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A line-art illustration of an elderly person with white hair and glasses, wearing a white long-sleeved shirt and light-colored pants. They are leaning forward, using a silver walker for support. Their right hand is resting on the head of a small, light-colored dog. The background shows a simple room with a door, a window with a hanging plant, and a table with a chair. The overall style is clean and minimalist, using black outlines and light gray shading.

Housing Matters for People with Parkinson's disease

Accessibility, Meaning, Control and Activities of Daily Living

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FACULTY OF MEDICINE | LUND UNIVERSITY



Housing Matters for People with Parkinson's disease

Accessibility, Meaning, Control
and Activities of Daily Living

Nilla Andersson



LUND
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DOCTORAL DISSERTATION

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Abstract			
<p>Parkinson´s disease (PD) is one of the most common neurological diseases with both motor and non-motor symptoms that can be perceived as difficult to control despite medical treatment. This leads to several consequences in everyday life for example difficulties in activities of daily living (ADL), sometimes already at diagnosis. Therefore, rehabilitation is important to manage the consequences of the disease and to improve health. Furthermore, ADL performance is dependent on the environment one interacts with, and housing is one environment associated with different health outcomes in the ageing population. However, housing matters constitutes a knowledge gap for people with PD. Therefore, the overall aim of this thesis was to increase the knowledge of housing matters for people with PD living in ordinary housing in Sweden, covering both objective and perceived aspect of housing. Furthermore, psychometric evaluations of instruments capturing perceived housing were performed.</p> <p>This thesis has a quantitative approach and is based on baseline and three-year follow-up data from the longitudinal study "Home and health in people ageing with PD" (HHPD). The data collection was done through questionnaires and clinical assessments at home visits. Study I was a three-year cohort study that included 138 participants and explored environmental barriers and housing accessibility for people with PD. Both parametric and non-parametric statistics were used to explore change over time. The results show that the top ten environmental barriers that generated accessibility problems were largely the same over the three years, although with notable changes in order and magnitude. Barriers in hygiene areas, kitchens and entrances were ranked at the top at baseline, while a barrier in the exterior surrounding generated the most accessibility problems after three years. Studies II and III were cross-sectional and evaluated psychometric properties of the Meaning of Home Questionnaire (MOH) and external Housing-Related Control Belief Questionnaire (HCQ) for 145 participants each. Data quality, structural validity, construct validity, scaling assumptions, floor- and ceiling effects and internal consistency reliability were evaluated. The results of both studies suggested revised versions of the instruments based on the evaluation of structural validity. Further evaluations showed that data quality was high and construct validity was largely supported for both instruments. Also, internal consistency and homogeneity of the instruments surpassed the recommended values in both studies. Study IV was a cohort study including 154 participants at baseline and at follow-up, that explored the direction of the relationship between external housing-related control beliefs and ADL. Linear and logistic regression analyses were used. The results suggest that difficulties in ADL lead to higher external control beliefs related to the home, while the other direction could not be confirmed. This finding regarding people with PD is contrary to theories in environmental gerontology.</p> <p>The findings from this thesis can be applied in several ways. The knowledge of accessibility problems can be used in individual rehabilitation to enable more farsighted housing adaptations for people with PD. However, not all problems can be efficiently solved through individual rehabilitation, rather some should be addressed on the societal level to meet some of the housing needs for people with PD. The psychometric evaluation suggested that the revised versions of MOH and external HCQ are reliable and valid for use among people with PD, which is a prerequisite to enable high quality research on perceived housing. The novel findings that difficulties in ADL lead to higher external control beliefs related to the home, add to the overall understanding of housing and health interactions for people with PD.</p>			
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Housing Matters for People with Parkinson's disease

Accessibility, Meaning, Control
and Activities of Daily Living

Nilla Andersson



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*“A house is made of walls and beams, a home is built with love and dreams”
-Ralph Waldo Emerson*

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Svensk populärvetenskaplig sammanfattning

Miljöns betydelse för hälsa är välkänd och en stödjande miljö är viktigt för att kunna vara så självständig som möjlig och bo kvar i sin bostad. Personer som lever med Parkinsons sjukdom (PS) upplever ofta svårigheter i aktiviteter i det dagliga livet (ADL); därför är det viktigt att de miljöer personen vistas i gynnar personens aktiviteter. Trots att PS är en av de vanligaste neurologiska sjukdomarna, har forskning visat att kunskap saknas om bostäder för personer som lever med PS.

Denna avhandling syftar till att öka kunskapen om flera aspekter av boendet för personer med PS. Forskningen bidrar med ny kunskap om såväl tillgänglighet som upplevda aspekter av bostäder för personer med PS som bor i ordinärt boende i Sverige.

Att leva med Parkinsons sjukdom

PS är en livslång fortskridande neurologisk sjukdom som cirka 20 000 personer lever med i Sverige idag. Förekomsten ökar med ålder och antalet personer som lever med PS väntas dubblas till 2040. Att leva med PS är förknippat med både kroppsliga och icke-kroppsliga symtom, så som stelhet, nedsatt balans, skakningar, långsamma rörelser, kognitiv nedsättning och ökad trötthet. Symtomen upplevs ofta som svåra att kontrollera och förutse, vilket leder till olika konsekvenser i vardagen. Bland annat upplever personer med PS ofta svårigheter i aktiviteter i det dagliga livet (ADL), ofta redan vid diagnos.

Personer med PS erbjuds ofta medicinsk behandling, men eftersom det inte finns något botemedel för sjukdomen krävs det ofta rehabiliterande insatser för att hantera konsekvenserna av sjukdomen. Rehabiliteringens mål är att öka hälsa och välbefinnande och ges ofta i multidisciplinära team där flera professioner inblandade. Arbetsterapeuter är inte sällan en del av de team som personer med PS träffar, med ett specifikt fokus på de aktiviteter som personen vill och behöver göra i den miljön personen befinner sig.

Parkinsons sjukdom och boende

Hur man klarar att utföra sina aktiviteter beror bland annat på den miljö man befinner sig i. Bostaden är en miljö där många tillbringar mycket tid, och därmed är den också platsen för många aktiviteter. För den generellt åldrande befolkningen har bostaden visat sig ha stor betydelse för hälsa. Trots det, saknas kunskap om bostäder för olika grupper av den åldrande befolkningen, och för personer med PS har detta konstaterats vara en kunskapslucka. Därför är syftet med avhandlingen att öka kunskapen om olika aspekter av boendet för personer med PS. Detta har studerats genom att utforska tillgänglighet och upplevda aspekter av bostaden. Avhandling

innehåller fyra vetenskapliga artiklar och kvantitativa metoder har använts för att svara på syftet. Data som används i avhandlingen samlades in genom frågeformulär och bedömningar vid hembesök hos personer med PS.

Studier i avhandlingen

Studie I undersökte miljöhinder och tillgänglighetsproblem i bostäder för personer med PS. Resultatet visade att de tio hinder som gav mest tillgänglighetsproblem var i stort sett de samma i en uppföljning efter tre år. Miljöhindren ”Brist på handtag i badrum”, ”Trappa var enda vägen” i entréer och ”Väggplacerade skåp och hyllor var högt placerade” i kök bidrog till mest tillgänglighetsproblem vid första mättillfället, medan att ”Soptunna var svårt” i utomhusmiljön bidrog till mest problem vid uppföljningen. Denna kunskap kan användas i individuell rehabilitering för att möjliggöra mer förutseende och effektiva bostadsanpassningar för personer med PS. Resultatet tyder också på att man inte kommer åt alla hinder enbart genom individuell rehabilitering, utan att vissa behöver avhjälpas genom samhälleliga åtgärder, som exemplet med soptunnorna.

Upplevda aspekterna av boendet studerades med frågeformulär. När man använder frågeformulär i en ny grupp, i detta fall personer med PS, behöver man utvärdera så att dessa är stabila och tillförlitliga för gruppen. Därför utvärderar Studie II och III mätegenskaper för två frågeformulär som mäter upplevda aspekter av boendet. Det ena formuläret heter Meaning of Home Questionnaire (MOH) och mäter om person upplever sitt hem som meningsfullt. Det andra formuläret heter external Housing-Related Control Belief Questionnaire (HCQ) och mäter tron på extern kontroll i förhållande till bostaden, dvs om man tror att andra personer kommer hjälpa en; eller om man tror på chansen eller slumpen i relation till sitt hem, tex att det beror på slumpen om man kan bo kvar i sin bostad. Studierna visade att något anpassade versioner av frågeformulären bör användas för att mäta mening och extern tro på kontroll i relation till hemmet för personer med PS. Denna grundläggande forskning är en förutsättning för att studier gällande upplevda aspekter av boende ska hålla hög kvalitet gäller framöver.

Studie IV utforskar förhållandet mellan tro på extern kontroll i förhållande till bostaden och ADL över tid. Tidigare forskning har visat att det finns ett samband mellan tro på extern kontroll i förhållande till bostaden och svårigheter i ADL för personer med PS, men ingen har undersökt på om extern kontroll i förhållande till bostaden påverkar svårigheter i ADL eller tvärtom. Därför undersöktes båda möjliga riktningarna av detta förhållande i Studie IV. Resultatet visar att svårigheter i svårigheter i ADL påverkar tron på extern kontroll i förhållande till bostaden. Dessa resultat är i motsats till vad tidigare miljögerontologisk litteratur visat och behöver därför utvärderas av andra studier. Denna nya kunskap bidrar till en ökad förståelse för relationen mellan boende och hälsa för personer med PS.

Sammanfattningsvis kan kunskapen från denna avhandling användas av arbetsterapeuter som jobbar med individuell rehabilitering, men den kan också användas på samhällsnivå för att möta de behov personer med PS har när det gäller bostäder. Avhandlingen bidrar också med grundläggande kunskap om hur frågeformulär som mäter upplevda aspekter av bostaden bör användas för personer med PS, vilket möjliggör forskning av god kvalitet när det gäller upplevda aspekter av boendet framöver. Kunskap om relationen mellan upplevda aspekter av bostaden och hälsa (ADL) för personer med PS fördjupades också i avhandlingen. Detta är viktigt för att fortsatt bygga en kunskapsbas och öka förståelsen för relationen mellan boende och hälsa för personer med PS.

Abstract

Parkinson's disease (PD) is one of the most common neurological diseases with both motor and non-motor symptoms that can be perceived as difficult to control despite medical treatment. This leads to several consequences in everyday life for example difficulties in activities of daily living (ADL), sometimes already at diagnosis. Therefore, rehabilitation is important to manage the consequences of the disease and to improve health. Furthermore, ADL performance is dependent on the environment one interacts with, and housing is one environment associated with different health outcomes in the ageing population. However, housing matters constitutes a knowledge gap for people with PD. Therefore, the overall aim of this thesis was to increase the knowledge of housing matters for people with PD living in ordinary housing in Sweden, covering both objective and perceived aspect of housing. Furthermore, psychometric evaluations of instruments capturing perceived housing were performed.

This thesis has a quantitative approach and is based on baseline and three-year follow-up data from the longitudinal study "Home and health in people ageing with PD" (HHPD). The data collection was done through questionnaires and clinical assessments at home visits. Study I was a three-year cohort study that included 138 participants and explored environmental barriers and housing accessibility for people with PD. Both parametric and non-parametric statistics were used to explore change over time. The results show that the top ten environmental barriers that generated accessibility problems were largely the same over the three years, although with notable changes in order and magnitude. Barriers in hygiene areas, kitchens and entrances were ranked at the top at baseline, while a barrier in the exterior surrounding generated the most accessibility problems after three years. Studies II and III were cross-sectional and evaluated psychometric properties of the Meaning of Home Questionnaire (MOH) and external Housing-Related Control Belief Questionnaire (HCQ) for 145 participants each. Data quality, structural validity, construct validity, scaling assumptions, floor- and ceiling effects and internal consistency reliability were evaluated. The results of both studies suggested revised versions of the instruments based on the evaluation of structural validity. Further evaluations showed that data quality was high and construct validity was largely supported for both instruments. Also, internal consistency and homogeneity of the instruments surpassed the recommended values in both studies. Study IV was a cohort study including 154 participants at baseline and at follow-up, that explored the direction of the relationship between external housing-related control beliefs and ADL. Linear and logistic regression analyses were used. The results suggest that difficulties in ADL lead to higher external control beliefs related to the home, while the other direction could not be confirmed. This finding regarding people with PD is contrary to theories in environmental gerontology.

The findings from this thesis can be applied in several ways. The knowledge of accessibility problems can be used in individual rehabilitation to enable more farsighted housing adaptations for people with PD. However, not all problems can be efficiently solved through individual rehabilitation, rather some should be addressed on the societal level to meet some of the housing needs for people with PD. The psychometric evaluation suggested that the revised versions of MOH and external HCQ are reliable and valid for use among people with PD, which is a prerequisite to enable high quality research on perceived housing. The novel findings that difficulties in ADL lead to higher external control beliefs related to the home, add to the overall understanding of housing and health interactions for people with PD.

My journey

During my undergraduate studies in occupational therapy, my fellow students and I were encouraged to read current scientific articles on the topics addressed in our education. This sparked an interest to know more, and my interest continued to grow as I started working at a neurorehabilitation clinic with close ties to research. With inspiring colleagues and role models who pushed me to pursue my interest further I started my master's degree. When a PhD position exploring housing aspects for people with Parkinson's diseases (PD) was announced, I was just about to finish my master. Becoming a doctoral student had been a dream for a long time, so I felt like it was now or never.

As an occupational therapist I have often addressed housing matters (mainly housing accessibility) in rehabilitation for people with PD to enable them to deal with consequences of the disease and maintain daily activities. When I started as a PhD student in the summer of 2018, it was with that clinical perspective I went into the PhD project. It has been very exciting to be part of a project that has been close to my clinical experiences and that has addressed aspects that I have dealt with and also wanted to know more about as a clinician. Personally, I have learnt so much during this education, but I also hope that the scientific knowledge and practical implications gained from this thesis can be applied in individual rehabilitation and on a societal level as well as in research, to further develop our knowledge of housing matters for people with PD.

Thesis development

Given my background in rehabilitation, it felt natural to address an aspect of housing that would be familiar to occupational therapists working with people with PD, namely housing accessibility. As I learned more about housing, I realised there were other considerations to be aware of. Although perceived housing is an established research topic in other research fields, it is an uncommon in both occupational therapy and PD research. Two instruments that address perceived housing were therefore explored in this thesis. A methodological study addressing both instruments was planned to ensure that they were psychometrically sound for use in a PD population. However, because the results of the two instruments developed in different ways, the psychometric study was split into two by necessity. This decision affected the overarching plan for the four studies included in the thesis, which led to a removal of an intended qualitative study.

Context of thesis

This thesis in health sciences, with a focus on occupational therapy, was carried out in the research group Active and Healthy Ageing at the Department of Health Sciences, Faculty of Medicine at Lund University. The research group is affiliated with the interdisciplinary Centre for Ageing and Supportive Environments (CASE). The learning process of the author was supported by the Swedish National Graduate School on Ageing and Health (SWEAH) and Multidisciplinary Research on Parkinson's disease (MultiPark).

All the data in this thesis come from the longitudinal cohort study "Home and health in people ageing with Parkinson's disease" (PI: M.H. Nilsson), which is a part of the "Home, Health and Disability along the Process of Ageing" programme (PI:S. Iwarsson).

List of publications

- I. Andersson, N., Slaug, B., Nilsson, M.H., & Iwarsson, S. (2021). Environmental barriers and housing accessibility problems for people with Parkinson's disease. *Scandinavian Journal of Occupational Therapy*, 6:1-12. <https://doi.org/10.1080/11038128.2021.200799>
- II. Andersson, N., Nilsson, MH., Slaug, B., Oswald, F., & Iwarsson, S. (2020). The meaning of home questionnaire revisited: Psychometric analyses among people with Parkinson's disease reveals new dimensions. *PLoS ONE* 15(12):e0242792. <https://doi.org/10.1371/journal.pone.0242792>
- III. Andersson, N., Nilsson, M.H., Slaug, B., Oswald, F., & Iwarsson, S. (2020). Psychometric properties of the external Housing-Related Control Beliefs Questionnaire among people with Parkinson's disease. *Ageing Clinical and Experimental Research*, 32:12:2639-2647. <https://doi.org/10.1080/11038128.2012.2007998>
- IV. Andersson, N., Iwarsson, S., Ullén, S., Slaug, B., & Nilsson, M.N. Exploring the directions of the relationship between Housing-Related Control Beliefs and Activities of Daily Living among people with Parkinson's Disease: A Three-year Follow-up Study. Submitted.

Thesis at a glance

Study I. Changes in objective housing	
Aim	To determine the most severe environmental barriers in terms of housing accessibility problems and how these evolve over three years among people with PD.
Method	This was a cohort study (N=138), including baseline and three-year follow-up data. Data were collected during interviews and clinical assessments at home visits. Statistics used were paired samples t-test and McNemar's test.
Results	The ten most prevalent barriers remained largely the same over the three years, but with notable change in order and magnitude. Items in hygiene areas, entrances and kitchen generated the most accessibility problems at baseline, while at follow-up a barrier in the exterior surroundings was ranked at the top. Exploring the summed magnitude of accessibility problems for the top ten barriers per housing section showed that the exterior surrounding was the only section that increased significantly over three years.
Conclusion	Knowledge on how accessibility problems evolve over time for people with PD could be applied in rehabilitation but must also be addressed systematically on the societal level.
Study II. Psychometric evaluation of Meaning of Home Questionnaire (MOH)	
Aim	To examine the psychometric properties of MOH Questionnaire, to identify whether it is valid and reliable for use for people with PD.
Method	This was a cross-sectional study (N=245) using baseline data. Data were collected during interviews and clinical assessments at home visits. Evaluation of data quality, structural validity, floor and ceiling effects, corrected item total correlations, internal consistency and construct validity (convergent and discriminant) were made.
Result	Structural validity suggested a removal of five items and revealed three new factors: "My home is my castle", "My home is my prison" and "My home is my social hub". In the revised MOH version, the corrected item total correlations were >0.3 for all items and internal consistency was >0.70 for all sub-scales. No floor or ceiling effects were found, except for the sub-scale "My home is my castle". Also, construct validity was largely supported.
Conclusion	The revised version of MOH was reliable and valid for use in a PD population.
Study III. Psychometric evaluation of external Housing-Related Control belief Questionnaire (HCQ)	
Aim	To examine the psychometric properties of external HCQ, to identify whether it is valid and reliable for use for people with PD.
Method	This was a cross-sectional study (N=245) using baseline data. Data were collected during interviews and clinical assessments at home visits. Evaluation of data quality, structural validity, floor and ceiling effects, corrected item-total correlations, internal consistency, and construct validity (known group and convergent) were made.
Result	Structural validity showed a unidimensional construct with the removal of two items. In this revised version of external HCQ, internal consistency was >0.70 and the corrected item-total correlation was >0.30 for all items. No floor or ceiling effects were found and construct validity was supported.
Conclusion	The revised version of external HCQ was reliable and valid for use in a PD population.
Study IV. The directions of the relationship between external control beliefs related to the home and ADL	
Aim	To explore the direction of the relationship between external control beliefs related to the home and ADL among people with PD.
Method	This was a cohort study (N=154), including both baseline and three-year follow-up data. Data were collected during interviews and clinical assessments at home visits. Both linear and logistic regression analyses were applied.
Result	The adjusted linear regression analysis showed that more difficulties in ADL lead to higher external control beliefs related to the home, supporting hypothesis 1. However, hypothesis 2 was not supported, by the adjusted logistic regression analysis.
Conclusion	In contrast to gerontological theories addressing older adults, this study suggests that more difficulties in ADL lead to higher external control beliefs related to the home among people with PD, and not the other way around.

Abbreviations

ADL	Activities of Daily Living
CTT	Classical Test Theory
ETA	Ecological Theory of Ageing
GDS	Geriatric Depression Scale
GSE	General Self-Efficacy scale
HCQ	Housing-Related Control Belief questionnaire
HE	Housing Enabler Instrument
HHPD	The longitudinal cohort study “Housing and health in people ageing with Parkinson’s disease”
HY	Hoehn & Yahr scale
Lisat-11	Life Satisfaction Questionnaire -11
MOH	Meaning of Home Questionnaire
MoCA	Montreal Cognitive Assessment
PADLS	Parkinson’s disease Activity of Daily Living Scale
PD	Parkinson’s disease
P-E fit	Person-Environment fit
PEOP	Person-Environment-Occupation-Performance model
QoL	Quality of Life
RAPS	Relative Accessibility Problem Score
SEM	Standard Error of Measurement
UIMH	Usability in My Home Questionnaire
UPDRS	Unified Parkinson’s Disease Rating Scale
WHO	World Health Organization

Setting the scene

PD research is a large and ground-breaking field. Many aspects of the disease are addressed, such as mechanisms of the disease, medications, treatments and care and rehabilitation of the disease. Furthermore, there is literature addressing aspects of living and ageing with PD, covering activities of daily living (ADL), quality of life (QoL) and well-being. However, there is a notable knowledge gap on housing matters for people with PD.

In general, people age in their homes regardless of health decline and disabilities. Furthermore, housing has shown to be important for various health aspects in the general older population, but little is known for different sub-groups. PD is one of the most common neurological diseases and its incidence is expected to increase. As there are no curative treatments for PD, rehabilitation interventions are needed to cope with the consequences of the disease. As part of the rehabilitation team, occupational therapists often address the environment that a person lives in to compensate for disease symptoms affecting daily activities. People living with PD have expressed a desire to age in their own homes, which makes housing an important area to address to meet the housing needs of people living with PD.

Introduction

Living with Parkinson's disease

Parkinson's disease (PD) is a progressive neurodegenerative disorder caused by dopaminergic cell death in the brain (Váradi, 2020). This cell death makes it harder for the brain to control the nerve signals regulating body movements. There is limited knowledge on what causes PD, although both environmental and genetic factors are considered (Kalia & Lang, 2015). PD is uncommon among people younger than 40 years but it affects 1-2% of adults over the age of 65 and 4% over 85 (Váradi, 2020). This makes PD the second most common neurological disease, and its incidence increases with age. As life expectancy grows globally, the number of people with PD is expected to double with over 12 million people by 2040 (Dorsey et al., 2018). The onset of the disease is around 60 years and the majority of people with PD are older adults, which implies that people living with PD represents an ageing population (Fereshtehnejad & Lökk, 2014). Despite this, older people are often excluded from PD research (Fitzsimmons et al., 2012).

There are no tests to confirm a PD diagnosis as it is based purely on clinical observations and assessments of motor symptoms. The characteristic symptoms of PD are bradykinesia (slowness of movements), rigidity (stiffness), tremor (shaking) and postural instability (poor balance) (Postuma et al., 2015). Although the disease is associated with motor-symptoms, non-motor symptoms are also common such as sleep disturbance, cognitive impairments, depression, anxiety, pain, fatigue, olfactory dysfunction and autonomic dysfunction (e.g. constipation, high blood pressure). The non-motor symptoms are more frequent early in the disease, even before diagnosis, and are associated with decreased health related QoL. The progression of the disease is often characterised by motor symptoms deteriorating over time and with an increased complexity (Kalia & Lang, 2015).

There is no curative treatment for PD, meaning that all available treatments are symptomatic (Kalia & Lang, 2015). In the early phase of PD, medication with levodopa is often effective. However, as the disease progresses, the effect of medical treatment decreases and “on and off fluctuations” become more common. “On” indicate that medication is effective and PD symptoms are somewhat reduced, while “off” refers to periods with more PD symptoms (Hickey & Stacy, 2016). More advanced treatments can benefit persons with severe PD, such as deep brain stimulation (DBS) (Bratsos et al., 2018) or continuous medicine through a pump

(Hickey & Stacy, 2016). For the last decade clinical trials have been ongoing to treat PD with stem cell therapies (Parmar, 2018). Furthermore, the late stages of PD are associated with significant costs to society due to treatments and formal care (Hjalte et al., 2021).

Both motor and non-motor symptoms fluctuate in PD, and the disease can therefore be perceived as unpredictable and difficult to control (Chaudhuri et al., 2011). Thus, living with PD affects health in several ways.

Health of people with Parkinson's disease

In 1948 the WHO published a highly influential definition of health, viewing it from a broad perspective as a state of well-being: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). This definition has been criticised foremost for using the word "complete" in relation to well-being, which becomes particularly difficult in relation to people living with a chronic disease (Huber et al., 2011). Instead, Huber and colleagues (2011) suggested a definition of health as "the ability to adapt and self-manage". This definition seems to be more suitable in relation to people with PD, as it reflects that positive aspects of health can be experienced despite functional limitations. The Huber definition of health is also in line with a basic assumption in occupational therapy, that activity promotes health and wellbeing. From this perspective, health is often viewed as being able to do what you find meaningful and need, in a desired way within the persons context (Christiansen et al., 2015; Swedish Association of Occupational Therapists, 2018). Furthermore, when asking older adults to define health the ability to do activities independently and managing symptoms were important factors (Song & Kong, 2015), which supports Huber's definition.

When addressing health in a population the concept public health is often used. This can apply to a country's population but it can also cover smaller groups such as the ageing population or people with a specific diagnosis. Two common approaches to address public health are health prevention and health promotion. Health prevention is intended to prevent disease and ill health, whereas health promotion builds on health factors to support health. That is, health promotion can mean supporting health for people living with a disease (Wilhelmsson & Tengland, 2016). The World Health Organization (WHO) recently published a report about people with PD that applies a public health approach (2022a). The WHO states that there is an urgent need for public health responses to meet the health requirements of people with PD and suggests interventions on several levels, such as prevention, including the reduction of risks for PD, global health policies to support people with PD as well as increased access to treatment, care and rehabilitation to manage the consequences of the disease (promotion) (WHO, 2022a).

Consequences of Parkinson´s disease in activities of daily living

Living with a chronic disease like PD affects everyday life in many ways (Thordardottir et al., 2014; Sjö Dahl-Hammarlund et al., 2018; Sperens et al., 2020). One consequence of PD is that the symptoms lead to difficulties in activities of daily living (ADL), which can arise already before diagnosis (Hariz & Forsgren, 2011). ADL is a widely used measure of disability (Katz et al., 1963) that affect health. It covers fundamental skills needed to care for oneself in daily life, and covers both personal (P)ADL (e.g. eating, dressing, bathing and walking) and instrumental (I)ADL (e.g. cleaning, shopping, and transportation) (Mlilanic & Feng, 2016). Activity limitations for people with PD commonly cover both PADL and IADL (Hariz & Forsgren, 2011; Sperens et al., 2020) and deteriorate as the disease progresses (Sperens et al, 2020). Examples of PADL that can be affected are eating, toilette activities, dressing, personal hygiene, and communication (Sperens et al., 2020). Furthermore, gait and mobility are often affected for people with PD (Mirelman et al., 2019), which not only impact walking itself but also other more complex activities that require walking (Hammarlund et al., 2014). This leads to a high risk of falling (Mirelman et al., 2019) and fear of falling is common (Jonasson et al., 2018). Walking is important for independence, and people with PD have expressed walking as a prerequisite for living an independent life and participating in society (Hammarlund et al., 2014).

In terms of IADL, cooking, shopping and cleaning are reported to be affected over time (Sperens et al., 2020). Work is yet another activity that can be affected due to the symptoms of the disease. Research has shown that people with PD have problems to managing workload (Jennum et al., 2011) and report more sick leave than controls (Timpka et al., 2018). In sum, the consequence of PD affects many ADL, which in turn impact aspects of health such as QoL and well-being for people with PD (Hariz & Forsgren, 2011; Vescovelli et al., 2018). ADL is often a common focus for assessment and intervention in rehabilitation for people with PD.

Rehabilitation of people with Parkinson´s disease

The primary goal of rehabilitation is to support health and well-being by optimizing function and reducing disability for people with health conditions (WHO, 2022b). There are different kinds of collaborative teams in rehabilitation. For example, monodisciplinary teams are centred around a physician who asks other professionals for assessments or interventions on a consultation basis, whereas multidisciplinary rehabilitation involves several health care professionals who work independently and in parallel within their disciplines to address the person of interest. An interdisciplinary approach is an extension of the multidisciplinary team, but with more coordinated and complex interventions and with a clear person-centred approach (Lidstone et al., 2020). Due to the complexity and progression of the

disease, a multidisciplinary or an interdisciplinary team approach has been suggested to best meet the needs of people with PD (National Board of Health and Welfare, 2016; Lidstone et al., 2020; WHO, 2022b). It can be delivered in different settings such as inpatients, outpatients and in community settings and should cover both assessments and intervention (Lidstone et al., 2020). The rehabilitation teams can consist of different professionals, but commonly include physicians, nurses, occupational therapists, physiotherapists and social workers (Lidstone et al., 2020). Rehabilitation in general is built on three types of interventions, to eliminate, compensate and exercise (Lexell & Rivano-Fischer, 2017), although a literature review covering PD showed that interventions addressing exercise and education are most common in PD rehabilitation (Lidstone et al., 2020). Furthermore, multidisciplinary interventions have been shown to improve functional limitations, reduce falls and improve health-related QoL (Lidstone et al., 2020). Despite this, only 16% of the 105 countries covered in the WHO report (WHO, 2022b) can offer specialised rehabilitation services for people with PD worldwide.

National guidelines for supporting the treatment, care and rehabilitation of people with PD in Sweden have been published (National Board of Health and Welfare, 2016). According to the guidelines, regular check-ups should be offered to people with PD twice a year by an experienced neurologist. This commonly takes place at specialised outpatient neurology or geriatric clinics in Sweden, although some people with PD receive such care via primary care. The national guidelines also recommend interdisciplinary team rehabilitation to optimise function, reduce disability and to teach people how to cope with the disease (National Board of Health and Welfare, 2016). Also, health staff employed in Swedish municipalities can support people with PD in their homes with mobility aids, environmental adaptations, physical exercise or other interventions. This is often done using a multidisciplinary team approach (Giladi et al., 2014; National Board of Health and Welfare, 2016). Team-based rehabilitation in a community setting has been shown to improve mobility and ADL for people with PD (Clarke et al., 2016).

Occupational therapy for people with Parkinson´s disease

As described, occupational therapists are often involved in PD rehabilitation (Meek et al., 2010; Jansa et al., 2011; Chapman & Nelson, 2014; Lidstone et al., 2020). Due to the progression of the disease (Váradí, 2020), contact with an occupational therapist is often needed over many years. Typical occupational therapy interventions for people with PD address compensatory strategies such as mobility aids or adjusting the home environment, information about the disease and the consequences or training skills in activities (Gage & Storey, 2004; Sturkenboom et al., 2014; Lidstone., 2020). Occupational therapy improves self-perceived performance in meaningful activities (Sturkenboom et al., 2014) and has an effect on mobility, independence in ADL and QoL (Gage & Storey, 2004).

Furthermore, occupational therapy research and practice have the potential to provide knowledge on the societal level that goes beyond individual rehabilitation (Iwarsson, 2022a). That is, health professionals should pursue health promotion by working on health policies and supportive environments, for example as part of a public health approach (WHO, 1948). Such an overarching perspective has also been recognised in occupational therapy literature (Law et al., 1996; Iwarsson, 2022a), but is still an uncommon approach in both practice and research. A public health approach was also recently highlighted in WHO's report on people with PD, which outlined key actions for the future such as advocacy and awareness raising, strengthening health and social systems and career support for people with PD (WHO, 2022a). In such health promotion efforts, occupational therapists could contribute with their specific knowledge on the transaction between the person, environment and occupation and their relation to health.

Many occupational therapy theories have acknowledged the relationship between the person, the environment, and the occupation (Townsend & Polatajko, 2007; Baum et al., 2015; Fisher & Martella, 2019). The Person-Environment-Occupation-Performance (PEOP) model is a transactional model that includes these three aspects, with occupational performance as the main outcome and the primary goal of supporting participation and well-being. The close overlap or fit between the person, environment and occupation generates a more optimal occupational performance. However, a change in any of these aspects can affect occupational performance in either positively or negatively (Baum et al., 2015). Based on theories addressing the environmental perspective (Lawton & Nahemow, 1973), PEOP underscores the interdependent transaction of the person and the environment as important (Baum et al., 2015). To address occupational performance and well-being at large, an understanding of underlying aspects, such as the person-environment transaction, are important. With a progressively declining disease such as PD (Váradi, 2020), this person-environment transaction is likely to change due to the nature of the disease and must therefore be re-evaluated regularly to support occupational performance over time. PEOP also recognises that the environment can facilitate or hinder occupational performance and therefore underlines that the environment is an important factor especially when addressing vulnerable populations (Christiansen et al., 2015), such as people with PD.

Furthermore, activity and occupation are a strong focus in occupational therapy (Swedish Association of Occupational Therapists, 2018). Although the two concepts are different, they are in many cases used interchangeably (Pierce, 2001). This thesis will mainly focus on activity hence forward. Also, when assessing activity performance, ADL measures are often used (Christiansen et al., 2015). Although these measures are widely applied, there are different ways of evaluating ADL (Law et al., 2005). One of the most common approaches is to address ADL through independence/dependence, that is, what a person can manage by themselves or dependence on assistance or/help from others (Katz et al., 1963; Law et al., 2005).

This has proved to be informative, but with low variance in the responses. By addressing difficulties in ADL instead, the measure becomes more sensitive and gives a more diversified picture of ADL (Iwarsson et al., 2009). Such considerations are important, as ADL is often used both as goals and means in rehabilitation (Strukenboom et al., 2014; Swedish Association of Occupational Therapists, 2018).

People with Parkinson's disease and housing

When people perform activities, they interact with their environment (Christiansen et al., 2015). Older adults have reported to spend up to 72% of their time on their homes (Spalt et al., 2016), making this a major arena for ADL. As both the general ageing population and people ageing with a chronic disease are increasing (Chatterji et al., 2015), addressing housing issues is vital to meet the housing needs for different sub-groups of the ageing population.

Housing has been acknowledged to have major implications for health globally (WHO, 2018), yet research on housing is scarce for people with PD (Iwarsson et al., 2022b). An example of the absence of addressing housing in PD research is the proposed framework addressing ageing among people with PD, called "Active Aging Model for Parkinson's disease" (Fereshtehnejad & Lökk, 2014). Although housing is described to be important in the ageing process (Roy et al., 2018; Oswald & Wahl, 2019), environmental considerations are not mentioned in the framework regarding people ageing with PD (Fereshtehnejad & Lökk, 2014). The scarce existing literature addressing housing for people with PD focuses on aspects of admission to nursing homes, sensors in housing to monitor movements or housing adaptations (Vossius et al., 2009; Bhidaysairi et al., 2015; Stack et al., 2016).

Housing context

Housing, or the need for shelter, is a fundamental human need (Gonyea, 2021). In Sweden, society has an overall responsibility, shared between the state and the municipalities, for providing housing to the population. This responsibility covers the provision of both ordinary housing and residential care facilities (SOU, 2015:85). Sweden, like many western countries, strongly promotes an ageing in place policy that encourages older people to age in their homes (Pani-Harreman et al., 2021). Although, there are few definitions of ageing in place, Grimmer and colleagues (2015) speak about it as the possibility to remain at home in old age for as long as possible, without having to move to a long-term care facility. Also, when older people are asked what they want, many express the wish to stay at home for as long as possible (AARP, 2011; Wiles et al., 2012), emphasising that they want to decide for themselves where and how they want to live as they age (Wiles et al.,

2012). Despite well-developed home-care systems to support older people at home (e.g. home care services, housing adaptations, safety alarms) in Sweden, ageing in place systems also show weaknesses. Such as the risk of loneliness and social isolation due to functional limitations and lack of social support (Herbert & Molinsky, 2019). A recent literature review concluded that attachment to the home and social networks play an important part in the ageing in place policy. That is, psychological aspects related to housing, for example emotional bonds to the home, could hinder people from moving to more physically appropriate homes. This affects how ageing in place should be addressed; it is not merely the building or town that one has lived in for a long time, but relates to social bonds and the psychological aspects of housing (Pani-Harreman et al., 2021). This shifts the focus from ageing in place to ageing in the right place.

Concerning the built environment, the most common type of buildings in Sweden for people over 60 is single-family houses (54 %), followed by apartment buildings (41 %) and residential care facilities (3%) (Statistics Sweden, 2022). The European Commission considers the housing standard in Sweden as high (2015), even though the Swedish authorities wants an increased focus on housing issues to promote accessibility of the housing stock. To exemplify accessibility problems, government reports highlight that for people over 60 living in apartment buildings, about half do not have elevators in their homes (SOU, 2015:85). Furthermore, research on housing in the ageing population also acknowledges the complexity of meeting the demands for suitable housing for all people despite functional limitations and individual accessibility problems (Granbom et al., 2016; Pettersson et al., 2018).

Furthermore, with the recent health care reform “good local care” (In Swedish: God och nära vård) (SOU 2020:19), more and more care and rehabilitation will take place in people’s homes in the near future. This shift towards a wider use of the home as a place of care and rehabilitation will be challenging for healthcare, communities and the person living there. Therefore, it is important to increase our understanding of different housing aspects in general and for specific sub-groups as well as in relation to the places where rehabilitation will be carried out.

Core concepts and theories in housing and the relation to health

Housing is a multifaceted concept that has been explored in several research fields such as public health, economics, social sciences and gerontology (Oswald & Wahl, 2004; Grander, 2017; Anacker, 2019; Rolfe et al., 2020). In a systematic review, Roy and colleagues (2018) suggest factors related to housing in six dimensions: built and natural environment; time and space-time; economic; socioeconomic and health; psychological and psychosocial and social. Although this review addresses housing decisions in relation to relocation (Roy et al., 2018), these dimensions are also highly relevant for other housing matters. Interestingly, it was found that the effects of specific population characteristics in relation to housing is understudied

for the general older population (Roy et al., 2018), which also specifically applies for people with PD (Iwarsson et al., 2022b).

In the research field of environmental gerontology, there is an assumption that the interaction between the person (P) and the environment (E) affects health in different ways (Lawton & Nahemow, 1973; Oswald & Wahl, 2019). It has been argued that both physical as well as psychological competencies and preferences of the person interacts with the physical environment in complex ways and cannot be separated (Lawton, 2001; Oswald & Wahl, 2004; Oswald & Wahl, 2019). In an attempt to integrate and expand environmental concepts, frameworks have suggested that both objective and perceived aspects of housing need to be addressed (Wahl & Oswald, 2016; Chaudhury & Oswald, 2019). These frameworks build on empirical findings that have confirmed the relation between objective and perceived housing (Nygren et al., 2007; Wahl et al., 2009; Tomsone et al., 2013).

Objective housing

Objective housing refers to objectively observable physical design features (such as houses built with attributes like walls, floor and stairs) that influence human behaviour (Oswald & Wahl, 2004) and thereby affect a person's well-being and independence. This concept is based on the "Ecological theory of ageing" (ETA) (Lawton & Nahemow, 1973), which highlights the person-environment (P-E) fit. That is, the person (P) has a set of competences (e.g., physical, cognitive and sensory) and the environment (E) is defined in terms of its demands or press (design features such as environmental barriers). The greater competences a person holds, the greater environmental press the person can handle. When the person has enough competencies to handle the environmental press, this results in a match called the P-E fit. One facet of the P-E fit in relation to the home is housing accessibility (Iwarsson & Ståhl, 2003). Among older adults, research has shown that a good P-E fit (less accessibility problems) is associated with higher life satisfaction, higher perceived health, and independence in ADL (Iwarsson et al., 2007; Wahl et al., 2009).

However, the P-E fit is not a static interaction, as both the persons capacities and the environmental press can change. Factors like old age or disease can bring a decline in competences, making people more vulnerable to environmental press and causing a lack of fit (Lawton & Nahemow, 1973). Living and ageing with Parkinson's disease comes with both motor and non-motor symptoms (Fereshtehnejad & Lökk, 2014), that is, decreased personal competencies according to the ETA. This group therefore has an increased risk for environmental press and objective housing in terms of housing accessibility problems is therefore an important aspect to explore for people with PD.

The research that exists on objective housing for people with PD typically addresses housing accessibility and housing adaptations. For example, it has been shown that

people with PD have more accessibility problems than controls, due to more functional limitations (Nilsson et al., 2013; Slaug et al., 2013). Housing accessibility has also been found to vary according to different disease stages (Hoehn & Yahr) (Slaug et al., 2017a). Two studies have also explored the environmental barriers causing most accessibility problems for people with PD. The barriers that contributed most to accessibility problems in both studies were: “Wall-mounted cupboard and shelves placed high” and “No grab bar at shower/bath and/or toilette” (Slaug et al., 2013; Slaug et al., 2017a), although only four out of the ten most prevalent barriers were the same when comparing the two studies. From an architectural perspective, the role of design features of the environment, including housing, has also been studied for people with PD. For example, design features such as pavement characteristics, unsteady surfaces and level differences were a cause of falls. Furthermore, ground-based obstacles and narrow spaces disturbed the gait (Ramos et al., 2020). Moreover, the evidence for environmental adaptations targeting people with PD has also been addressed in research. One literature review concluded that research-based evaluation strategies are needed to address housing adaptations due to a discrepancy of the P-E fit (Bhidayasiri et al., 2015). To promote accessible housing, it is important that occupational therapy practices and research explore key environmental barriers for people with PD in order to nurture efficient individual and societal interventions, not least because housing accessibility is associated with independence (Gefenaite et al., 2020a). Also, as PD is a progressive disease (Váradi et al., 2020), a longitudinal perspective on housing accessibility is needed to see how the P-E fit changes over time.

Perceived housing

When a person interacts with a space while doing activities or creating experiences, complex processes transform the space into a place (Rowles & Bernard, 2013). This is referred to as perceived housing and includes subjective experiences and symbolic representations related to the home that contribute to feelings of attachment (Oswald et al., 2006). This concept builds on theories of place attachment and identity (Low & Altman, 1992; Rubinstein & Parmelee, 1992; Stedman, 2002) and has been addressed in “the four-domain model of perceived housing”. It comprises four facets including housing satisfaction, usability of the home, meaning of home and housing-related control beliefs (Oswald et al., 2006). Both the “Agency and Belonging” framework (Wahl & Oswald, 2016) and the “Integrative conceptual framework of the P-E” (Chaudhury & Oswald, 2019) address and highlight two underlying processes of perceived housing, the behaviour-driven agency process and the experience-driven belonging process. Agency is the process of becoming an agency of change in one’s own life through intentional and proactive behaviour imposed by the environment (Bandura, 2001). It includes reacting, compensating, adapting, retrofitting and sustaining the places in relation to the home (Oswald & Wahl, 2019). One example of an agency process is housing-related control beliefs, which are control beliefs in related to the home, such as believing in one’s own abilities,

powerful others or chance. Belonging is a non-goal oriented process reflecting cognitive and emotional aspect of behaviour that make a space into a place over time. While belonging often increases with time, agency tends to decrease as people age. Furthermore, the processes of agency and belonging are related to health outcomes. Both frameworks include identity and autonomy as health outcomes (Wahl & Oswald, 2016; Chaudhury & Oswald, 2019), although the “Agency and Belonging” framework also includes well-being and the overarching goal of ageing well (Wahl & Oswald, 2016). Empirical findings have informed these frameworks; for example, several studies have shown that perceived housing is associated with ADL, well-being and life satisfaction for older adults (Oswald et al., 2007a; Wahl et al., 2009; Tomson et al., 2013; Kylén et al., 2017).

Meaning of home

Meaning of home refers to the subjective experience of personal meaning related to the home. It is a process manifested through symbolic representation, familiarity and routines that lead to meaningful bonds to the place. Meaning of home has been suggested to consist of several bonds to the home: physical, behavioural, cognitive, emotional and social bonds. A quantitative instrument has been developed to measure meaningfulness towards the home called, Meaning of Home Questionnaire (MOH) (Oswald & Wahl, 2004; 2005). Studies using this measure, indicate that there could be different meaning patterns for different groups with various impairments (Oswald & Wahl, 2005). For example, some findings support that meaning of home depends on the individual’s health status, indicating that older adults with functional limitations seem to have a stronger bond to the home than older adults with no functional limitations (Wahl et al., 2009). As people with PD have both motor and non-motor symptoms that deteriorate over time (Váradi, 2020), meaning of home could be specific for people with PD.

Meaning of home has hardly been addressed in relation to people with PD (Nilsson et al., 2013; Nilsson et al., 2016). One study found that people with self-reported PD perceived less meaning towards the home regarding physical and behavioural aspects compared to matched controls (Nilsson et al., 2013). A second study found that people with PD who have more functional limitations perceived their housing as less meaningful from a behavioural point of view (Nilsson et al., 2016).

Housing-related control beliefs

Housing-related control beliefs address how people think they can deal with everyday issues within their home environment. This concept explains whether housing-related events are perceived as depending on one’s own behaviour (internal control beliefs) or if one relies upon external influences (external control beliefs) (Oswald et al., 2003). External control beliefs include believing in chance, luck and fate as well as powerful others in relation to the home. Although, internal and external control beliefs are not direct opposites, high external control beliefs tend to

be associated with low internal control beliefs and vice versa (Oswald et al., 2003; Oswald et al., 2007a). To measure housing-related control beliefs quantitatively, the Housing-Related Control Belief Questionnaire (HCQ) consisting of three sub-scales (internal control, external control: powerful others and external control: chance) was developed (Oswald et al., 2003). It was developed for and mainly used among older adults in the general population (Oswald et al., 2003; Oswald et al., 2007a; Oswald & Kaspar, 2012). Although, when psychometric evaluations were made the internal sub-scale showed low internal consistency and were recommended to not be used (Oswald., 2006).

Processes including external control beliefs have been shown to be particularly critical for health at old age, due to decreasing functional and cognitive capacities (Oswald & Wahl, 2019). As this is also the case for people with PD (Postuma et al., 2015), and a shift from an internal to an external locus of control has been found (Sjödahl-Hammarlund et al., 2018), external control beliefs related to the home among people with PD is an important aspect to address. In PD research, external control beliefs related to the home has only been addressed in three studies. A first study found no significant differences between people with self-reported PD and matched controls regarding external control beliefs related to the home (Nilsson et al., 2013). Another study reported that those with more functional limitations and dependence in daily activities have a tendency to rely more on external influences in relation to housing (Nilsson et al., 2016). Furthermore, a third study found that external control beliefs related to the home had a moderating effect on the relationship between accessibility problems and ADL among people with PD (Gefenaite et al., 2020a). This result differs from findings on this relationship for a younger older population, where external HCQ had a mediating effect on the relationship of housing accessibility and ADL (Gefenaite et al., 2020b). This indicates that the relationship between housing and health aspects could be unique for different sub-groups such as people with PD.

Moreover, previous research among older adults has not addressed both directions of the relationship between external control beliefs related to the home and ADL dependence (Oswald et al., 2007b; Tomsone et al., 2013; Gefenaite et al., 2020b). Moreover, the existing literature is based on the presumption that more external control beliefs lead to more health problems over time (Oswald et al., 2006; Wahl & Oswald, 2016; Chaudhury & Oswald, 2019). As the symptoms of PD can be perceived difficult to control (Chaudhuri et al., 2011), the relationship between external control beliefs related to the home and ADL could be specific for people with PD. Therefore, an exploration of both directions of the relationship between external control beliefs related to the home and ADL is warranted for understanding this P-E exchange.

The focus on housing and health for people with PD in this thesis

Housing is a complex concept that has different aspects and should therefore be explored in different ways for people with PD. This thesis was guided by core concepts and frameworks that addressed objective and perceived housing based on the P-E exchange. Objective housing was addressed with housing accessibility in this thesis. Despite PD being a progressive disease that worsens over time (Váradi, 2020), housing accessibility has not been explored longitudinally for people with PD. Such knowledge could be useful for occupational therapists in order to inform and develop rehabilitation and to contribute to health promotion, with the goal of meeting the housing needs of people with PD.

Furthermore, perceived housing was addressed in this thesis with focus on meaning of home and external control beliefs related to the home among people with PD. With both fluctuating symptoms over the course of a day (or an hour) and the progress of the disease (Váradi, 2020), PD can be perceived as unpredictable and difficult to control (Chaudhuri et al., 2011). This uncertainty and potential perceived loss of control could impact both perceived meaningfulness and control beliefs in relation to the home. Also, the words “housing” and “home” are used interchangeably, though with a clear distinction between objective or perceived housing; see Figure 1.

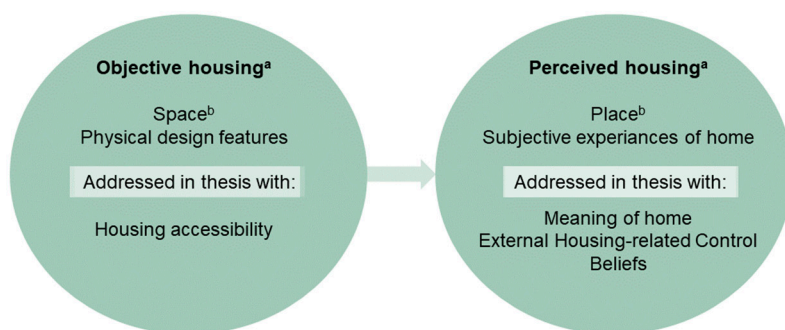


Figure 1. The relationship between the concepts of objective and perceived housing and instruments used in this thesis to capture aspects of these concepts. ^aOswald & Wahl (2019). ^bRowles & Bernard (2013).

Furthermore, when addressing housing using a quantitative approach, high-quality instruments are needed to accurately measure these housing aspects. Neither MOH nor the external HCQ has been psychometrically evaluated for use in people with PD. Such assessments are essential, as the psychometric properties of an instrument are sample dependent and a basic requirement when targeting new populations (Hobart & Cano, 2009). Methodological studies addressing the psychometrics of

MOH and external HCQ are therefore a prerequisite for enabling quality research on perceived housing for people with PD.

Research for the general ageing population has shown that perceived housing aspects are associated to health (Oswald et al., 2007b; Kylén et al., 2017; Gefenaite et al., 2020b), still this is an uncommon focus in PD-research. Therefore, one focus of this thesis was to explore the relationship between external control beliefs related to the home and ADL. This relationship has not been explored in all potential directions previously, and such knowledge is warranted in research to further the understanding of housing and health among people with PD.

Aim

The overall aim of this thesis is to increase knowledge on housing matters for people with PD who live in ordinary housing (in their own homes) in Sweden. The thesis addresses objective as well as perceived aspects of housing, reflecting the individual as well as the societal level. With regards to objective aspects, housing accessibility problems have been explored with a focus on change over time. As to perceived aspects, a specific aim has been to contribute to the much needed psychometric testing and optimisation of self-rating instruments for use in research targeting people with PD. As an example of studies making use of such methodology, the direction of the association between external control beliefs related to the home and ADL was explored.

Specific aims:

- To determine the most severe environmental barriers in terms of housing accessibility problems and how these evolve over three years among people with PD.
- To examine the psychometric properties of the MOH instrument to identify whether it is valid and reliable for people with PD.
- To examine the psychometric properties of the external HCQ to identify whether it is valid and reliable for people with PD.
- To explore the direction of the relationship between external control beliefs related to the home and ADL, with specific attention to change, for people with PD.

Method

Overall study design

All studies in this thesis are based on data from the larger longitudinal study “Home and health in people ageing with Parkinson’s disease” (HHPD), PI: MH Nilsson. A study protocol with more details of HHPD has been published (Nilsson & Iwarsson, 2013). The data used includes two time points: the baseline assessment (T1) collected during November 2012-November 2013 (N=255) and the three-year follow-up (T2) was collected during January 2016-December 2016 (N=165). Studies II and III used cross-sectional data (T1), whereas studies I and IV included both baseline and follow-up data (T1/T2).

This thesis takes a quantitative research approach and encompasses empirical studies addressing different aspects of housing as well as methodological development of instruments (Table 1).

Table 1. Overview of the four studies included in the thesis.

	Study I Changes in objective housing	Study II Psychometric evaluation MOH	Study III Psychometric evaluation HCQ	Study IV Directions of relationship HCB - ADL
Study design	Cohort study	Cross-sectional studies		Cohort study
Participants	N=138	N=245		N=154
Data collection	Questionnaires (Self and interview administered) and clinical assessments			
Statistical analysis	Paired samples t-test and McNemar’s test	Data quality, structural validity, floor and ceiling effects, corrected item total correlations, internal consistency and construct validity		Linear and logistic regression analyses

MOH=Meaning of Home Questionnaire; HCQ=Housing-Related Control Beliefs Questionnaire; HCB=Housing-Related Control Beliefs; ADL=Activities of Daily Living.

Recruitment and participants

Home and health in people aging with Parkinson's disease (HHPD)

Baseline (T1)

In the HHPD study the participants were recruited from three different hospitals in Skåne County, Sweden. According to the power calculation, the recruitment process was carried out to reach a sample size of 250 participants (Nilsson & Iwarsson, 2013). The inclusion criterion was to have been diagnosed with PD (ICD -10 G20.9) for at least one year. The exclusion criteria included severe cognitive problems, difficulties understanding or speaking Swedish, or other reasons (such as recent stroke, hallucinations) that made them unable to give informed consent or take part in the majority of the data collection. A specialist PD nurse evaluated the inclusion and exclusion criteria at each clinic and by screening medical records if needed.

At baseline, 653 participants met the inclusion criterion. Out of those, 216 individuals were excluded based on the exclusion criteria (see Figure 2). This resulted in 437 potential participants, who were invited to participate in the study. However, 157 declined to participate, 22 were unreachable, two had their diagnosis changed and one was excluded due to extensive missing data. The final sample of the baseline recruitment consisted of 255 participants.

For those who declined (N=157) to participate at baseline compared to those who completed the assessments (N=255), there was a statistically significant difference regarding age. That is, the participants who declined to take part in the HHPD at baseline were older than those who completed the assessments (Kader, 2018a).

Three-year follow-up (T2)

The 255 participants who completed the baseline assessment had agreed to be contacted again and were considered eligible for the three-year follow-up data collection. Out of those, 229 were invited to participate in the follow-up, as three had moved, one was outside the follow-up window (i.e., 3 years \pm 3 months) and 22 were deceased. For different reasons (explained in Figure 2), 64 participants could not participate, which resulted in a final sample of 165 participants for the three-year follow-up. The participants that dropped out between baseline and follow-up (n=90) were significantly older and had a more severe PD at baseline (Nilsson et al., 2020). Brief sample characteristics of the baseline and the three-year follow-up sample are presented in Table 2.

Table 2. Characteristics of the baseline and the three-year follow-up sample in the HHPD study.

Variable	Baseline sample (T1), N=255	Three-year follow-up sample (T2), N=165	Missing T1/T2, n (%)
Sex (men), n (%)	153 (60)	107 (64.8)	-
Age, mean (SD)	70.0 (9.2)	71.6 (8.8)	-
PD duration, mean (SD)	9.72 (6.4)	12 (8.8)	-
Disease severity (HY during on), n (%)			-
HY I	50 (19.6)	10 (6.1)	
HY II	73 (28.6)	69 (41.8)	
HY III	67 (26.3)	37 (22.4)	
HY IV	58 (22.7)	39 (23.6)	
HY V	7 (2.7) ^a	10 (6.1)	
Motor symptoms (UPDRS III), median (q1-q3)	30 (22-39.2)	27 (21-40)	8/10
Cognitive function (MoCA), median (q1-q3)	26 (22-28)	26 (23-28)	5/13
Depressive symptoms (GDS -15), median (q1-q3)	2 (1-4)	3 (1-4)	7/25
ADL (ADL Staircase), median (q1-q3)	4 (0.2-10)	4 (0.7-9.2)	7/23
ADL (PADLS), n (%)			2/1
No difficulties	54 (21.3)	22 (13.4)	
Mild difficulties	131 (51.8)	83 (50.6)	
Moderate difficulties	49 (19.4)	32 (19.5)	
Severe difficulties	12 (4.7)	19 (11.6)	
Extreme difficulties	7 (2.8)	8 (4.9)	
Type of housing, n (%)			2/3
Apartment	109 (43.1)	70 (43.2)	
Single-family house	139 (54.9)	89 (54.9)	
Other	5 (2)	3 (1.9)	
Housing adaptation (yes), n (%) ^b	84 (32.9)	33 (21)	0/8

HHPD=The longitudinal study "Home and health in people aging with Parkinson's disease"; PD=Parkinson's disease; SD=Standard deviation; HY=Hoehn & Yahr, possible scores 1-5 (higher=worse disease severity); UPDRS=Unified Parkinson's disease rating scale, part III, possible scores 0-108 (higher=more motor symptoms); MoCA=Montreal Cognitive Assessment, possible scores 0-30 (higher=better cognitive function); GDS=Geriatric Depression Scale, possible scores 0-15 (higher=more depressive symptoms); ADL Staircase=Activities of Daily Living Staircase, possible scores 0-27 (higher=more dependent). PADLS=Parkinson's Disease Activities of Daily Living Scale, possible scores 1-5 (higher scores=more difficulties in ADL). ^aDue to rounding of decimals, the percentage of disease severity at T1 is not 100%. ^bInformation provided by participants in interview

Changes in objective housing over time

Study I addressed changes in accessibility problems for people with PD, and both baseline and three-year follow-up data were used. Participants who had moved between the two data collections (n=18) and those living in residential care facilities were excluded (n=9). Accordingly, the final study sample consisted of 138 participants.

Psychometric evaluations

Baseline data were used in Study II and III, covering psychometric properties of the instruments MOH and external HCQ. Participants with extensive missing data on core variables were excluded (n=8) and those living in residential care facilities (n=2). Both studies had a final study sample of 245 participants.

Directions of relationship between control beliefs related to the home and ADL

Study IV addressed the direction of the relationship between external control beliefs related to the home and PADLS, both baseline and three-year follow-up data were used. Participants with extensive missing data on main variables at both data collections (external HCQ, n=10/PADLS, n=1) were excluded. The final study sample for Study IV consisted of 154 participants.

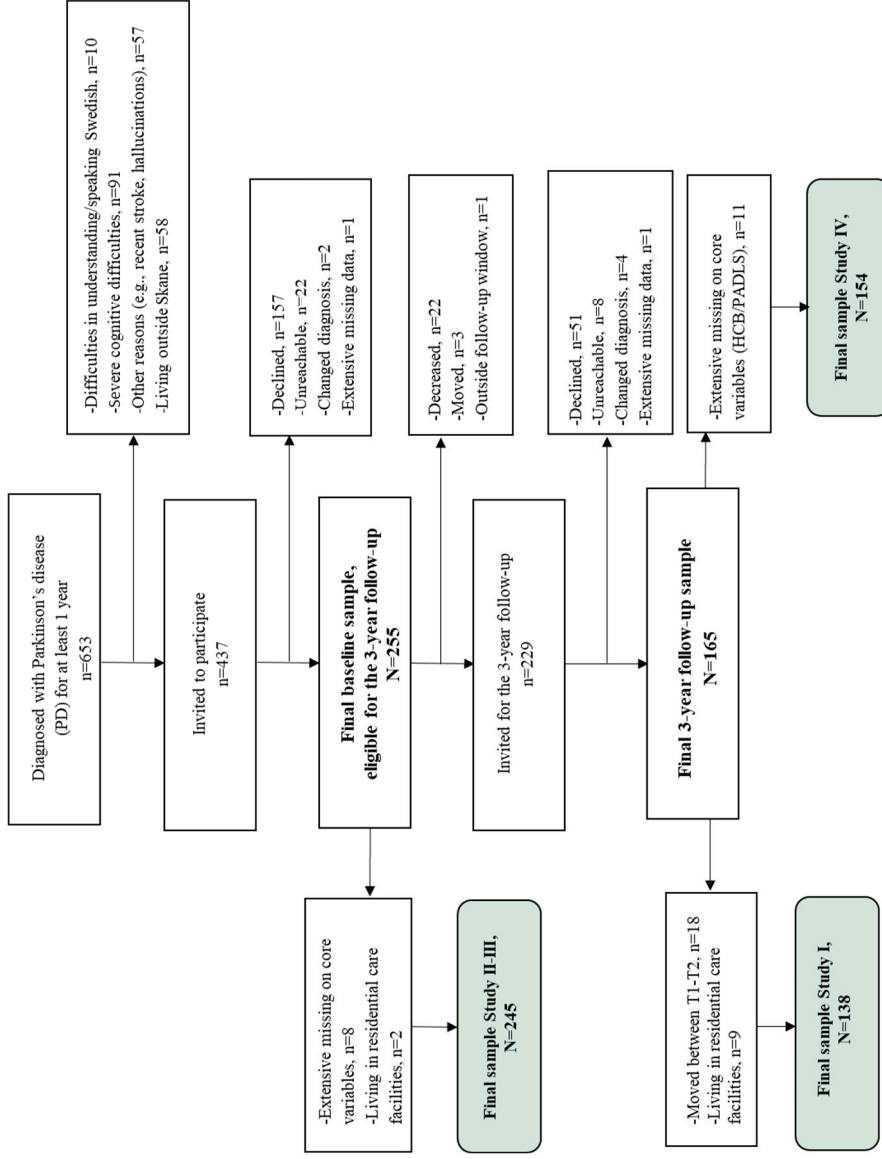


Figure 2. Flowchart: the recruitment process in Home and health in people ageing with Parkinson's disease* (HHPD) for the baseline and the 3-year follow-up data collections, which resulted in the study samples for Studies I-IV.

Procedures

Two research administrators collected the data at baseline and two other administrators and a PhD student at follow-up. All administrators underwent project-specific training prior to the data collection.

Written information about the study was sent out by mail to the potential participants and were then contacted by phone. For those who wanted to participate, a date for a home visit was scheduled. A postal survey with self-administered questionnaires was sent to the participants about ten days before the home visit. During the home visit, interview-administrated questionnaires, observations, and clinical assessments were performed. The home visit typically lasted for two hours and was scheduled at a time when the participants usually felt at their best (in “on” state). If any participant found the data collection stressful or too long, they were offered to have the home visit split and re-scheduled for another day (within a maximum of 14 days). This was the case for eight participants at baseline and for two participants at follow-up. If the participant declined to take part in the HHPD study, no further contact was made. Among those who agreed to participate, all were asked if they could be contacted again for the follow-up data collection; all agreed.

At the three-year follow-up, all participants got information about the new data collection by mail. Thereafter, they were contacted by phone. If they agreed to participate, the data collection procedure was similar to the baseline procedure. That is, self-administered questionnaires were sent home to the participants followed by a subsequent home visit.

Instruments and clinical assessments

Parkinson’s disease characteristics

Unified Parkinson’s Disease Rating Scale (UPDRS), part III

UPDRS part III was used as a clinical assessment of motor symptoms of PD. It covers speech, facial expression, tremor, rigidity, finger taps, hand movements, leg agility, rising from chair, posture, gait, postural stability, body bradykinesia and hypokinesia. It consists of 14 items rated on a four-grade scale (0-4), with the total score ranging from 0 to 108 points (higher scores=more motor symptoms) (Fahn et al., 1987).

Hoehn & Yahr (HY)

Disease severity of PD was assessed with the HY scale (Hoehn & Yahr, 1967). It is a widely used, clinical established rating scale for describing disease severity that consists of five stages (see Table 3).

Table 3. Description of the Hoehn & Yahr (HY) stages.

HY stage	Description
Stage I	Unilateral disease, regardless of severity.
Stage II	Bilateral disease, no postural instability.
Stage III	Bilateral disease with postural instability, or unilateral disease with postural instability. Functionally somewhat restricted, but physically capable of leading independent lives (i.e. do not need help from others or mobility devices to manage ADL).
Stage IV	Bilateral disease with postural instability. Can rise unassisted (but may need several attempts). Can stand and walk unassisted (even without support from another person), but impaired gait. Falls can be a problem when significant postural reflex impairment occurs. Severe disability and marked incapacity.
Stage V	Confinement to chair or bed unless aided. Cannot arise/stand or walk without assistance. May be able to walk with e.g., visual cues.

HY=Hoehn & Yahr; ADL=activities of daily living.

In the HHPD data collection, HY is assessed with the approach “rate-as-you-see” (Goetz et al., 2004). Meaning that, all impairments/disabilities observed are rated based on the HY stages regardless of their direct relationship with PD. If a person uses mobility aids indoors, they were classified as at least HY stage IV.

Objective housing

Housing Enabler (HE) Instrument

Objective housing was evaluated by measuring numbers of environmental barriers and magnitude of housing accessibility problems. The scientifically established instrument HE was used (Iwarsson & Slaug, 2010; Iwarsson et al., 2012), which is based on the P-E fit (Lawton & Nahemow, 1973). The assessment of HE consists of three steps. In step 1, the person (P) component is dichotomously assessed (present/not present) through interviews and observations of functional limitations (12 item) and dependence on mobility devices (two items). If functional limitations vary over time, the rating should reflect the “worst-case scenario”. (Iwarsson et al., 2012). In step 2, the environmental (E) component is dichotomously assessed (present/not present). The E component consists of 161 environmental barriers and is categorised into three housing sections: indoor environments (n=87 items), entrances (n=46 items), and the immediate exterior surrounding (n=28). The E component is based on national standards and guidelines for housing design in Sweden. In step 3, a case-specific accessibility problem score is calculated. This is done by juxtaposing the collected data of the components P (functional limitations and dependence on mobility devices) and E (environmental barriers) according to a scoring matrix. At each intersection where a functional limitation/dependence on

mobility device and a barrier are met, the matrix provides a predefined severity score (0-4, higher score=greater problem). These ratings are summed to a total accessibility problem score (HE score), where higher scores indicate more accessibility problems with a theoretical maximum score of 1,844 scores (Iwarsson & Slaug, 2010). If there are no functional limitations/dependence on mobility devices the score is 0. HE has primarily been used in cross-national research on home and health for the ageing population (Iwarsson et al., 2016) and is reported to be valid and reliable for use in ordinary housing (Iwarsson et al., 2012). Measures of objective housing (HE) are the main variable in Study I but have been addressed in all four studies. Furthermore, the Relative Accessibility Problem Score (RAPS, which is based on HE) was used in Study IV. As previous research has shown that HE score variance is mostly attributed to the P component (Slaug et al., 2013), RAPS was computed to separate the P x E interaction from the main effects of P and E (Slaug et al., 2019). The categories in RAPS are as follows: 1) “Expected number of barriers/no barriers due to no functional limitations”, 2) “Fewer barriers than expected” and 3) “More barriers than expected”. As cut-off for categorisation, the difference from the expected number of barriers in any direction of at least four environmental barriers more or less than expected was used (Slaug et al., 2019).

Perceived housing

Meaning of Home Questionnaire (MOH)

MOH is an instrument addressing the symbolic representation of space, place and personal meaning towards the home (Oswald & Wahl, 2005). It consists of 28 items, covering four sub-scales: physical (7 items), behavioural (6 items), cognitive/emotional (10 items), and social (5 items). The items are answered on an 11-point scale marked with endpoints, ranging from strongly disagree (0) to strongly agree (10). Three items are negatively phrased (no. 11, 16, 21) and eight items are reversed (no. 6, 9, 11, 15, 19, 21, 25, 27). The reversed items are inverted when the data is processed. Higher scores indicate more perceived meaning to the home (Oswald & Wahl, 2004; 2005).

The MOH has primarily been used in the general older population and some psychometrics aspects have been evaluated for this group. That is, internal consistency (Cronbach’s alpha, α) was evaluated for the four sub-scales: physical $\alpha=0.60$, behavioural $\alpha=0.67$, cognitive/emotional $\alpha=0.62$ and social $\alpha=0.44$. This result was interpreted as acceptable internal consistency for all sub-scales, except for the social sub-scale (Oswald et al., 2006). The MOH was used in Study II in this thesis; see Appendix I for the original English version of MOH.

External Housing-Related Control Beliefs Questionnaire (HCQ)

Extern HCQ consists of 16 items divided into two sub-scales, that is external control: chance (eight items addressing the belief in chance, luck or faith in relation to the home) and external control: powerful others (eight items addressing the belief that someone else is responsible in relation to the home) (Oswald et al., 2003). The items are rated each statement on a five-point scale, with the response options; 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree. The total sum score ranges from 16 to 80 points (higher scores=higher external HCQ) (Oswald et al., 2006). The two external sub-scales were previously used as one scale in some studies (Oswald et al., 2006; Nygren et al., 2007; Iwarsson et al., 2007). In the HHPD, a 16-item version covering both external sub-scales were used and called external HCQ.

The external HCQ has been psychometrically evaluated among older adults in two samples (sample 1, 66-69 years, N=485/ sample 2, 65-91 years, N=107) regarding internal consistency and test-retest reliability. For the external sub-scale powerful others, the internal consistency was (Cronbach's alpha) $\alpha=0.66$ (sample 1) and $\alpha=0.72$ (sample 2), while the test-retest was $rtt=0.78$. The sub-scale chance showed an internal consistency value of $\alpha=0.83$ (sample 1) and $\alpha=0.76$ (sample 2), the test-retest reliability was $rtt=0.50$ (Oswald et al., 2003). Both external sub-scales have also been combined, then the internal consistency was $\alpha=0.67$ in the general older population (Oswald et al., 2006). In this thesis, external HCQ was addressed in Study II, where the psychometric properties of the instrument were evaluated in a PD sample. But it was also used in Study IV, which explored the relationship between external control beliefs related to the home and ADL. See Appendix III, for the original English version of external HCQ.

Activities of daily living

PADLS

The Parkinson's Disease Activities of Daily Living Scale (PADLS) is a single-item, self-administrated instrument developed to address ADL among people with PD (Hobson et al., 2001). The question in PADLS, revolve around how PD affects day-to-day activities over the past month and consists of five response options that can be summarized as: 1=no difficulties, 2=mild difficulties, 3=moderate difficulties, 4=high levels of difficulties, 5=extreme difficulties. The absolute score ranges from 1 to 5 (higher scores=more difficulties in ADL). The response options have also been dichotomized in other studies (Lindholm et al., 2014; Jonasson et al., 2017), meaning "no/mild difficulties" (scores 1-2=0) or "moderate to extreme difficulties" (scores 3-5=1).

PADLS has been psychometrically evaluated for people with PD with acceptable results regarding aspects of reliability and validity (Hobson et al., 2001; Jonasson et

al., 2017). Hobson and colleagues (2001) evaluated test-retest reliability (1 week in between) by using a correlation coefficient ($r=0.89$, $p < 0.001$). Furthermore, acceptable targeting and general support for construct validity (moderate to strong significant correlations with self-rated disease severity, walking difficulties and ADL dependency) have been reported regarding PADLS (Jonasson et al., 2017). To summarise, PADLS has been suggested as a rough indicator of ADL for people with PD (Jonasson et al., 2017). In this thesis, PADLS was used as a main variable in Study IV, but ADL was also addressed in Studies I-III.

Statistical analyses

Descriptive statistics were computed in all four studies. Continuous variables were described by means (standard deviation, SD) and ordinal variables with medians (first and third quartiles, q_1 - q_3). Categorical variables are expressed by number of participants (%).

The level of statistical significance was set to $p < 0.05$ in all studies. IBM SPSS Statistics 27 (IBM Corporation, Armonk, NY, USA) and the HE software (Veten & Skapen HB and Slaug Enabling Development, Lund and Staffanstorp) were used for data and statistical analyses.

Changes in objective housing

Study I explored housing accessibility problems over time in people with PD. To determine which environmental barriers contributed the most to housing accessibility problems, an average magnitude score (HE score) was calculated for each of the 161 barriers at both baseline (T1) and the three-year follow-up (T2). Based on the HE scores, the top ten environmental barriers that generated most problems at both test occasions were sorted in descending order to provide a ranking list of T1 and T2. McNemar's test was used to analyse change over time in frequencies of environmental barriers. To analyse change between the measure points in HE scores of the top ten environmental barriers, delta values were calculated ($T_2 - T_1$) and analysed with paired samples t-test. To analyse potential change for the summed HE scores per housing section, paired samples t-test was also used.

Psychometric evaluations

In Study II and III psychometric evaluations of the instruments MOH and external HCQ were conducted based on Classical Test Theory (CTT), in which reliability and validity are addressed through the instrument's items (Hobart & Cano, 2009). The psychometric properties evaluated were data quality, scaling assumptions, floor

and ceiling effects, reliability and validity. All parts of the analyses will be presented separately.

Data quality

To evaluate the extent to which the instrument can be administered in the population of interest, data quality was analysed. This was done by calculating the percentage of missing item scores and total sum scores. As low data quality could indicate that the instrument is difficult to understand or irrelevant for the participants, it is important to consider the number of missing responses (Hobart & Cano, 2009).

Validity

The validity of an instrument refers to the extent to which it measures what it is purposed to measure (Hobart & Cano, 2009). In this thesis, construct and structural validity were analysed for MOH and external HCQ.

Structural validity was used to study and identify patterns of the items in the instruments by using exploratory factor analysis. As the data were ordinal and not normally distributed, principal axis factoring was used in both analyses. Visual examination of scree plots and assessment of factor loadings were used to determine the number of factors included in the models, with the following criteria: no factor less than three items, few cross-loadings and all items with factor loadings <0.33 (Tabachnik & Fidell, 2013). The factor solution was first individually assessed and then discussed in the author constellation until consensus was achieved.

Furthermore, construct validity was used to address how well the instrument measures the intended concept. This builds upon testing relevant hypotheses of how the instrument is anticipated to perform and then comparing the empirical data accordingly. This can be explored in different ways, for example by examining the relation to other known concepts, by comparing the given instrument with closely related variables (convergent validity) or with instruments that measure dissimilar concepts (discriminant validity) (Streiner et al., 2015). Known group validity can also be used to distinguish the results between predictable groups, also called group difference construct validity (Hobart & Cano, 2004; U.S. Department of Health and Human Services, 2009). Although the different wordings of the name regarding this aspects of construct validity, “known group validity” has been used in self-reported instruments concerning various aspects related to health and health care (McConnell et al., 2001; Jakobsson et al., 2011; Rodrigues et al., 2019).

In this thesis, construct validity was based on pre-defined hypotheses with known concepts and assessed with convergent and discriminant validity for MOH, and external HCQ was evaluated with convergent and known group validity. Spearman’s rank correlation and the Mann-Whitney U test were used to analyse construct validity.

Scaling assumptions

Scaling assumption regards the legitimacy to adding the items to produce a total sum score. This was analysed in two ways. First, mean scores, standard deviations/median, quartiles and distribution of item responses were reported. Frequencies should be approximately equal across items and the total mean score should be close to the midpoint. To test if the items contribute with similar proportion of information, corrected item-total correlations were also evaluated. This analysis was made with a correlation between each item and the total sum score computed from the remaining items in the scale. Correlations >0.3 have been suggested as an acceptable value; furthermore, values >0.4 indicate that the items measure the same underlying construct (Ware & Gandek, 1998; Hobart & Cano, 2009).

Floor and ceiling effects

Floor and ceiling effects were assessed with the percentage of respondents who scored the minimum (floor) or maximum (ceiling) score of the instrument. An upper limit off 15-20% was suggested for both floor and ceiling effects and exceeding this could indicate that there were not enough response options (Hobart & Cano, 2009). When addressing floor and ceiling effects on item level, Hobart and Cano suggested a 75% cut off (2004).

Reliability

Overall reliability concerns the degree to which the instrument score is precise and free from measurement errors (Hobart & Cano, 2009). In this thesis, internal consistency reliability and standard error of measurement (SEM) were used. Internal consistency measures how closely the items in an instrument measure the same underlying construct. Cronbach's alpha (α) is a measure for evaluating internal consistency (Cronbach, 1951), and the items are considered to represent a similar construct when alpha is >0.70 (Hobart & Cano, 2009). Another useful aspect of reliability is SEM, which concerns the measurement error of the instrument. It is an assessment of the smallest difference in scores indicating a change on a group level. SEM was calculated by using the formula $SD_{baseline} \times \sqrt{1 - reliability}$ and complemented with a 95% confidential interval (Hobart & Cano, 2009).

Directions of the relationship between control beliefs related to the home and ADL

Study IV explores two opposing hypotheses:

1. More difficulties in ADL lead to higher external control beliefs related to the home
2. Higher external control beliefs related to the home lead to more difficulties in ADL

To explore these hypotheses, one linear and one logistic regression analysis were conducted to explore both directions of the relationship between the variables external HCQ and PADLS, based on the nature of the dependent variable in each regression.

Multicollinearity was evaluated using Spearman's (rs) correlation to assess the relationships among the independent variables (external HCQ/PADLS, age, MOCA, HY and RAPS; all at baseline). Correlations >0.7 were considered as multicollinear (Tabachnick & Fidell, 2013); no correlation were >0.5 . Also, the basic assumptions of linear regression (linear relation between external HCQ (T2) and PADLS (T1), the variance of residuals was constant of all variables, and normal distribution of the residuals) and goodness of fit of logistic regression analyses (Hosmer & Lemeshow test) were checked and fulfilled (Tabachnick & Fidell, 2013; Hosmer et al., 2013).

Linear regression analysis was used in hypothesis 1 where external HCQ (T2) was the dependent variable. Logistics regression analysis was applied when PADLS (T2) was the dependent variable. As PADLS is an ordinal variable, it was dichotomised into "no/mild difficulties" (scores 1-2=0) or "moderate to extreme difficulties" (3-5=1) in the logistic regression analysis. Both regression analyses were first computed, controlling for the baseline value of the dependent variable (linear regression=HCQ T1/logistic regression=PADLS T1). This was followed by controlling for the baseline value of the dependent variable and confounders (HY, MOCA, RAPS and age, all at T1).

Imputation was used to reduce internal missing data on the individual level and was used for participants with only one or two missing answers on the external HCQ. A mean of the other recorded values was used to impute a score, generating a total sum score. This was the case for 11 participants regarding the variable external HCQ (measuring external control beliefs related to the home) at the three-year follow-up. No imputation was done for PADLS.

Ethical considerations

The research process should be conducted in accordance with good research practice and ethics should always be considered, especially when the research involves humans (Swedish Research Council, 2017). While research strives to generate new knowledge, the interests and rights of the study participants must at all times come first (World Medical Association, 2013). Several ethical aspects have been considered in this thesis.

Firstly, the HHPD was approved by the Regional Ethical Review Board in Lund, Sweden (Nos. 2012/558 and 2015/611) and conducted in accordance with the

Helsinki Declaration (World Medical Association, 2013). During the data collection several ethical aspects were considered in relation to the study population.

All participants gave their informed consent to participate in the study. The potential participants got information about the study via mail and were then contacted via telephone by the project administrator about the study. Verbal consent to participate in the study was obtained during this first telephone contact, which was also when the project administrators booked the home visit. During the subsequent home visit, a written informed consent was signed. At the baseline home visit, the participants were asked if they wished to be contacted again for a follow-up data collection, which also was the case at the follow-up regarding a forthcoming data collection.

A study like HHPD poses both risks and benefits, and the scientific value should always outweigh any potential risks. The benefits of a longitudinal study like HHPD are many; for example this study did not have any age limitations, which enabled all age groups to participate. This was important as it has previously been common to exclude the oldest in PD research (Fitzsimmons et al., 2012). Furthermore, HHPD addresses new perspectives in PD research. For example, housing matters was addressed in several ways, which is a knowledge gap for this group. This kind of research could bring new knowledge about several aspects for people with PD, but there are of course potential risks. Examples include the risk of falls or accidents during the data collection at the home visits. However, the clinical assessments were not more challenging than everyday activities and no fall incidents were reported. Another potential risk is that this rather vulnerable population might struggle to answer all the questions and clinical assessments in the study, and maybe choose not to participate or not be able to complete the data collection. These kinds of risks were considered in the planning phase of the HHPD and resulted in several routines in the data collection. For example, when the research administrators planned the home visit with the participants, the appointment was booked when the participant felt the best (“on” state). Still, people with PD may have communicative and cognitive difficulties which could affect their ability to participate in long meetings. As the home visits were rather time consuming (in general two hours/visit), the participants could choose to have the home visit on two occasions if necessary. This happened at eight occasions at baseline and at two at follow-up. Also, for those with more advanced PD who had difficulties completing the home visit, the project administrator could opt to gather a minimal data set. In that case, selected instruments and essential assessments were conducted based on the original intended battery of instruments.

Furthermore, if new needs for assistance were discovered during the home visit, such as contact with a nurse, the need for assistive devices or interventions from home care services, the project administrator could provide contact to the right person.

Results

Changes in objective housing over time

In the study on housing accessibility problems among people with PD (Study I), a ranking list of the top ten barriers that generated most accessibility problems were listed, see Table 4. The top three barriers were: “No grab bar at shower/bath/toilette” in hygiene areas, “Stairs the only route” in entrances and “Wall-mounted cupboards placed high” in kitchens. The barriers generating the most problems at T2 were: “Refuse bin difficult to reach” in the exterior surrounding, “Wall-mounted cupboards placed high” in kitchens and “No grab bar at shower/bath/toilette” in hygiene areas. Barriers were found in all housing sections (Table 2).

Exploring the changes in magnitude of accessibility problems, six barriers contributed roughly the to the same magnitude of accessibility problems over the study period. However, one barrier in the exterior surrounding section rose to the top of the rank list at T2; “Refuse bin difficult to reach”. This increased significantly in number of barriers as well as in magnitude of accessibility problems after three years. In contrast, “Grab bars at shower/bath and/or toilette” and “Stairs the only route” decreased significantly both in number of barriers and in magnitude of accessibility problems, indicating that those were less of an issue at T2 (Table 4). Together, these findings suggested that the top ten environmental barriers were mainly the same over the three years studied, but with noteworthy changes in order and magnitude.

Table 4. Top 10 environmental barriers that generated most accessibility problems (HE scores) at baseline and the 3-year follow-up, N=138.

Environmental barriers (EB)	EB n (%)		p value ^b	HE score Mean (SD)		Δ (95% CI)	p value	Rank list ^c	
	T1	T2		T1	T2			T1	T2
No grab bar at shower/bath/toilette (C)	124 (90)	85 (62)	<0.001	7.39 (6.28)	5.92 (6.48)	-1.47 (-2.88; -0.06)	0.041	1	3↓
Stairs the only route (B)	75 (54)	47 (34)	<0.001	6.50 (7.77)	4.61 (7.34)	-1.89 (-3.06; -0.72)	0.002	2	8↓
Wall-mounted cupboards and shelves placed high (C)	79 (57)	74 (54) ^a	0.659	6.26 (7.53)	6.71 (8.48)	0.45 (-1.08; 1.98)	0.562	3	2↑
Refuse bin difficult to reach (A)	86 (62) ^a	122 (88)	<0.001	4.15 (4.84)	8.24 (5.75)	4.09 (3.15; 5.02)	<0.001	4	1↑
High thresholds and/or steps (B)	133 (96)	134 (97)	1.000	4.15 (3.44)	4.93 (3.57)	0.78 (0.16; 1.41)	0.015	4	6↓
Storage areas can only be reached via stairs/threshold (C)	129 (93) ^a	126 (91)	0.454	3.95 (3.40)	4.72 (3.80)	0.77 (0.15; 1.38)	0.015	6	7↓
Insufficient manoeuvring space in relation to movable furniture (C)	134 (97)	115 (83)	<0.001	3.73 (3.10)	4.38 (3.76)	0.64 (0.06; 1.23)	0.030	7	(11) ↓ ^d
Doors cannot be fastened in open position (B)	111 (80)	108 (78)	0.775	3.65 (3.57)	4.57 (4.11)	0.92 (0.15; 1.69)	0.019	8	9↓
High thresholds/levels differences/steps (sitting-out place/balcony) (B)	115 (83)	122 (88)	0.210	3.63 (3.54)	4.48 (3.75)	0.85 (0.17; 1.53)	0.015	9	10↓
Letterbox difficult to reach (A)	75 (54) ^a	87 (63)	0.193	3.53 (4.64)	5.50 (5.87)	1.97 (0.87; 3.07)	0.001	10	4↑
Insufficient manoeuvring spaces around white goods/storage units (C)	55 (40)	94 (68) ^a	<0.001	1.93 (3.54)	4.94 (5.03)	3.01 (2.13; 3.88)	<0.001	(27) ^d	5↑

EB=Environmental barriers; T1=Baseline; T2=3-year follow-up; HE score=Magnitude of accessibility problems (higher scores=more accessibility problems); Δ (Delta)=HE score change between T2-T1 analysed with paired sample t-test; p values <0.05 were considered statistically significant; A=Exterior surrounding; B=Entrance; C=Indoor environment. ^aMissing value, n=1; ^bP value refers to the change in frequencies of EB T2-T1, analysed with McNemar's test; ^cRank list is based on HE score; ^dOnly top 10 EB at baseline/follow-up.

Furthermore, when the magnitude of accessibility problems generated by the top ten barriers were summed per housing section, the result showed that barriers in the indoor environment and entrances contributed most to the magnitude of accessibility problems at both T1 and T2. However, the only section that increased statistically significant in magnitude of accessibility problems over the three years studied was the exterior surrounding (Figure 3).

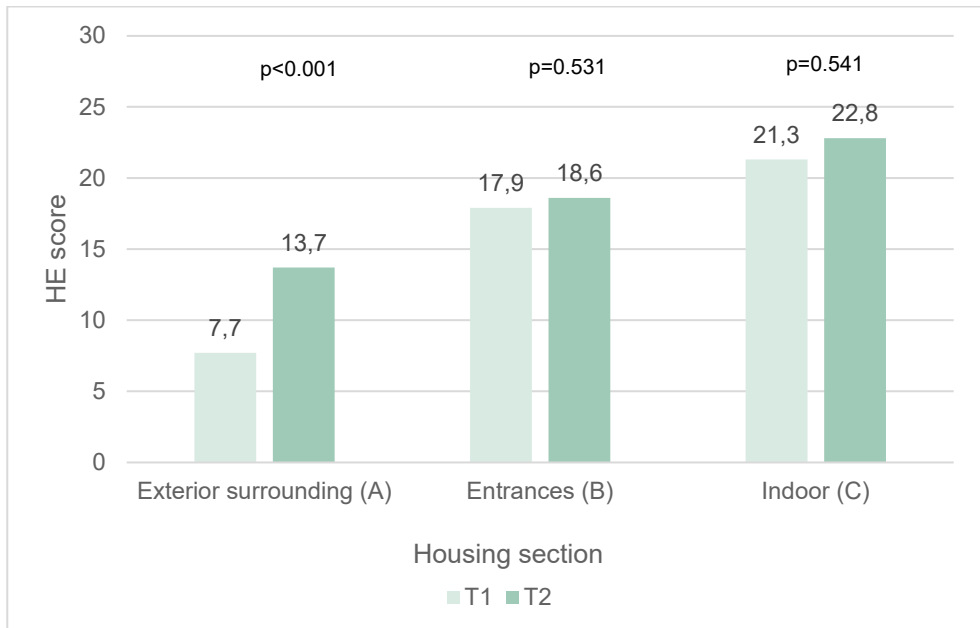


Figure 3. Development of magnitude of accessibility problems (HE score) per housing section at baseline (T1) and the 3-year follow-up (T2). The figure is based on summed HE scores from the top 10 environmental barriers that contributed most to housing accessibility problems per section, at both measure points. The p-values were analysed with paired samples *t*-test.

Psychometric evaluations of instruments capturing perceived housing

The results of the studies on the psychometric evaluations for the instruments MOH (Study II) and external HCQ (Study III) are described in this section.

Data quality

There were very few missing item responses for both MOH and external HCQ, demonstrating a high overall data quality. More specifically, in the original version of MOH five items had no missing responses and the response rate for the items

with missing answers ranged between 98.8-99.6%. Regarding external HCQ, 11 of the original 16 items had no missing responses. For the four items that had missing values, the response rate varied between 99.2-99.6%.

Structural validity: new domains of MOH and HCQ shortened

Regarding MOH, the exploratory factor analysis revealed a new three-factor solution explaining 33% of the variance. Furthermore, five items from the original MOH were suggested to be excluded, as four of them had low factor loadings (<0.33) and one item loaded low on all three factors. The new three-factor solution, with re-grouped items, was considered meaningful among the authors from a conceptual perspective with the considered population in mind. Based on the factor analysis, the items of the new factors were used as summed sub-scales, with the suggested labels: “My home is my castle” (eight items, eligible scores 0-80), “My home is my prison” (eight items, eligible scores 0-80) and “My home is my social hub” (seven items, eligible scores 0-70), see Figure 4. The new labels were agreed among the authors after iterative discussions.

Regarding the external HCQ, the exploratory factor analysis showed a one-factor solution, explaining 21.4 % of the variance. Moreover, two items were suggested to be excluded due to low factor loadings (<0.33) and low corrected-item correlations (<0.3). The new factor solution of the external HCQ consisted of 14 items (eligible scores 14-70).

The result of the psychometric evaluations presented henceforward will reflect the revised versions of MOH and external HCQ. For more details on the evaluation process of structural validity for MOH and external HCQ, see Papers II and III.

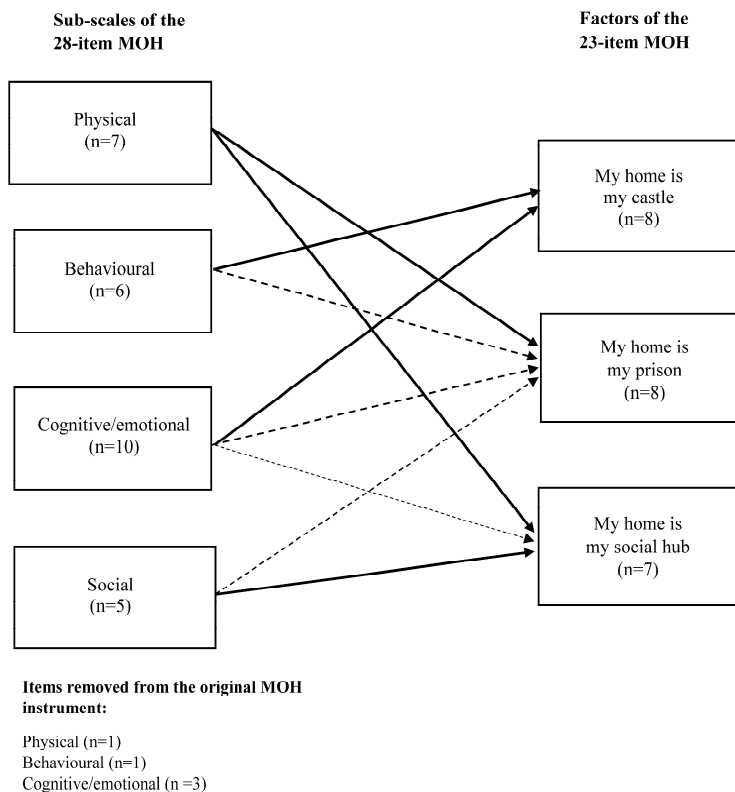


Figure 4. Items movements from the sub-scales of the original version to the new revised version of MOH. -----▶ =1-2 items; —▶ =3-4 items.

Construct validity

Based on hypotheses, construct validity was examined for both instruments. The findings of convergent and discriminant validity of MOH show that higher MOH scores were statistically significantly correlated with higher life satisfaction, higher usability, lower ADL dependence and number of environmental barriers, as hypothesised. Furthermore, higher MOH scores for the sub-scale “My home is my social hub” correlated significantly with time lived in the dwelling, but not for the other two sub-scales. As to external HCQ, convergent validity showed that higher external HCQ scores were significantly correlated with more housing accessibility problems, dependence in ADL and lower general self-efficacy. Known group validity indicated there was a significant difference between the different HY stages related to external HCQ. That is, those in HY stages I-III had lower external HCQ scores than those in the more advanced HY stages (IV-V), see Table 5.

Table 5. Hypotheses and results of construct validity for MOH and external HCQ, N=245.

Hypotheses	Hypotheses confirmed
MOH	
<i>Convergent validity</i>	
Higher MOH scores are expected to correlate significantly with higher life satisfaction (1 item, Lisat -11)	Yes, for all sub-scales
Higher MOH scores are expected to significantly correlate with low to moderate strength with higher scores of Usability in My Home (UIMH)	Yes, for all sub-scales
Higher MOH scores are expected to correlate significantly for those who have lived longer in their dwelling (number of years)	No, for MOH 1 & 2 Yes, for MOH 3
Higher MOH scores are expected to correlate significantly with lower ADL dependence	Yes, for all sub-scales
<i>Discriminant validity</i>	
Higher MOH scores are expected to not correlate significantly with number of environmental barriers in the dwelling (HE)	Yes, for all sub-scales
External HCQ	
<i>Known group validity</i>	
External HCQ scores are expected to be significantly lower for HY I-III than for IV-V	Yes
<i>Convergent validity</i>	
Higher external HCQ scores are expected to significantly correlate with living with more accessibility problems (HE) ($r^2>0.37$)	Yes
Higher external HCQ scores are expected to significantly correlate with being dependent in ADL ($r^2>0.26$)	Yes
Higher external HCQ scores are expected to significantly correlate with lower GSE	Yes

MOH=Meaning of Home Questionnaire, 23-item version with 3 sub-scales; Lisat -11=Life satisfaction Questionnaire, item 1 (higher scores=greater life satisfaction); MOH 1=The sub-scale "My home is my castle" (higher score=perceive more meaning); MOH 2=The sub-scale "My home is my prison" (higher score=perceive more meaning); MOH 3=The sub-scale "My home is my social hub" (higher score=perceive more meaning); UIMH=Usability in My Home, consisting of 2 sub-scales: activity aspect (higher scores=more usable) & physical aspect (higher scores=more usable); ADL= Activities of Daily Living, measured with ADL Staircase higher scores=more dependent); Number of environmental barriers measured with HE=Housing Enabler Instrument (higher scores=more barriers); External HCQ=External Housing-Related Control Beliefs Questionnaire, 14-item version in one scale (higher scores=higher beliefs in external influences related to the home); HY=Hoehn & Yahr, (higher scores=worse disease severity); HE=Housing Enabler Instrument (higher scores=more accessibility problems); GSE=General Self Efficacy Scale (higher scores=greater self-efficacy).

Scaling assumptions

The median total sum score was at the higher end for MOH sub-scales, while the value was more in the middle of the scale for external HCQ. The distribution of the quartiles (q1-q3) was not evenly distributed across the items in any of the instruments. Furthermore, all items of the revised version of MOH had corrected item-total correlations values >0.3 , and only two items had values <0.4 . Addressing corrected item-total correlation in the revised version of external HCQ, all values were >0.3 with a range between 0.31-0.53, see Table 6.

Floor and ceiling effects

For MOH, no floor or ceiling effects were found on the item level, or for two of the sub-scales. There was a tendency, though, towards a ceiling effect for the sub-scale “My home is my castle”, as 15.6% had selected the response option “strongly agree”. No floor or ceiling effects were found regarding the total sum score for external HCQ.

Table 6. Psychometric properties of the 23-item MOH and the 14-item external HCQ. N=245.

	MOH			Ext HCQ
	“My home is my castle”	“My home is my prison”	“My home is my social hub”	
Missing responses, n (%)	12 (4.9)	11 (4.5)	9 (3.7)	4 (1.6)
Total sum scores				
Median (q1-q3),	68 (59-76)	68 (59-75)	58 (50-65)	32 (26-39)
Min-max	29-80	32-80	23-70	14-62
Floor/ceiling effect, %	0/15.6	0/12.3	0/8.3	0.8/0
Corrected item-total correlation	0.43-0.62	0.38-0.53	0.40-0.55	0.31-0.53
Cronbach’s alpha	0.80	0.74	0.76	0.78
SEM (CI 95%)	5 (-5:15)	6 (-6:17)	5 (-5:15)	4.47 (-4.3:13.2)

MOH=Meaning of Home Questionnaire, in all sub-scales higher scores=perceiving more meaning; MOH sub-scale “My home is my castle” possible sum scores: 0-80; MOH sub-scale “My home is my prison” possible sum scores: 0-80; MOH sub-scale “My home is my social hub” possible sum scores: 0-70; external HCQ=external Housing-related Control beliefs Questionnaire, possible sum score 14-70 (higher scores=higher beliefs in external influences related to the home).

Reliability

For both instruments Cronbach’s alpha values were above the recommended value of >0.70. Exploring the SEM score, the MOH sub-scales had scores ranging between 5-6 points, while the SEM was 4.47 points for the external HCQ, see Table 6.

Directions of relationship between external control beliefs related to the home and ADL

The study exploring the directions of the relationship between external control beliefs related to the home and PADLS (Study IV) showed that hypothesis 1 was confirmed by the adjusted linear regression when controlling for external HCB, age, HY, MoCA and RAPS; all baseline variables. That is, an increase with 1 point on PADLS implies an average 3.07 point ($p<0.001$) increase on external control beliefs related to the home. This indicates that more difficulties in PADLS lead to higher external control beliefs related to the home in people with PD (Figure 5 & Table 7).

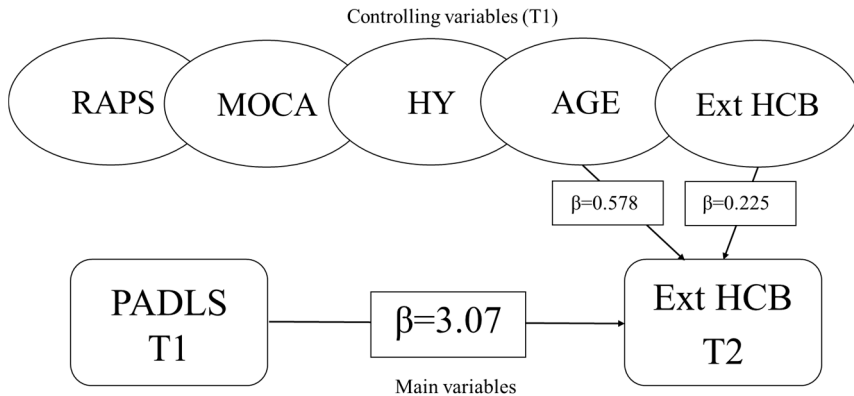


Figure 5. Linear regression analysis supporting hypothesis 1; PADLS (Parkinson’s disease Activities of Daily Livings Scale, measures difficulties in ADL) at baseline significantly ($p<0.001$) predicts external HCB at follow-up, when adjusting for the confounders: external HCB (external Housing-related Control Beliefs (measures beliefs in external influences related to the home) age, HY (Hoehn & Yahr, measures disease severity), MOCA (Montreal Cognitive Assessment, measures global cognitive function) and RAPS (Relative Accessibility Problem Score, measures housing accessibility problems) all at T1. T1=baseline; T2=3-year follow-up; Arrows indicate significant impact on external HCB, while an absence of arrows indicates non-significant impact.

The reversed direction of the relationship, however, was not confirmed. That is, the adjusted logistic regression analysis exploring hypothesis 2 showed no statistically independent effect between external control beliefs related to the home and PADLS ($p=0.136$) when controlling for age, HY, MoCA and RAPS all at baseline (Table 7).

Table 7. Linear and logistic regression analyses for exploring the direction of association between external HCB and PADL among people with Parkinson’s disease. (N=152).

Linear regression analyses (Dependent variable: External HCB, T2)			
Hypothesis 1 (more difficulties in ADL leads to higher external HCB)			
Independent variable: PADLS (T1)	Regression coefficient (β)	95% CI	p value
Analysis adjusted for HCB (T1)	2.36	0.63-4.09	0.008
Analysis adjusted for HCB (T1) + confounding factors ^a	3.07	1.28-4.85	<0.001
Logistic regression analyses (Dependent variable: PADLS ^b , T2)			
Hypothesis 2 (higher external HCB leads to more difficulties in ADL)			
Independent variable: External HCB (T1)	OR	95% CI	p value
Analysis adjusted for PADLS (T1)	1.05	1.01-1.10	0.021
Analysis adjusted fo PADLS (T1) + confounding factors ^a	1.04	0.99-1.09	0.136

HCB=External Housing-Related Control Belief Questionnaire, possible score 14-70 (higher scores=higher beliefs in external influences related to the home); T2=3-year follow-up; PADLS=Parkinson’s Disease Activities of Daily Living Scale, possible scores 1-5 (higher scores=more difficulties in ADL); T1=Baseline; Regression coefficient (β)=unstandardized beta coefficient; OR=Odds ratio; CI=Confidence interval.

^aAdjusted with the following variables at T1: age, relative housing accessibility problems scores (RAPS), disease severity (Hoehn & Yahr) and global cognitive functioning (Montreal Cognitive Assessment).

^bDichotomization of PADLS: no difficulties – mild difficulties, scores 1-2=0; moderate difficulties - extreme difficulties scores 3-5=1.

Discussion

As a knowledge gap has been found on housing for people with PD (Iwarsson et al., 2022), this thesis aspires to advance the understanding of housing aspects for people with PD. The overall aim has been to increase the knowledge of housing matters, in terms of objective as well as perceived housing for people living with PD in Sweden. The more specific aims were to determine the most severe environmental barriers in terms of housing accessibility problems and how those evolved over time (Study I), examine the psychometric properties of instruments that measure perceived housing (Study II & III), and to explore the directions of the relationship between one perceived housing aspect and ADL for people with PD (Study IV). These aims were addressed using a quantitative methodology through studies covering different aspects of housing as well as methodological development of instruments.

The main findings from the four studies are that environmental barriers that pose housing accessibility problems among people with PD remain roughly the same over a three-year period, but with notable changes in order and magnitude (Study I). Furthermore, the revised versions of the instruments MOH and external HCQ, which capture aspects of perceived housing showed sufficiently psychometric properties for use in PD samples (Study II & III). Using one of these instruments in a study exploring the direction of the relationship between perceived housing and health, showed that difficulties in ADL lead to higher external control beliefs related to the home for people with PD (Study IV).

Together, the findings from this thesis add to the overall understanding of different housing aspects and their relation to health for people with PD, as well as how perceived housing can be assessed in this population. Such knowledge can be of use in both individual rehabilitation, at the societal level and in research to address and meet various needs related to housing for people with PD.

Assessing perceived meaning and control beliefs

As no psychometric evaluations of the instruments MOH and external HCQ have been done among people with PD, the findings from Studies II and III contribute to the methodological development of these instruments. The results of the exploratory

factor analyses suggested changes for both instruments regarding number of items as well as sub-scale structure, which differed from the original instruments (Oswald et al., 2003; Oswald & Wahl, 2005). The results indicated that MOH should consist of 23 items categorised into three new sub-scales and that the external HCQ should be treated as one scale with 14 items, although other solutions were examined. Previous factor analyses have been done regarding external HCQ and MOH, although none are comparable with the analyses in this thesis. That is, one analysis was made in the development process of HCQ (including both the internal and both external sub-scales) (Oswald et al., 2003), and another attempt was made to reconsider MOH and external HCQ together for use in the general population of older adults (Oswald & Kaspar, 2012). Furthermore, both original versions of MOH and external HCQ were developed based on well-known concepts and theories in psychology (Oswald et al., 2003; Oswald & Wahl, 2005; Oswald & Wahl, 2019), while the psychometric evaluation principles guided the process in Study II and III. These various courses of action and the new population addressed could explain some of the differences found in the structure of the instruments, and the discrepancies reaffirm that psychometric properties are sample dependent (Hobart & Cano, 2009).

Besides structural validity, the psychometric evaluation of the original instruments covered internal consistency reliability (Oswald et al., 2003; Oswald et al., 2006). Regarding Cronbach's alpha, the original version of MOH had Cronbach's alpha values between 0.44-0.67 (Oswald et al., 2006), but as the sub-scales were revised in Study II comparisons were not possible. Regarding the revised version of external HCQ, the findings suggested a slightly stronger internal consistency than the original external HCQ ($\alpha=0.78$ versus $\alpha=0.67$) (Oswald et al., 2003). Cronbach's alpha is dependent on the number of items in the instrument evaluated, that is, the alpha score increases with more items. Still, a high alpha value (>0.90) could indicate item redundancy (Streiner, 2003). As the revised version of external HCQ showed acceptable Cronbach's alpha, even though two items were excluded from the original instrument, it could indicate that this revised version is internally consistent. Moreover, construct validity was largely supported with significant correlations of expected strength to other concepts, according to predefined hypotheses. At large, these poor to fair correlations were in line with previous literature (Oswald et al., 2006; Oswald et al., 2007a) and showed that MOH as well as external HCQ are related to similar concepts yet differs from concepts such as ADL, usability of the home and housing accessibility.

The findings of the psychometric evaluations are promising, but future studies need to confirm these results for use in PD samples and should address additional aspects such as test-retest reliability. Nevertheless, it is unclear whether the revised versions proposed in the thesis should be considered PD-specific versions, and more studies are needed in different populations to be able to determine whether there are variations between different populations that warrant recommending different

versions of the instruments. Such studies are important as psychometrically sound instruments are a prerequisite for high-quality research on perceived housing among people with PD.

Exploring housing accessibility, control beliefs and activities of daily living

The findings from the studies on housing accessibility (Study I) and the relationship between external control beliefs related to the home and ADL (Study IV) contribute knowledge for further the understanding of different housing aspects among people with PD. Study I is the first study to address accessibility problems over time in a PD sample. Compared to previous studies, Study I revealed both similar as well as different results. That is, most environmental barriers generating accessibility problems were in line with a previous cross-sectional study of people with PD (Slaug et al., 2017a), although the magnitude of accessibility problems generated by the barriers varied. In contrary, the ten most prevalent barriers identified at baseline in Study I differed partly in comparison to yet another cross-sectional study (Slaug et al., 2013), as only four barriers were the same. Study I showed that indoor barriers generated most problems, while Slaug and colleagues (2013) suggested that barriers in the exterior surrounding contributed to more accessibility problems. Slaug and colleagues (2013) had an older study sample (mean age 82 years), which could possibly explain some of these differences compared to the findings in Study I. Still, the results that barriers in the exterior surrounding contributed to a higher extent to accessibility problems is interesting, as Study I suggest that the exterior surrounding was the only housing section where summed magnitudes of accessibility problems increased significantly over three years. Accessibility problems in exterior surroundings are in many cases caused by balance problems or dependence on walking aids (Iwarsson & Slaug, 2010) and as people with PD often such problems that increase with the disease progresses (Mirelman et al., 2019), it is likely that accessibility problems in the exterior surrounding become more pronounced with time. Together this points to that studies with longer time perspectives are warranted to explore accessibility problems for people with PD.

Turning to perceived housing, Study IV explored the relationship between external control beliefs related to the home and ADL. The findings show that difficulties in ADL seem to lead to higher external control beliefs related to the home, while the opposing direction could not be confirmed. This result is not comparable to any of the previous studies addressing this relationship in PD samples, since one study only reported the association of the relationship not addressing the direction (Nilsson et al., 2016) and the second study explored the relationship between accessibility and ADL and found that external control beliefs in relation to the home had a moderating

effect of that relationship (Gefenaite et al., 2020a). The results from Gefenaite and colleagues (2020a) differs from the findings of in this thesis, but the results are not incompatible as Study IV investigated another aspect of the relationship. It should be noted that the previous studies are also based on data from the HHPD (Nilsson et al., 2016; Gefenaite et al., 2020a), although the possible direction that ADL difficulties can influence external control beliefs in relation to the home has not been addressed before.

Furthermore, empirical studies addressing different sub-groups of older adults have also found an association between external control beliefs related to the home and ADL but have neither targeted the direction of the relationship (Oswald et al., 2007a; Tomson et al., 2013; Genefnaite et al., 2020b). Still, studies and frameworks in environmental gerontology have assumed that processes including external control beliefs related to the home may lead to negative health outcomes, such as ADL difficulties (Wahl & Oswald, 2016; Chaudhury & Oswald, 2019). Accordingly, the finding of Study IV differs from such frameworks. The “Integrative conceptual framework of the P-E” suggests that such a P-E exchange is likely to change due to physical and cognitive decline (Chaudhury & Oswald, 2019). As people with PD often have a combination of physical (e.g. bradykinesia and postural instability) and cognitive symptoms (e.g. cognitive decline and fatigue) (Váradi, 2020), it is not surprising that this relationship is different for people with PD compared to the general ageing population. This exemplifies that housing and health relationships could be diagnose-specific and the characteristic PD symptoms provide a possible explanation for the diverging results. While the findings from Study IV add to the knowledge of housing and health interactions for people with PD, more research is needed to confirm these results and to explore them in other populations to see if such results are PD specific.

To summarise, both objective and perceived housing seem to matter for people with PD. The nature of PD seems to impact both housing accessibility (Study I) as well as control beliefs in relation to the home (Studies IV) in specific ways. The knowledge gained from Study I can be used in PD rehabilitation as well as on the societal level to meet the housing needs of people with PD. The findings from Study IV are useful in research for building a knowledge base on housing and health for people with PD.

Occupational therapy practices and housing

In occupational therapy, the traditional approach when addressing housing focuses on objective aspects, such as housing accessibility (Fänge & Iwarsson, 2005; Norin et al., 2021; Wellecke et al., 2022). Although, this is a common way to target housing, mapping of environmental barriers generating accessibility problems for

specific diagnosis groups are lacking (Iwarsson et al., 2022a). The findings from Study I can therefore be useful in occupational therapy practices when addressing the housing environment for people with PD. For example, the barriers “No grab bar at shower/bath/toilette”, “Stairs the only route” and “Wall-mounted cupboards and shelves placed high” generated the most accessibility problems at baseline. According to the Swedish National Board of Housing, Building and Planning (2019), grab bar and ramp installations are the most frequently made housing adaptations in Sweden that address some of the barriers found in Study I. The fact that the found barriers (“No grab bar at shower/bath/toilette” and “Stairs the only route”) were less frequent and generated a lower magnitude of accessibility problems at follow-up indicate that they had been effectively addressed during the three-year studied through, for example, housing adaptations. The results also suggest that several environmental barriers generated a higher magnitude of accessibility problems over time such as the barriers “Doors that cannot be fastened in open position” in entrances and “High thresholds/levels differences/steps” indoors. This indicate that these are barriers generate more accessibility problems over time and are important to be aware of when addressing housing for people with PD. Also, the fact that the number of these barriers were largely the same at both test occasions implies that those had not been addressed during the study period. This supports that there is a need for knowledge on environmental barriers and their development over time for occupational therapist working in PD rehabilitation.

Furthermore, the barrier “Insufficient manoeuvring spaces around movable furniture” decreased in frequency of barriers, suggesting that some modification has been done between the two assessments. Still, this barrier was ranked lower at follow-up, although it generated significantly more accessibility problems. Dependence on mobility devices such as rollators or wheelchairs, is often generating more accessibility problems for barriers that addresses insufficient manoeuvrings spaces in HE. It is therefore essential to consider both components of the P-E fit (Lawton & Nahemow, 1973) when evaluating the environment. This is especially important in populations that are frequent users of mobility devices, such as people with PD. Previous research has advocated the need to develop research-based strategies on housing adaptations for people with PD (Bhiadaysairi et al., 2015), and the results of Study I can therefore be valuable when developing such strategies, for example in occupational therapy programmes for people with PD.

As the time period investigated was only three years, it is likely that there will be even larger accessibility problems over a longer period of time due to disease progression. This also supports the idea that regular follow-ups of the housing environment and adaptations made should be a part of individual housing interventions to maintain occupational performance for people with PD. As previous research shows that recurring housing adaptations cost time and money (Malmgren Fänge, 2004), occupational therapists working in PD rehabilitation should take a

proactive approach when addressing housing adaptation to enable ageing in place for people with PD.

Turning to aspects of perceived housing, neither MOH nor external HCQ is used in clinical settings. The result of Study IV shows that both ADL difficulties and external control beliefs related to housing increase with time, which is in line with previous literature (Sperens et al., 2020; Chaudhury & Oswald, 2019). Such basic knowledge is beneficial for forthcoming studies on people with PD and has the potential to inform the development of assessments and interventions in PD rehabilitation. The findings that ADL difficulties lead to higher external control beliefs in relation to the home is novel and further research is warranted to confirm these results. As increased difficulties in ADL indicate a disease progression that may lead to rehabilitation needs, the result of Study IV implies that external control beliefs related to the home represents a housing aspect to be aware of for occupational therapists working in PD rehabilitation. Still, a further exploration is needed on how such a housing aspect could be used in a clinical setting.

Knowledge on different housing aspects, such as objective and subjective housing, is also important in light of the new Swedish health care reform “good local care” (God och nära vård). The reform suggests that more care and rehabilitation should take place in people’s homes, even in the advanced phases of the disease (SOU, 2020:19). The home as a place for care and rehabilitation is a global movement, yet little is known about what local care means for people with complex rehabilitation needs and how the built environment can contribute to good care (Elf et al., 2020). For example, there will be higher demands for accessible housing when care and rehabilitation is situated in the homes of persons needing care. This may also affect feelings of control and meaning towards the home among those receiving such care. This health care reform is therefore another reason why research on housing matters is important for people with PD.

The relevance of housing for health promotion

Several global organisations have acknowledged that housing has major implications for health (United Nations, 2006; WHO, 2018; WHO, 2020), aiming to creating inclusive and accessible environments. Still, such recommendations have not been considered in relation to people with PD. Although research shows that there is an association between the housing environment and health variables among people with PD (Nilsson et al., 2016; Gefenaite et al., 2020a) WHO’s report emphasising a public health approach (WHO, 2022a) does not mention environmental aspects in general or related to housing. The findings of this thesis imply that knowledge on foremost objective housing could be useful from a societal perspective to promote health.

The findings from Study I suggest that not all housing accessibility problems can be solved by individual housing adaptations, but rather that some environmental barriers need to be addressed at the societal level. For example, changes in magnitude of accessibility problems per housing section was examined in Study I. The findings revealed that the indoor environment and entrances generated the most magnitude at both baseline and the follow-up, but that the exterior surrounding was the only housing sections where the accessibility problems increased significantly over the three years studied. Although used by many, community areas can generate accessibility problems for individuals (Carlsson et al., 2021), such as the exterior surrounding of a house. Still, housing adaptations are mostly addressed in the indoor environment (Swedish National Board of Housing, Building and Planning, 2019). It is therefore important that the society plan for and take into account the needs of specific populations in such areas.

An example of this was the barrier “Refuse bin difficult to reach”, which generated the most magnitude of accessibility problems at follow-up in Study I. A potential explanation for this finding is the change in Sweden’s the waste management system since the 1990s (Johansson, 2004). This change involved which waste to sort and how, as well as the design and location of rubbish stations. The increase in both numbers of barriers and magnitude of accessibility problems over three years indicates that some of these waste management changes do not benefit people with PD and therefore need such barriers to be addressed at a societal level.

Housing accessibility for people with functional impairments is a priority area globally (WHO, 2018), which underscores the importance of the findings from Study I. The results at baseline showed, for example, that barriers in bathrooms, entrances and kitchens generated the most accessibility problems for people with PD. These areas have also been shown to cause accessibility problems for people with diagnoses such as multiple sclerosis (Bishop et al., 2013) and dementia (Marquardt et al., 2011) as well as for the general older population (Granbom et al., 2016; Slaug et al., 2017b). As similar environmental barriers generate accessibility problems among people with PD and other diagnosis groups as well as the general ageing population, increases the incentive to address housing accessibility problems at the societal level (Jonsson et al., 2021). The findings on which barriers contribute to the most accessibility problems for people with PD can add to the knowledge base on housing accessibility to enhance public health policies and standards for housing design. Although not common, occupational therapist has the potential to take an expert role in such initiatives, with their specific competencies on environmental barriers related to P-E fit (Iwarsson et al., 2022a).

Housing standards are important in creating enabling environments (World Health Organization & The World Bank, 2011), but the knowledge of housing standards is low. Although, research has shown that building according to such standards lower societal costs and improve ADL dependence for older adults (Slaug et al., 2017b), houses are often not applied according to standards. Furthermore, there is a need

and demand for affordable houses for individuals (Anacker, 2019). This means that houses with barriers are still being built. For example, newly constructed multi-dwelling houses contain a considerable number of barriers (Granbom et al., 2016), that can potentially lead to health issues for the persons living there. Taking into account that people with more complex diagnoses and more pronounced symptoms also reside in such houses, the accessibility problems will probably be even larger for such people. Therefore, it should be considered whether there are populations in the community with specific needs going beyond today's housing standard. Study I show that people with PD face housing accessibility problems and that these increase with time. Consequently, it is important that the housing construction sector and policymakers comply to the housing standards and educate themselves about what type of designs represent barriers for the persons living there and can in turn cause health problems.

Turning to perceived housing, Study IV addresses external housing-related control beliefs and the relation to health. Such aspects of housing have not been recognised globally. For example, in the WHO's housing and health guidelines (WHO, 2018), objective aspects of housing are acknowledged to be important for health, but perceived housing is not considered. Therefore, more research is needed on perceived housing and the relation to health.

Theoretical considerations

Core concepts

Turning to the concepts used in this thesis, perceived housing deserves some attention. This is an umbrella term consisting of several underlying concepts that are not easy to capture quantitatively with instruments. For example, external housing-related control beliefs measured with external HCQ originally consisted of two sub-scales called external control beliefs: chance and powerful others, based on psychology literature and a factor analysis (Levenson, 1973; Oswald et al., 2003). Still, external HCQ were suggested to be used as on single scale for people with PD in Study III. A possible reason for the different results compared to the general ageing population is that not having control in relation to housing could be connected to the disease as such. Potentially the experience of increasing symptoms leading to ADL difficulties could mean that the division of these concepts is not that relevant in relation to PD. Also, the psychometric evaluation of MOH rendered in three new sub-scales (Study II). In the exploratory factor analysis, the items were clustered in ways so that similarities were formed around different relations to the home (as a castle, as a prison or as a social hub) rather than the nature or character of meaning expressed (physical, behavioural, emotional, etc.). For instance, the sub-

scale “My home is my castle” includes questions of both behavioural and cognitive/emotional meaning, but all questions concern a certain relation to the home that was found to be suitably captured by the label “My home is my castle”. This revised version of MOH sparks an interest in gaining a deeper understanding of what meaning of home means to people with PD. Therefore, qualitative studies addressing meaning of home among people with PD are needed and could maybe explain some of the findings in Study II.

The home often represents a high amount of meaning and personal values in old age (Rubinstein, 1989). The literature covering meaning towards the home has anticipated that a higher amount of MOH is positive (Oswald & Wahl, 2004; Oswald et al., 2006; Oswald et al., 2007), although considering the sub-scales suggested in Study II has led to other thoughts. Attachment to the home could also make the person feel confined there if the environment does not fit the person’s competencies. Although people with PD express a wish to age in place (Habermann & Shin, 2017), Study I suggest that people with PD have accessibility problems that change over time. Therefore, if feelings towards the home are strong, this might prevent proactive decisions to relocate (Rowles & Watkins, 2003), even if relocation would be necessary to sustain a good P-E fit. This could eventually lead to the experience that the person is a prisoner in their own home (Study II) and possibly change their feelings about their home. This makes meaning of home important to address among people with PD.

There are other psychological concepts that could deepen the understanding of P-E exchange for people with PD. For example, the concept embodiment (Rubinstein, 1989) could be important to consider. That is, when facets of the environment (e.g. a cane, glasses, or a handrail on stairs) becomes important for the person to cope with their daily activities, blurry borders can arise between the environment and the body. Including difficulties knowing where the body ends and the environment begins (Rubinstein, 1989). With the characteristic symptoms of PD, a familiar home environment might enable activities that could be difficult or even impossible to perform in other environments. Furthermore, Rubinstein also introduced the concept of environmental centralisation in relation to the housing environment, suggesting that when functional limitations increase, the person centralises around a smaller area in the home to manage daily activities. One example is, gathering important things (e.g. TV-remote, telephone, newspaper, a glass of water) around a favourite place, such as a sofa or comfortable chair, when activities become more difficult to perform. The suggested MOH sub-scale “My home is my prison” could be an expression of this concept, exemplified by the item “Being confined to rooms inside the house”. Concepts such as embodiment and environmental centralisation could be important to bear in mind when discussing the P-E exchange for people with PD and could be useful to address in future research on housing and health for people with PD.

Frameworks and models

Turning to the frameworks and models used, the gerontological literature and frameworks as well as occupational therapy models have influenced this thesis. The findings support the relevance of using and combining different perspective when exploring housing matters for people with PD.

The PEOP model (Baum et al., 2015) and “the integrative conceptual framework of person-environment exchange” (Chaudhury & Oswald, 2019) have common themes in their theoretical base where interaction between the person and the environments is important aspects, although calling this interaction differently (P-E transaction vs P-E exchange). Considering how these model and framework were addressed in the four studies, facets from both were addressed. That is, Study I considered the P-E exchange in relation to objective housing (housing accessibility), whereas Study II and III focused on this relation while addressing perceived housing (Study II and III). The outcome autonomy of “the integrative conceptual framework of person-environment exchange” was also addressed in Study IV by addressing ADL. This is also applicable of the three aspects in the PEOP model, that is the P-E-O addressed in the thesis (Baum et al., 2015). Both the environmental gerontology and the occupational therapy perspective the have supported and guided the process during the work with this thesis, and have given me a broad theoretical basis.

Furthermore, the findings from Studies I and IV shows that both objective and perceived housing change over time, which is in line with the theoretical perspectives used in the thesis (Baum et al., 2015; Chaudhury & Oswald, 2019). The role of time is important to address in this dynamic P-E exchange especially when targeting people with a progressive disease, such as PD. Chaudhury and Oswald (2019) reason that when physical or cognitive functions decline over time the P-E exchange changes. An example of this is that both magnitude of accessibility problems (Study I) and external control beliefs related to the home (Study IV) increased over the three years studied. Therefore, studies addressing longer time periods than three years are warranted to explore the dynamic P-E exchange further among people with PD.

Comparing the frameworks and models that have guided this thesis, with syntheses of housing research. For example, Roy and colleagues (2018) conducted a systematic review on housing covering six dimensions. The studies conducted in this thesis cover the following four dimensions from their work: time and space-time (ADL), built and natural environment (accessibility), psychological and psychosocial (meaning and control) and socioeconomic and health (PD). Furthermore, the review includes several other factors that are seldom addressed in PD research (Iwarsson et al., 2022b), such as a well-developed economic dimension related to housing as well as a social dimension. Therefore, the work of Roy and colleagues (2018) is an important source of knowledge for defining new research questions on housing and health for people with PD.

Methodological reflections

During this work, it became clear that housing is a rare topic in PD research. This led to the decision to incorporate more housing aspects than perceived housing only, as originally planned. Therefore, both objective and perceived housing were included, though most studies in the thesis addressed perceived housing. To measure an aspect that addresses perceptions of the home strictly quantitatively is perhaps not the most obvious methodological choice. In light of the results on perceived housing (the revised versions of the instruments and new insights on the directions of the relationship between external control beliefs related to housing and ADL) I would argue that this quantitative approach is one approach needed in PD research to cover some aspects of the knowledge gap on housing for people with PD and nurture further research.

Psychometric evaluation is an ongoing process (Hobart & Cano, 2009) and based on the results of Studies II and III revised versions of the external HCQ and MOH were suggested when used in PD samples. The new findings were guided by the explorative factor analyses, and there are different traditions when analysing such results (Costello & Osbourne, 2005; Hobart & Cano, 2009). Some may argue that statistics and cut-off values of the analyses were not strictly followed in this process, as the author constellation evaluated the statistics while also taking a conceptual approach by considering the development process. This kind of process was possible because one of the original authors of the instruments was a co-author of Studies II and III. As an example, some items were removed due to low factor loadings and others were kept due to their significance in the instrument's development process (called signature items) in the evaluation of MOH. Such considerations are important to keep in mind when interpreting the results.

Even though the instruments measuring perceived housing were evaluated rather extensively in this thesis in terms of validity and reliability for people with PD, other methods of modern test theory could be used to learn more about the instruments. For example, an analysis using the Rasch measurement model could potentially lead to additional instrument development (Hobart & Cano, 2009). Reflecting also on the content of the instruments, revisions might be beneficial due to changes in society over time. As the instruments were developed 20 years ago, developments in society since then could prompt the study of new aspects that affect perceived housing. Over the last few decades, technology has developed in leaps and bounds, potentially affecting feelings about the home. For example, older adults perceive technology as supporting healthy behaviour, like increasing autonomy and safety and enabling greater participation in society (Carretero, 2015; Swedish Agency for Health and Care Services Analysis, 2021). Thus, the use of technology could affect how people think and feels about their home. Technology is also addressed in the gerontology framework used in this thesis as a component affecting the P-E

exchange (Chaudhury & Oswald, 2019). In sum, the instruments addressing perceived housing could benefit from further instrument development.

Strengths and limitations

Considering the drop-out rate for the HHPD study, it was 35% for the invited participants at baseline as well as between baseline and follow-up. Although, this can be seen as a considerable drop-out rate, it was accounted for in the study protocol based on power calculations and previous experiences (Nilsson & Iwarsson, 2013).

When considering the participants included in the four studies, there was a representative gender distribution for the PD population (Van Den Eeden et al., 2003) and a broad age range of almost 50 years. This is especially important as older people with PD are often excluded from PD research (Fitzsimmons et al., 2012). Another strength is that participants from all stages of HY and ADL were included in the studies, thus representing the full spectrum of disease severity and difficulties in ADL to be able to generalise the results to the PD population. Although fewer cases were included in HY V (1.3-3.5%) and few had extreme difficulties in ADL (0.6-2.9%), it is an advantage to have participants representing all stages. Also, when it comes to housing, persons living in residential care units were excluded in three of the four studies, and in Study IV nearly all participants lived in ordinary housing (99.4%). Consequently, the results of this thesis can be considered representative for people with PD living in ordinary housing, who are not in the most advanced stages of PD.

Study I used the HE instrument that was developed and psychometrically evaluated for older adults (Iwarsson & Slaug, 2010; Helle et al., 2010). Although psychometrically sound instruments are important when addressing new populations (Hobart & Cano, 2009), the HE was not evaluated for use among people with PD. Still, it is essential to learn from previous evaluations; for example, the HE has been psychometrically evaluated for people with spinal cord injuries (Norin et al., 2019). Although there are many differences between spinal cord injuries and PD, there are some similarities, such as the frequent use of mobility devices by these groups (Kader et al., 2018b; Norin et al., 2019). In the psychometric evaluation of HE among people with spinal cord injuries, specific attention was paid to people that used mobility devices, suggesting that rollators and powered wheelchairs compensate for some environmental barriers. The recommendation was therefore to make a distinction between manual and powered wheelchairs as well as between rollators and other walking assistive devices in the analyses of accessibility problems (Norin et al., 2019). As rollators are commonly used among people with

PD (Kader et al., 2018b), this information also applies to this group and the results of Study I should be interpreted based on this knowledge.

Moreover, the internal scale of control beliefs in relation to housing was never included in the HHPD data collection, based on previous recommendations due to low internal consistency (Oswald et al 2006; Iwarsson et al., 2007; Nygren et al., 2007). Thus, only the external aspects of housing-related control beliefs were addressed in this thesis. Not being able to address the entire concept of control beliefs in relation to housing is therefore a limitation in this thesis. Furthermore, similar to what was found in Study III (to treat external HCQ as one scale), previous literature has combined the two external sub-scales (Oswald et al., 2006). One should consider that these previous recommendations were only made to achieve an acceptable internal consistency in group comparisons and were not based on statistical analyses as in this thesis.

In Study IV two different kinds of regression analyses were made due to the nature of the two dependent variables used, that is linear and logistic regression. This hampers the possibility to make comparisons of the results when exploring the hypotheses. Also, ordinal regression analysis was considered as a possible analysis method in the planning phase, as PADLS is of ordinal nature. As the sample size was at the lower end and the assumptions of ordinal regression were not fulfilled (Armstrong & Sloan, 1989), logistic regression was chosen instead.

Conclusions

Housing matters have seldom been addressed in PD research and this thesis contributes new findings on different housing aspects for people with PD living in ordinary housing. The studies address both objective and perceived housing and provide new knowledge on the relationship between perceived housing and health. Furthermore, the thesis lays a methodological ground for capturing perceived housing for people with PD quantitatively.

- Regarding objective housing in terms of accessibility problems, hygiene areas, entrances and kitchens are spaces with a high frequency of environmental barriers as well as generating high amounts of housing accessibility for people with PD. Also, barriers in the exterior surrounding generated accessibility problems over time. Consequently, those areas of the home environment need specific attention in PD rehabilitation addressing the home environment.
- Going beyond individual rehabilitation, some barriers that generate accessibility problems for people with PD need to be addressed at a societal level. Barriers in the exterior surrounding outside the house was one such example that needs to be acted on systematically for people with PD.
- Measuring perceived housing, the revised versions of MOH and external HCQ are psychometrically sound for use among people with PD.
- Exploring perceived housing and the relationship to health, showed that difficulties in ADL were suggested to lead to higher external control beliefs related to the home among people with PD. This direction of the relationship could be specific for this population, although more studies need to confirm these findings.

Implications for practice, research, and policies

- The knowledge gained about changes in environmental barriers and housing accessibility over time can support more foresighted and sustainable individual housing adaptations as well as ageing in place for people with PD. Such knowledge could for example be used in occupational therapy programmes for PD rehabilitation to support occupational therapists addressing accessibility problems for people with PD.
- Occupational therapist should take a proactive approach when addressing housing adaptations for people with PD, due to the nature of the disease. Furthermore, regular follow-ups to evaluate the environment and the housing adaptations made are important for enhancing the P-E fit for people with PD.
- The findings on housing accessibility problems and developments over time have the potential to be applied on the societal level, as input to support housing provision and public health policies to meet the housing needs of people with PD.
- The revised versions of MOH and external HCQ enables more high qualitative studies on perceived aspects of housing among people with PD. This is important for building a knowledge base on housing matters for the PD population.
- The new finding that ADL difficulties lead to higher perceived control beliefs in relation to the home is useful in research to build a knowledge base on housing and health for people with PD. Furthermore, this result indicate that external control beliefs related to the home is a housing aspects to be aware of for occupational therapist working in PD rehabilitation, although more research is needed to understand how such knowledge could be used in rehabilitation.

Future perspectives

This thesis contributes with new knowledge on different housing aspects for people with PD, although more research is needed to fill the knowledge gap housing for this population.

The result of this thesis suggests that people with PD have housing accessibility problems that change over three years. With a progressive disease like PD, more research is needed that consider longer time perspectives to explore how housing accessibility change over time. It would also be interesting to see what housing accessibility looks like in other countries for people with PD, with a different housing stock than Sweden.

The instruments MOH and external HCQ measuring perceived housing were evaluated for people with PD in this thesis. Still, the original instruments were developed about 20 years ago, therefore could methodological studies addressing instrument development in general shed new light on perceived housing. Also, as the psychometric evaluation showed that revised versions with new sub-scales should be used for people with PD. This sparks a curiosity to get a deeper understanding of what these concepts mean to people with PD. Qualitative studies addressing these concepts could generate such knowledge and might explain some of the findings from this thesis.

The exploration of the relationship between external control beliefs related to housing and ADL, lead to new findings in this thesis. It is also intriguing to know if this direction of the relationship could be found in other populations with different diagnosis.

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Appendix I-III

Appendix I. The original version of the Meaning of Home Questionnaire

Interviewer: Obligatory introductory comments:

"A person's home can have many different meanings for the resident. It is not just a place where the everyday routine is performed. For example: A home can be meaningful because one can do as one pleases. It can be a place where an individual might feel on the one hand safe, or on the other hand confined within its limits or many other things.

The following statements refer to different meanings of home. I will read these statements aloud, and ask you to judge to what extent you personally agree or disagree with each statement at present. You may choose between the following possible answers:"

Interviewer: Present the scale.

strongly disagree					strongly agree					
0	1	2	3	4	5	6	7	8	9	10

Obligatory Interviewer statement:

"If you agreed fully with a statement, please respond with '10'; if it does not reflect your situation at all, please respond with '0'. If you neither strongly agree nor disagree with a statement, please choose the answer on the scale between 1 and 9 which best corresponds to your situation."

Interviewer should begin each statement with the phrase "Being at home means for me..."

No.	Items	Enter response (0-10)
1.	living in a place which is well-designed and geared to my needs	
2.	managing things without the help of others	
3.	being familiar with my immediate surroundings	
4.	feeling safe	
5.	meeting family, friends, and acquaintances	
6.	having to live in poor housing conditions	
7.	having a nice view	
8.	doing everyday tasks (e.g. housework)	

9.	being bored	
10.	knowing my home like the back of my hand	
11.	living in a place where I can get no support or help from others	
12.	living in a place that is comfortable and tastefully furnished	
13.	being able to change or rearrange things as I please	
14.	being able to relax	
15.	feeling that the home has become a burden	
16.	not having to accommodate anyone's wishes but my own	
17.	thinking about the past (e.g., important persons and events)	
18.	enjoying my privacy and being undisturbed	
19.	being excluded from social and community life	
20.	having a base from which I can pursue activities	
21.	no longer being able to keep up with the demands of my home (e.g. maintenance)	
22.	thinking about what living here will be like in the future	
23.	feeling comfortable and cosy	
24.	being able to receive visitors	
25.	being confined to the rooms (and things) inside the home	
26.	being able to do whatever I please	
27.	feeling lonely	
28.	having a good relationship with the neighbours	

Appendix 2. The revised version of the Meaning of Home Questionnaire.

No.	Items	Sub-scale
1.	<i>living in a place which is well-designed and geared to my needs*</i>	<i>Excluded</i>
2.	<i>managing things without the help of others*</i>	<i>Excluded</i>
3.	being familiar with my immediate surroundings	My home is my social hub
4.	<i>feeling safe*</i>	<i>Excluded</i>
5.	meeting family, friends, and acquaintances	My home is my social hub
6.	having to live in poor housing conditions	My home is my prison
7.	having a nice view	My home is my social hub
8.	doing everyday tasks (e.g. housework)	My home is my castle
9.	being bored	My home is my prison
10.	knowing my home like the back of my hand	My home is my castle
11.	living in a place where I can get no support or help from others	My home is my prison
12.	living in a place that is comfortable and tastefully furnished	My home is my social hub
13.	being able to change or rearrange things as I please	My home is my castle
14.	being able to relax	My home is my castle
15.	feeling that the home has become a burden	My home is my prison
16.	not having to accommodate anyone's wishes but my own	My home is my castle
17.	<i>thinking about the past (e.g., important persons and events)*</i>	<i>Excluded</i>
18.	enjoying my privacy and being undisturbed	My home is my castle
19.	being excluded from social and community life	My home is my prison
20.	having a base from which I can pursue activities	My home is my social hub
21.	no longer being able to keep up with the demands of my home (e.g. maintenance)	My home is my prison
22.	<i>thinking about what living here will be like in the future*</i>	<i>Excluded</i>
23.	feeling comfortable and cosy	My home is my castle
24.	being able to receive visitors	My home is my social hub

25.	being confined to the rooms (and things) inside the home	My home is my prison
26.	being able to do whatever I please	My home is my castle
27.	feeling lonely	My home is my prison
28.	having a good relationship with the neighbours	My home is my social hub

*Items marked italicized are excluded from the new revised version of the MOH.

Appendix III. The original and the revised version of the external Housing-related control beliefs Questionnaire (HCQ)

Interviewer: Obligatory introductory comments

"The following statements describe how people might react to and feel about their home. I will read the statements aloud and ask you to judge to what extent each one reflects your personal situation. You may choose between the following range of answers:"

Interviewer: Present the scale.

strongly disagree	disagree	neutral	agree	strongly agree
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Interviewer: Obligatory introductory comments

"You may choose between 'strongly disagree', 'disagree', 'neutral' - that is, a statement might be partly true and partly not - 'agree' or 'strongly agree'. Please choose the category which - in your opinion - best applies to you."

Interviewer: If the interviewee needs additional assistance, please add (optional):

"Don't give too much thought to your responses; just tell me what occurs to you spontaneously. There are no right or wrong answers - I only want to know what you personally think about the various statements."

No.	Items	Interviewer: Please mark with a cross				
2.	I rely to a great extent upon the advice of <u>others</u> when it comes to helpful improvements to my home.	strongly disagree	disagree	neutral	Agree	strongly agree
3.	Having a nice place is all <u>luck</u> . You cannot influence it; you just have to accept it.	strongly disagree	disagree	neutral	Agree	strongly agree
5.	Whether or not I will be able to stay in my home will probably depend on <u>other people</u> .	strongly disagree	disagree	neutral	Agree	strongly agree
6.	It's purely a <u>matter of luck</u> whether or not neighbours will step in if I need help.	strongly disagree	disagree	neutral	Agree	strongly agree
8.	In order to do anything interesting outside of my home I have to rely on <u>others</u> .	strongly disagree	disagree	neutral	Agree	strongly agree
9.	Whether or not I can stay in my home depends on <u>luck and circumstance</u> *.	<i>strongly disagree</i>	<i>disagree</i>	<i>neutral</i>	<i>agree</i>	<i>strongly agree</i>

11.	I must rely on <u>others</u> when it comes to making use of support services and facilities in my local area.	strongly disagree	disagree	neutral	agree	strongly agree
12.	You just have to live with the way your home is; <u>you cannot do anything about it.</u>	strongly disagree	disagree	neutral	agree	strongly agree
14.	When <u>other people</u> offer to help around the house (e.g., with the housework) or help me outside the home, I can't say no.	strongly disagree	disagree	neutral	agree	strongly agree
15.	Where and how I live has happened more <u>by chance</u> than anything else*.	<i>strongly disagree</i>	<i>disagree</i>	<i>neutral</i>	<i>agree</i>	<i>strongly agree</i>
17.	<u>Other people</u> have told me how to arrange the furnishings in my home.	strongly disagree	disagree	neutral	agree	strongly agree
18.	It's a case of <u>luck or chance</u> whether I will be able to continue my present way of life in my home in the future.	strongly disagree	disagree	neutral	agree	strongly agree
20.	I listen to the advice of <u>others</u> when they tell me not to change anything in my own home.	strongly disagree	disagree	neutral	agree	strongly agree
21.	The way my home has been set up just happened <u>by chance</u> , over time.	strongly disagree	disagree	neutral	agree	strongly agree
23.	<u>Other people</u> are to blame if my home is not a place where I can enjoy life.	strongly disagree	disagree	neutral	agree	strongly agree
24.	Whether or not there are support services or community facilities in my neighbourhood is just a matter of <u>luck</u> .	strongly disagree	disagree	neutral	agree	strongly agree

*Excluded in the new revised version for use among people with PD.

Paper I-IV

Housing matters for people with Parkinson's disease

This thesis mainly focuses on different housing aspects for people with Parkinson's disease. The studies address both objective and perceived aspects of housing as well as activities of daily living and the data is based on a cohort study that included baseline assessments and a 3-year follow-up.



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