Walking in crowds	d4503 Walking around obstacles	
14. Walking on an uneven surface (e.g., rocky ground, poorly maintained pavement)	d4502 Walking on different surfaces (d4502) Walking on different surfaces (d4502) Walking on different surfaces	Rocky ground Poorly maintained pavement
15. Walking up or down a slope	d4502 Walking on different surfaces d4502 Walking on different surfaces	
16. Participating in a social event (e.g., family gathering, club meeting or religious service)	d9 Community, social and civic life (d9205) Socializing (d910) Community life (d9300) Organized religion	Participating in a social event Club meeting Religious service

Appendix 4

Detailed information of the linking of the Swedish version of the Falls Efficacy Scale (FES(S)) items to the International Classification of Functioning, Disability and Health (ICF)

Item	ICF category	Additional information
1. Get in and out of bed	d4100 Lying down d4100 Lying down	In bed Out of bed
2. Go to the toilet	d530 Toileting	
3. Wash yourself	d510 Washing oneself	
4. Get in and out of a chair	d4103 Sitting d4103 Sitting	In a chair Out of a chair
5. Get dressed and undressed	d540 Dressing d540 Dressing	
6. Take a bath or a shower	d5101 Washing whole body d5101 Washing whole body	
7. Go up and down stairs	d4551 Climbing d4551 Climbing	
8. Walk around the neighborhood	d4602 Moving around outside the home and other buildings	
9. Reach into cupboards/ closets	d4452 Reaching	Into cupboards/closets
10. Clean the apartment (i.e., sweep or dust)	d6402 Cleaning living area (d6402) Cleaning living area (d6402) Cleaning living area	
11. Prepare a meal that does not require carrying hot or heavy objects	d630 Preparing meals d4301 Carrying in the hands	Hot or heavy objects
12. Hurrying up to answer the telephone	d2401 Handling stress d3600 Using telecommunication devices	Hurrying up Answer the telephone
13. Simple shopping	d6200 Shopping	Simple shopping

Appendix 5

Detailed information of the linking of the Activities-specific Balance Confidence scale (ABC) items to the International Classification of Functioning, Disability and Health (ICF)

Item	ICF category	Additional information
1. Walk around the house	d4600 Moving around within the home	
2. Walk up or down stairs	d4551 Climbing d4551 Climbing	
3. Bend over and pick up a shoe from the floor	d4105 Bending d4452 Reaching	Shoe from the floor
4. Reach for a small can off a shelf at eye level	d4452 Reaching	Small can off a shelf at eye level
5. Stand on your tiptoes and reach for something above your head	d4154 Maintaining a standing position d4452 Reaching	On your tiptoes Above your head
6. Stand on a chair and reach for something	d4154 Maintaining a standing position d4452 Reaching	On a chair
7. Sweep or vacuum the floor	d6402 Cleaning living area d6403 Using household appliances	The floor
8. Walk to a taxi that is waiting by the sidewalk	d4500 Walking short distances	To a taxi
9. Get into or out of a car	d410 Changing basic body position d410 Changing basic body position	Get into a car Get out of a car
10. Cross a street	d4503 Walking around obstacles	Cross a street
11. Step onto or off a curb	d4551 Climbing d4551 Climbing	Step onto a curb Step off a curb
12. Walk on a street where people are rapidly passing	d4503 Walking around obstacles	
13. Others bump into you as you walk on the street	e Environmental factors d4503 Walking around obstacles	Others bump into you
14. Travel by bus *without* a bag of groceries	d4702 Using public motorized transportation	Without a bag of groceries
15. Travel by bus *with* a bag of groceries	d4702 Using public motorized transportation	With a bag of groceries
16. Walk on icy sidewalks	d4502 Walking on different surfaces	Icy sidewalks

Appendix 6

Detailed information of the linking of the modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE) items to the International Classification of Functioning, Disability and Health (ICF)

Item	ICF category	Additional information
1. Walk to the store and shop	d460 Moving around in different locations d6200 Shopping	
2. Clean your house	d6402 Cleaning living area	
3. Prepare simple meals	d6300 Preparing simple meals	
4. Go to the doctor or dentist	d5702 Maintaining one's health d5702 Maintaining one's health	Go to the doctor Go to the dentist
5. Take a bath	d5101 Washing whole body	
6. Take a shower	d5101 Washing whole body	
7. Go for a walk	d450 Walking	
8. Go out when it is slippery	d4502 Walking on different surfaces	Slippery
9. Visit a friend or relative	d9205 Socializing d9205 Socializing	
10. Walk to a place with crowds	d4503 Walking around obstacles	
11. Climb stairs	d4551 Climbing	
12. Walk around indoors	d460 Moving around in different locations	
13. Walk a kilometer	d4500 Walking short distances	A kilometer
14. Bend down to pick up something	d4105 Bending d4400 Picking up	
15. Travel by public transport	d4702 Using public motorized transportation	
16. Attend a social event or party	d9 Community, social, and civic life d9 Community, social, and civic life	Attend a social event Attend a party
17. Reach for something above your head	d4452 Reaching	Above your head