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## Housing accessibility and participation among older adults with long-standing spinal cord injury

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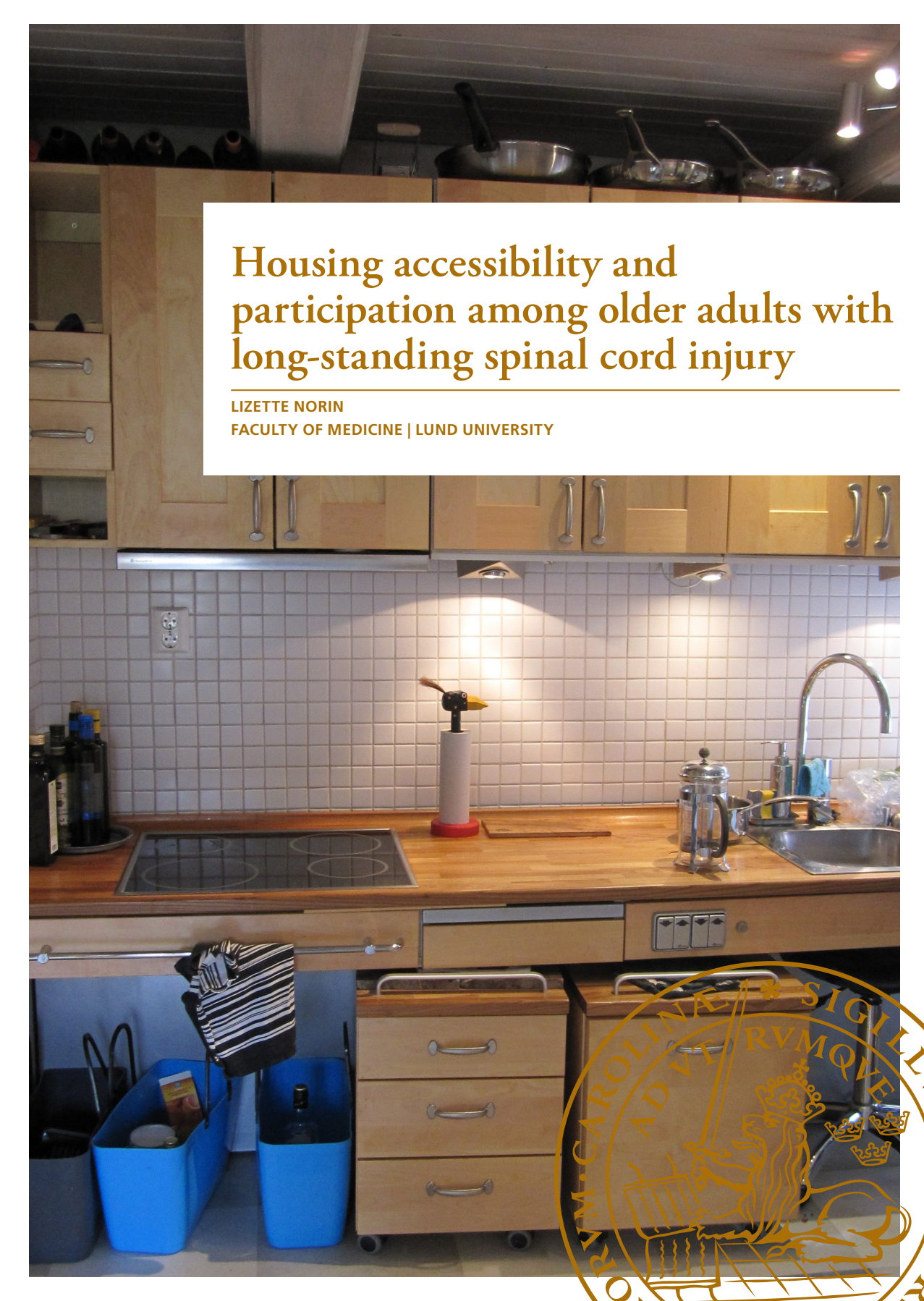
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# Housing accessibility and participation among older adults with long-standing spinal cord injury

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FACULTY OF MEDICINE | LUND UNIVERSITY





# Housing accessibility and participation among older adults with long-standing spinal cord injury

Lizette Norin



**LUND**  
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AKADEMISK AVHANDLING

Som för avläggande av filosofie doktorsexamen

vid Medicinska fakulteten, Lunds Universitet

kommer att offentligen försvaras i Hörsal 01, Health Sciences Centre,

Baravägen 3, Lund, fredagen den 18 Januari 2019, kl 9.00.

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Housing accessibility and participation among older adults with long-standing spinal cord injury	
<p>Advances in acute care and rehabilitation have increased longevity and improved survival after spinal cord injury (SCI) greatly. Adults with SCI are now entering older age in larger numbers, and a majority reside in ordinary housing in the community. Accessible housing environments are important in order to support autonomy and participation in later life in the general population, although the knowledge of the situation in this respect for older adults with long-standing SCI is insufficient.</p> <p>The overarching aim of this thesis project was to examine housing accessibility and its associations with participation among older adults with long-standing SCI in Sweden.</p> <p>The four sub-studies included in this thesis are based on selected baseline data from the Swedish Aging with Spinal Cord Injury Study (SASCIS), which is a longitudinal study aiming to deepen the understanding of aging with long-standing SCI in Sweden. Data was collected through home visits, including interviews and assessments, with people aged 50 or older who had their SCI at least 10 years ago. Descriptive data were used to characterise the sample (N=123). The association between housing accessibility and perceived participation was analysed by means of ordinal regressions. Cross-sectional data were utilized to qualitatively consider and review potential impact on reliability and content/construct validity of the Housing Enabler (HE) instrument in an iterative evaluation procedure. Simulations adjusting accessibility problem scores were conducted. Frequency analyses of housing adaptations and ranking of environmental barriers were performed.</p> <p>The majority of the injuries were traumatic, and traffic-related accidents were the most common cause. A majority of the participants perceived their participation as sufficient, although more accessibility problems were associated with a lower level of participation and more participation problems.</p> <p>Presence of housing adaptations and use of mobility devices were identified as posing considerable threats to reliability and validity of the HE instrument. Adjusted accessibility problem scores showed a modest overall impact on group level, although substantial in individual cases. The number of housing adaptations and environmental barriers in the dwelling differed between severity subgroups. Ramp at entrance, wheelchair accessible stovetop and ceiling lift in bedroom were the most common housing adaptations. Current accessibility problems were considerable, particularly in entrances, kitchens and hygiene areas.</p> <p>These baseline results of the SASCIS provide a description of housing accessibility and participation among older adults with long-standing SCI in Sweden. Data collection and analyses of housing accessibility using the HE in samples characterised by frequent housing adaptations and use of mobility devices require special attention. Further optimization of the HE is necessary to capture P-E fit in populations when used in samples with specific characteristics. The occurrence and extent of housing adaptations are diverse among older adults with long-standing SCI, and the reasons for remaining accessibility problems call for additional research. The findings in this thesis may serve as a foundation for occupational therapists and other professionals when planning and evaluating interventions concerning housing accessibility targeting older adults with long-standing SCI, not the least in a longterm perspective.</p>	
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# Housing accessibility and participation among older adults with long-standing spinal cord injury

Lizette Norin



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*Till min familj*



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## Preface

I have always been creative and have always been interested in people with different kinds of functional variations. When I had to decide what to do after leaving high school, I went to the career counsellor and told her my interests and asked what kind of profession she thought would suit me. She did a bit of typing on her computer, pressed the 'print' button and handed me a sheet saying 'occupational therapist' (OT). I had never heard of occupational therapy before, but decided to take on the Pippi Longstocking attitude "I have never done this before, so I am sure I will succeed".

Three years later I graduated from Lund University with a Bachelor of Science in occupational therapy and then worked as an OT, mainly in a community setting. After ten years I was ready for new challenges and while figuring out what they would be, I was working part-time as a project administrator collecting data for research at Lund University. The project administrator job was a temporary position for eight months, but I decided to terminate my permanent position as an occupational therapist to motivate myself to find a new job within that time.

Eventually, I was offered full time work as a project administrator. I also got involved in a project helping a PhD student with her data collection, doing home visits to older adults with SCI. I enjoyed this inspiring and challenging work as well as being in the academic atmosphere. The data collection was challenging, and gave rise to a lot of questions with no obvious answers. I was genuinely overwhelmed when I was asked if I wanted to address them in a PhD project. I had never aimed for a PhD education, but there I was, and it was too good an offer to reject, so I decided to accept.

The PhD education has been a challenging and overwhelming journey, and I am so grateful that I was given this opportunity. It has been a great experience and I look forward to seeing what the future will bring.

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Mina släktingar, för trevliga sammankomster och glada tillrop.

Johan, min man. Du är 'solid as a rock' och mitt största stöd. Tack för att du, Ida och Felix hjälper mig att komma ihåg vad som är viktigt i livet!

Detta doktorandprojekt har genomförts inom ramen för Centre for Ageing and Supportive Environments (CASE) vid Lunds universitet, finansierat av Forte, Forskningsrådet för hälsa, arbetsliv och välfärd. Delstudierna i doktorandprojektet har finansierats av: Vetenskapsrådet (VR), Konung Gustav V:s och Drottning Victorias Frimurarestiftelse, Ribbingska Minnesfonden, Formas, Norrbacka-Eugeniastiftelsen, Stiftelsen Promobilia, Neuroförbundet samt Gun och Bertil Stohnes stiftelse. Under lärandeprocessen har jag haft stöd av Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH), finansierat av Formas.

## Svensk sammanfattning

En stödjande miljö är centralt för att kunna upprätthålla ett självständigt liv och effektivt aktivitetsutförande, särskilt med ökande ålder. För personer med funktionella begränsningar, som konsekvenserna av en ryggmärgsskada, är balansen mellan personens funktionella kapacitet och miljöns krav av yttersta vikt för att kunna leva ett så välfungerande liv som möjligt. Livslängden efter en ryggmärgsskada har ökat dramatiskt sedan mitten av 1940-talet, även om den fortfarande är kortare än för befolkningen i allmänhet. Detta speglar både den ökande livslängden hos befolkningen i stort, och utvecklingen av akut omhändertagande, rehabilitering och vård av ryggmärgsskadade. Trots detta var det inte förrän under 1980-talet som personer med ryggmärgsskada började uppnå hög ålder i större utsträckning än tidigare. Ett övergripande syfte både i rehabilitering och arbetsterapi är förbättrad delaktighet, där olika miljöfaktorer kan stödja eller komplicera aktivitetsutförande. Bostadsanpassningar och hjälpmedelsförskrivning är vanliga metoder i arbetsterapeuters yrkesutövning, för att övervinna eller kompensera för funktionella begränsningar i utförandet av dagliga aktiviteter. Även om ryggmärgsskada är ett väl dokumenterat tillstånd och att åldras med en ryggmärgsskada är ett prioriterat forskningsfält, finns det fortfarande viktiga aspekter att belysa. Miljöns betydelse för hälsa och välbefinnande är väl känd, men kunskap om hur situationen ser ut för äldre med ryggmärgsskada avseende stödjande och tillgängliga miljöer är otillräcklig. Inte minst arbetsterapeuter behöver mer vetenskapligt stöd för sina interventioner för att äldre personer som levt länge med ryggmärgsskada ska kunna få så bra insatser som möjligt.

Det övergripande målet med avhandlingen var att beskriva tillgängligheten i bostaden och samband med delaktighet bland äldre som levt länge med ryggmärgsskada, i södra Sverige. Ytterligare ett mål var att fördjupa kunskapen om bedömningar av tillgänglighet i bostaden.

De fyra delstudierna i avhandlingen baserades på utvalda grunddata från Swedish Aging with Spinal Cord Injury Study (SASCIS), som är en longitudinell studie som riktar sig mot personer över 50 år som levt minst 10 år med ryggmärgsskada. Syftet med SASCIS är att öka kunskapen om hur det är att vara äldre och ha levt länge med ryggmärgsskada ur olika perspektiv. De 123 deltagarna rekryterades genom Rehabiliteringsmedicinska kliniken på Skånes Universitetssjukhus. Datainsamlingen skedde genom intervjuer och bedömningar under hembesök utförda av mig och S. Jörgensen 2011-2012.

Bostadsanpassningar och miljöhinder i bostaden var vanligt förekommande, och förekomsten tycks vara vanligare ju större skadans omfattning är. En majoritet av deltagarna uppfattade sin delaktighet som tillräcklig, vilket är positivt med tanke på skadeomfattningen över lag, likväl var fler tillgänglighetsproblem associerade med

en lägre nivå av upplevd delaktighet och fler delaktighetsproblem. Tillgängligheten i bostaden påverkar således delaktighet och har alltså inte enbart med den fysiska miljön att göra. Detta visar på vikten av en tillgänglig bostad, både ur ett tillgänglighets- och delaktighetsperspektiv.

Bostadsanpassningar och användning av förflyttningshjälpmedel visade sig hota reliabiliteten, innehålls- och begreppsvaliditeten i bedömningsinstrumentet Housing Enabler (HE), med vilket man kan bedöma tillgängligheten i bostaden. Höj- och sänkbara/knäfria funktioner, fjärrstyrda funktioner, hissar på andra ställen än i entrén samt taklyftar var de bostadsanpassningar som påverkade de psykometriska egenskaperna i instrumentet mest. Även användningen av rollator och elrullstol utgjorde hot mot de psykometriska egenskaperna, trots att instrumentet tar hänsyn till detta. De simulerade analyser som gjordes för att kontrollera begreppsvaliditeten visade på liten påverkan på tillgänglighetspoängen på gruppnivå, men väsentlig påverkan i enskilda fall. Bostadsanpassningar var det som vållade mest svårigheter i bedömningssituationen, men användandet av förflyttningshjälpmedel var det som påverkade poängsumman i instrumentet mest. Både bostadsanpassningar och användning av förflyttningshjälpmedel är vanligt förekommande såväl bland äldre med långvarig ryggmärgsskada som bland äldre med komplexa funktionella begränsningar på grund av andra diagnoser. Ytterligare optimering av HE är nödvändigt för att fånga relationen människa/miljö (P-E fit) i populationer med specifika karakteristika.

De vanligast förekommande bostadsanpassningarna var ramp vid entrén, knäfri spishäll och taklyft i sovrummet. Dessa resultat speglar de komplexa kombinationer av funktionella begränsningar äldre med ryggmärgsskada har, och de vanligaste bostadsanpassningarna skiljer sig något från befolkningen i allmänhet. Ramp i entrén är dock en vanlig anpassning både i Sverige i allmänhet och internationellt. Tillgänglighetsproblemen var betydande, särskilt i entréer, kök och badrum, trots att detta är de ställen i bostaden där bostadsanpassningar är vanligast förekommande. Hyllor/väggskap högt placerade i köket, nivåskillnad till förrådsutrymme, samt avsaknad av stödhandtag i hygienutrymme var de miljöhinder som genererade mest problem. Otillgänglig placering av föremål (ex. brevlåda, skåp, hyllor) och funktioner (ex. olika sorters reglage) var återkommande miljöhinder i hela bostaden och påverkade i stort sett alla deltagarna, trots att vanligt förekommande bostadsanpassningar riktade sig mot sådana miljöhinder. Omfattningen och den utbredda förekomsten av miljöhinder tyder på att tillgänglighetsstandarden i bostäderna inte motsvarar de behov äldre med ryggmärgsskada har. Tidigare forskning har visat att detta även gäller äldre i allmänhet och visar på behovet av förbättrad tillgänglighet, för att möta behoven i den åldrande befolkningen. För att minska behovet av individuella lösningar som bostadsanpassningar, bör man både vid renovering och nybyggnation sträva efter att utforma bostäderna så att de fungerar för alla i så stor utsträckning som möjligt.

Sammanfattningsvis visar resultaten att tillgängligheten i bostaden är relaterad till delaktighet och inte enbart rör den fysiska miljön. Därför är det viktigt med långsiktiga uppföljningar av bostadsanpassningar för att upprätthålla bästa möjliga förutsättningar, både för tillgängligheten och andra aspekter av hälsa. Tills det finns rekommendationer för hur man ska hantera bostadsanpassningar och användning av förflyttningshjälpmedel, bör HE användas med försiktighet i populationer där detta är vanligt förekommande, och noggrann dokumentation av anpassningar och hjälpmedel rekommenderas. Kök, entréer och hygienutrymmen är komplexa ur tillgänglighetsaspekt, och kräver noggranna överväganden när man planerar och bedömer tillgängligheten bland äldre med ryggmärgsskada för att uppnå så god tillgänglighet som möjligt. Denna avhandling bidrar med ny kunskap som kan vara en grund för arbetsterapeuter och andra professioner när man planerar och utvärderar interventioner avseende tillgänglighet i bostaden för äldre som levt länge med ryggmärgsskada, inte minst i ett långsiktigt perspektiv.



## List of papers

This thesis is based on the following papers:

- I. Jørgensen, S., Iwarsson, S., **Norin, L.**, Lexell, J. (2016). The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results. *PM&R; Journal of injury, function and rehabilitation*, 8(7), 667-677. DOI: <https://doi.org/10.1016/j.pmrj.2015.10.014>
- II. **Norin, L.\***, Slaug, B.\*, Haak, M., Jørgensen, S., Lexell, J., Iwarsson, S. (2016). Housing accessibility and its associations with participation among older adults living with long-standing spinal cord injury. *Journal of Spinal Cord Medicine*, 40(2), 230-240. DOI: 10.1080/10790268.2016.1224541 \* Shared first authorship
- III. **Norin, L.**, Iwarsson, S., Haak, M., Slaug, B. (2018). The Housing Enabler Instrument: Assessing threats to reliability and validity. *British Journal of Occupational Therapy*. First Published June 25, <https://doi.org/10.1177/0308022618782329>
- IV. **Norin, L.**, Slaug, B., Haak, M., Iwarsson, S. (2018). Housing adaptations and housing accessibility among older adults with long-standing spinal cord injury. In manuscript.

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## Thesis at a glance

<b>Housing accessibility and participation among older adults with long-standing spinal cord injury</b>	
<b>The Swedish Aging with Spinal Cord Injury Study (SASCIS): Methodology and initial results</b>	
Aim	To describe the methodology and initial results of the Swedish Aging with Spinal Cord Injury Study (SASCIS).
Method	Cross-sectional cohort study. Interviews and assessments during home visits.
Results	Out of 795 potential participants, 184 matched the inclusion criteria and the final sample comprised 123 participants (36 women and 87 men, mean age 63 ±9 years, mean time since injury 24 ±12 years). Traumatic spinal cord injury accounted for 62%, and 31% had sustained a complete spinal cord injury (SCI). Based on the American Spinal Injury Association Impairment Scale (AIS), three SCI severity groups were formed: The Tetraplegia AIS A-C group (N=22), the Paraplegia AIS A-C group (N=41) and the All AIS D group (N=60).
Conclusion	These baseline data of the SASCIS provide a description of older adults with long-standing SCI in southern Sweden. Forthcoming studies and subsequent follow-ups will generate new insights into factors that promote good and salutary aging and minimize disability in people aging with long-standing SCI.
<b>Housing accessibility and its associations with participation among older adults living with long-standing spinal cord injury</b>	
Aim	To describe the housing situation and aspects of participation among older adults with long-standing SCI, with attention to injury severity and to examine whether and how housing accessibility is associated with aspects of participation.
Method	Interviews and assessments during home visits. Cross-sectional data from the SASCIS baseline.
Results	Housing adaptations and environmental barriers in the dwelling differed between severity subgroups. A majority of the participants perceived their participation as sufficient. More accessibility problems were associated with a lower level of participation and autonomy and more participation problems.
Conclusion	The findings can be used for optimisation of the housing and health situation of people aging with SCI.
<b>The Housing Enabler instrument: Assessing threats to reliability and validity</b>	
Aim	To investigate whether the Housing Enabler (HE) instrument adequately and validly reflects accessibility problems among older adults with SCI living in ordinary housing.
Method	Cross-sectional data utilized to qualitatively consider and review potential impact on reliability and content/construct validity of the HE in an iterative evaluation procedure. Simulated analyses adjusting accessibility problem scores were conducted to evaluate construct validity.
Results	Considerable threats to reliability and validity of the HE were identified. Adjusted accessibility problem scores showed modest overall impact on group level, however substantial in some individual cases.
Conclusion	Data collection and analyses of housing accessibility using the HE in samples characterised by frequent housing adaptations and use of mobility devices require special attention. Further optimization of the HE is necessary to capture P-E fit in populations with specific characteristics.
<b>Housing adaptations and housing accessibility among older adults with long-standing spinal cord injury</b>	
Aim	To investigate and map out current housing adaptations and accessibility problems in the dwelling, despite housing adaptations, among older adults with long-standing SCI.
Method	Descriptive design, using cross-sectional data from the SASCIS baseline. Frequency analyses of housing adaptations and ranking of environmental barriers were performed.
Results	Ramp at entrance, wheelchair accessible stove top and ceiling lift in bedroom were the most common housing adaptations. Current accessibility problems were considerable, particularly in entrances, kitchens and hygiene areas.
Conclusion	Occurrence and extent of housing adaptations are diverse and reasons for current accessibility problems require additional research. Long-term follow-up on housing adaptations would be beneficial for maintaining P-E fit over time.

## Abbreviations and definitions

Accessibility	A combination of the person's ability and the demands from the physical environment (Iwarsson & Ståhl, 2003). Accessibility refers to compliance with official guidelines and standards and comprises two components; the person and the environment. Accessibility denotes the relationship between them.
Accessibility problem score	A score generated by the Housing Enabler instrument (Iwarsson & Slaug, 2010), expressing the magnitude of accessibility problems. At the item level, the score ranges from 0 (no problem) to 4 (impossibility). The total score ranges from 0 to 1844.
Autonomy	Being able to make decisions and exercise some measure of control over how, when and in what manner activities will be conducted (WHO, 2001).
Construct validity	That the measurement instrument validly measures the construct to be measured (De Vet, Terwee, Mokkink, & Knol, 2011).
Content validity	Whether the items in an instrument are sufficient to cover the domain of interest, without any irrelevant items (Streiner, Norman, & Cairny, 2015).
Dwelling	Residence, place of living.
ETA	Ecological Theory of Aging (Lawton & Nahemow, 1973).
Environmental component	One of the components of accessibility, that is, the demands of the physical environment (Iwarsson & Ståhl, 2003).
Functional limitation	Restricted capacity to perform basic general acts that are part of many composite activities (Nagi, 1991).
Functional profile	A specific, individual combination of functional limitations at individual or group level (Slaug, Schilling, Iwarsson, & Carlsson, 2011).
Housing adaptation	An individually tailored alteration to a dwelling to facilitate independence and the performance of daily activities. This terminology is used in Sweden, where housing adaptation grants are regulated by the

	Housing Adaptation Act (Lag (2018:222) om bostadsanpassningsbidrag). In other national contexts, the term home modification is commonly used.
Housing Enabler, HE	An instrument for rating/screening and analysing accessibility problems among adults in ordinary housing (Iwarsson & Slaug, 2010).
ICF	International Classification of Functioning, Disability and Health (WHO, 2001).
Mobility devices	Assistive devices to move around, in this thesis mainly rollators and powered wheelchairs.
OT	Occupational therapist
Older adult	In this thesis, a person aged 50 or older.
Participation	Involvement in a life situation (WHO, 2001). To take part in or become involved in an activity, which is a vital part of the human condition and experience.
Personal component	One of the components of accessibility, an individual's functional limitations and dependence on mobility devices (Iwarsson & Ståhl, 2003).
P-E fit	Person-environment fit (Lawton & Nahemow, 1973).
Reliability	To what extent an assessment is free from measurement error, to what extent true variation is detected and to what extent data obtained under similar conditions are stable and consistent, for example, across different raters (inter-rater reliability) and occasions (intra-rater reliability) (Mokkink et al., 2010).
SASCIS	Swedish Aging with Spinal Cord Injury Study (PI: J. Lexell, Lund University).
Spinal Cord Injury, SCI	Impairment or loss of motor and/or sensory function in the segments of the spinal cord due to damage to neural elements within the spinal canal (Kirshblum et al., 2011).
Universal Design	A process that enables and empowers a diverse population by improving human performance, health

and wellness, and social participation (Steinfeld & Maisel, 2012)

WHO

World Health Organization.

## Context of the thesis

This thesis in health sciences, specializing in occupational therapy, was carried out in the research group Active and Healthy Ageing at the Department of Health Sciences, Faculty of Medicine. The research group is affiliated with the interdisciplinary Centre of Ageing and Supportive Environments (CASE), at Lund University, Sweden.

The thesis is part of the research program “Home, Health and Disability along the Process of Ageing” (PI: S Iwarsson), and based on data from the Swedish Aging with Spinal Cord Injury Study (SASCIS). The SASCIS is a longitudinal study carried out within the Rehabilitation Medicine Research Group, Faculty of Medicine at Lund University, with the overall aim of generating knowledge on aging with SCI in southern Sweden (PI: Jan Lexell).



# Introduction

A supportive environment is central to maintaining an independent life and effective activity performance, especially with increasing age (Mallers, Claver & Lares, 2014). For people with functional limitations, like the consequences of a spinal cord injury (SCI), the balance between the person's functional capacity and the environmental demands is of utmost importance in order to live as well-functioning lives as possible. Life expectancy after a SCI has increased dramatically, and this reflects both the increasing life expectancy of the general population, and the development of emergency care, rehabilitation and care of SCI (Groah et al., 2012). However, life expectancy is still shorter compared to the general population (Savic & Charlifue, 2015).

An overarching aim in both rehabilitation and occupational therapy is improved participation (Law, 2002), where different environmental factors can support or complicate activity performance. As functional capacity declines with increasing age, and more time is spent at home (Gitlin, 2003), accessible housing is essential to enable effective activity performance throughout life. Housing adaptations and provision of assistive devices are important components of occupational therapy practice, in order to overcome or compensate for functional limitations. Despite the fact that SCI is a well-documented condition and aging with SCI is a prioritised research area, there are still important aspects that deserve attention. Research has shown that the physical environment is crucial for health and well-being as people age (Wahl, Schilling, Oswald, & Iwarsson, 2009), nevertheless, knowledge of the situation in this respect for older adults with long-standing SCI is insufficient.

Two doctoral theses have recently provided knowledge on adults with SCI in a Swedish context: one focusing on the person from medical and psychosocial perspectives (e.g. secondary health conditions, physical activity, life satisfaction) (Jørgensen, 2017), and the other on participation in everyday life (Lundström, 2015). The individual and occupation are central in occupational therapy, and the physical environment where activity takes place is a vital component also deserving research attention.

In this thesis, I will describe the housing accessibility situation and its associations with participation among older adults who have lived a long time with the consequences of SCI.





# Background

## Spinal cord injury

Acquiring a SCI is a dramatic, life-changing event most likely to result in altered body functioning in various ways. Contemporary SCI rehabilitation and treatment have their origins in the 1940s during the Second World War, when Guttmann started a structured SCI unit at the Stoke-Mandeville Hospital, in the United Kingdom (WHO, 2013). Before that, surviving with SCI more than a few weeks was not very likely. The early mortality rates of 80% within a few weeks from injury declined over time (WHO, 2013). However, it was only in the 1980s that people with SCI began to reach older ages to a greater extent than before (Savic & Charlifue, 2015), and today it is possible to lead a long life despite severe disability.

A SCI is the result of damage to the vertebra and spinal cord, and the extent of the consequences vary greatly. The spinal cord runs through the vertebra, and is the major link for sensory and motor information between the brain and the body. Every year globally, 250,000-500,000 people sustain a SCI (WHO, 2013). Traumatic SCI (TSCI), is the most common cause, acquired through abrupt force to the spinal cord, where falls and traffic accidents are the leading causes (NSCISC, 2018; WebRehab Sweden, 2017). In 2017, 294 people in Sweden sustained a SCI (55% TSCI), and the prevalence of TSCI in Sweden was estimated at 5,000 individuals in 2006 (Holtz & Levi, 2006). A non-traumatic SCI (NTSCI), is the result of internal damage to the spinal cord region, generally caused by infection, inflammation or a tumour (WebRehab Sweden, 2017; WHO, 2013). As there are fewer studies on NTSCI incidence in general, incidence rates are difficult to estimate. As people live longer there is an increased risk of ill health and falls, trending towards a higher average age at onset, and a higher number of NTSCI (WHO, 2013, WebRehab Sweden, 2017).

The extent of disability depends on the level of the lesion and severity of injury. Tetraplegia refers to damage to cervical segments of the spinal cord and affects both the upper and lower body and the trunk. Paraplegia refers to damage to thoracic, lumbar or sacral segments of the spinal cord and affects the lower body and to various degrees, the trunk. The severity (completeness) of injury is often classified according to the ASIA (American Spinal Injury Association) Impairment Scale (AIS), comprising five categories (Kirshblum et al., 2011), see Table 1.

**Table 1.**

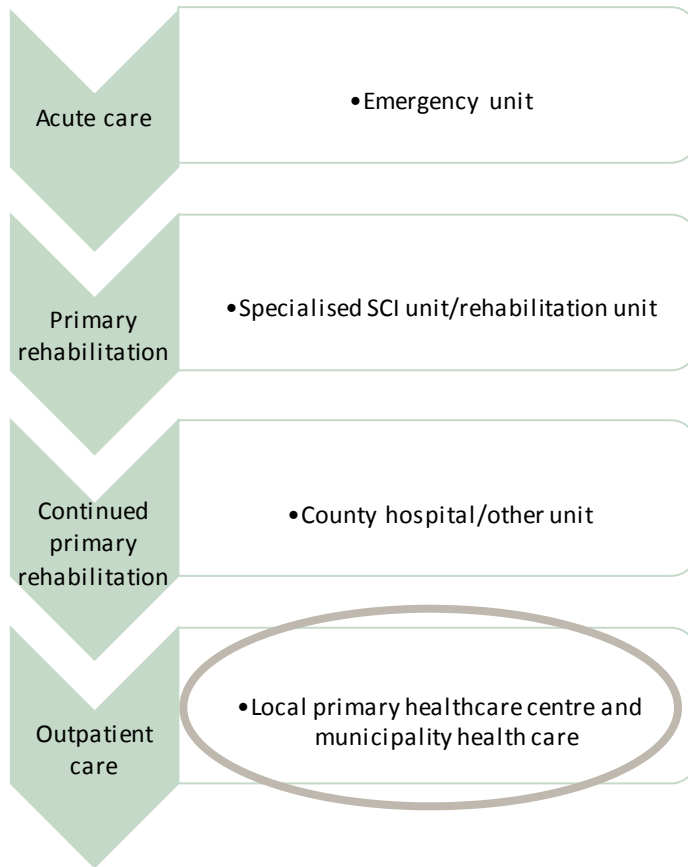
Classification of spinal cord injury according to the American Spinal Injury Association Impairment Scale (AIS)

Classification	Extent of injury
AIS A	Complete injury with no motor or sensory function below the level of injury
AIS B	No motor function but limited sensory function below the level of injury
AIS C	Limited motor and sensory function below the level of injury
AIS D	Limited motor function with muscle function with some strength below the level of injury
AIS E	Insignificant neurological constraints

Estimated life expectancy is reduced as compared to the general population, due to higher mortality rates among people with severe SCI and those injured at older ages (DeVivo, 2012, Groah et al., 2012). Figures available vary between estimated life expectancy of 50-88 % for TSCI, compared to the general population (Chamberlain, Meier, Mader, von Groote, & Brinkhof, 2015). The most common causes of death are respiratory and cardiovascular diseases, and malignancies (Savic & Charlifue, 2015).

## SCI and rehabilitation

SCI is a relatively rare diagnosis, and the complexity of the condition imposes high demands on healthcare services and requires a well-functioning care chain. The acute SCI care is provided at an emergency healthcare unit, after which primary rehabilitation takes place, mainly at one of the six specialised SCI units in Sweden. Continued primary rehabilitation takes place either at a specialised SCI unit or at a county hospital, depending on where the injured person resides. After discharge from acute care and primary rehabilitation, life-long follow-up at a specialised SCI unit is provided. Besides this, the long-term outpatient care is delivered by general healthcare services at the local primary healthcare centre and through the municipality health care. Older adults with long-standing SCI are found in the final phase of the care chain, and as they are in focus in this thesis, I will only briefly describe the previous phases. The SCI care chain is illustrated in Figure 1.



**Figure 1.**

The care chain after spinal cord injury with the different steps in the rehabilitation process and main care provider/s.

When the acute care is over, an intense phase of primary rehabilitation will follow. The exact forms of rehabilitation varies between rehabilitation units but works in a largely similar way. An interdisciplinary team-work is usually the core of the rehabilitation process (Lexell & Brogårdh, 2015), which is based upon the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The ICF is a framework for organizing and documenting information on functioning and disability, used as an international language to describe disability. According to the ICF, functioning and disability are results of the interaction between health conditions of a person and contextual factors (i.e. environmental and personal factors). The umbrella term disability includes impairments (i.e., problems in body functions or structures), activity limitations (i.e., difficulties in executing activities) and participation restrictions (problems experienced in involvement in a life situation). Personal factors make up a persons' life and living, such as social

background, gender and lifestyle. Environmental factors constitute the physical, social and attitudinal environment, which can facilitate or hinder functioning.

The rehabilitation process can be described in four steps: assessment, goal setting, interventions and outcome measures, which are coordinated into a rehabilitation plan (Lexell & Brogårdh, 2015). As the ICF provides a common language and classifications it is often used to facilitate the rehabilitation process and plans. Common professions in an interdisciplinary rehabilitation team are for example a physician, nurse, staff nurse, occupational therapist (OT), physiotherapist, social worker and psychologist. Occupational therapy interventions during primary rehabilitation is mainly aiming at educating and retraining performance of ADL, improving tolerance for activities and preventing complications (Mulcahey, Talero-Cabrejo, Kern, Horley, Koch, & Rude, 2015). Who is responsible for specific tasks like wheelchair testing and driving skills training, the OT or the physiotherapist, varies between rehabilitation units. An important step in the rehabilitation process is planning the discharge and return to the home, where a housing adaptation is often a prerequisite, and contact with the OT in the home municipality is usually initiated at an early stage.

SCI is a well-documented condition and the effects of aging with SCI is a prioritised research area (van Middendorp et al., 2016). As aging with SCI has become more common (Groah et al., 2012), longitudinal studies following people with SCI have been carried out for decades (Krause, Clark, & Saunders, 2015, Savic & Charlietue, 2010). The results from currently ongoing large-scale studies are capturing several aspects of what it is like to live with SCI. For example, the Dutch multicentre research program ALLRISC, is addressing inactive lifestyle and its consequences (van der Woude et al., 2013). The International Spinal Cord Injury Survey (InSCI), is a world-wide survey on community-dwelling people with SCI, focusing on the experience of living with SCI (Gross-Hemmi et al., 2017). The Swiss Spinal Cord Injury Cohort Study (SwiSCI) is a comprehensive cohort study in Switzerland focusing on functioning, health and quality of life of individuals with SCI (Post et al., 2011). However, these studies do not focus specifically on older adults.

## Being an older adult with long-standing SCI

Among the general population, body functions peak at about 25 years of age, and then start to decline by approximately with 1% a year (Frontera & Molett, 2017). There is evidence of premature aging after SCI (Frontera & Molett, 2017; Holtz & Levi, 2006), meaning individuals with SCI may experience age related decline earlier than the general population (Kemp, Adkins, & Thompson, 2004, Thompson & Yakura, 2001). Also, the age related physical decline may have

disproportionately negative consequences as the body's reserve capacity may have been used to a great extent in the initial stage of recovery at time of injury (Holtz & Levi, 2006; Savic & Charlifue, 2015).

As an older adult with long-standing SCI, you face several age-related changes. Research proposes five categories of change, namely: the effects of living with a long-standing SCI; secondary complications of the original injury; pathological processes unrelated to SCI; degenerative age-related changes, and environmental factors (McColl, Charlifue, Glass, Savic & Meehan, 2002).

The effects of living with a SCI for a long time may cause shoulder deterioration, chronic bladder infections or postural problems (McColl et al., 2002). Common secondary complications after SCI are pain, spasticity, and bowel- and bladder-related problems (Frontera & Molett, 2017). Older adults with SCI are not exempt from other chronic diseases (Mc Coll et al., 2002), and there is an increased risk of depressive symptoms after SCI, where longer time since injury is a risk factor (Krause et al., 2015). Common age-related health complications are osteoporosis, pressure sores, and cardiovascular disease (Frontera & Molett, 2017; Holtz & Levi, 2006). The frequency of such complications tend to increase with longer duration SCI (Frontera & Molett, 2017).

More or less all daily activities contribute to the cumulative stress of the body in people with SCI, and decrease in physical independence and increased need for physical assistance is likely to occur at an earlier stage than in the general population (Savic & Charlifue, 2015). Shoulder pain, weakness and fatigue are the most common reasons for needing more physical assistance (Savic & Charlifue, 2015). Loss of physical independence and inaccessible environments may limit the possibilities of active social participation, although appropriate interventions may prevent, delay or minimise negative effects of aging (Savic & Charlifue, 2015). Older adults with SCI generally report lower levels of well-being (Krause et al., 2015). Despite that, recent Swedish research (Jørgensen, 2017) showed low presence of probable depression and above average satisfaction with life among older adults with long-standing SCI.

Regardless of this body of research, there are still important aspects that deserves attention. Exposure to the surrounding environment is a common denominator for all people, and we are all affected by the environment at all times (Noreau, Fougeryrollas, & Boschen, 2002). Research has shown that the physical environment is crucial for health and well-being across the lifespan (Wahl et al., 2009). The environment is a broad concept, according to occupational therapy literature, with various dimensions (sociocultural, economic, political, virtual, physical) which all influence our occupational performance (Bass, Baum & Christiansen, 2015). Knowledge about how the physical environment impacts the life situation of older

adults with SCI is scarce, and when it comes to specific parts of the physical environment, like housing accessibility, research is virtually non-existent.

### **Older adults with SCI and occupational therapy**

Even if specialised follow-up is provided, once in a stable phase after rehabilitation it is the local healthcare services (primary healthcare and the municipality health care) that mainly serve as the outpatient care provider (see Figure 1). Older adults with long-standing SCI benefit from the competence at the specialised units when needed, but are in their everyday life referred to the local professionals. This puts high demands on the competences of the local professionals. In the outpatient phase, occupational therapy for older adults may target performance and engagement in instrumental activities of daily living such as community mobility and activities related to home, and resuming roles within different arenas like family life, leisure and work (Mulcahey et al., 2015). One core focus in occupational therapy is to enable everyday living (Bass et al., 2015), where environmental factors, facilitating or hindering activity performance, are of major concern (Mulcahey et al., 2015). As an OT in the municipality or primary healthcare you meet clients of different ages and stages of life with a rich diversity of functional limitations. Although practice guidelines for management of SCI are available (Mulcahey et al., 2015), seeing that SCI is one of many rare conditions, the possibilities of specialised knowledge on SCI are limited.

Recent research has shown that older adults with long-standing SCI are relatively physically independent (Jørgensen, 2017). Participation in everyday activities is prioritised due to personal and environmental factors, and can change over time in relation to time since injury (Lundström, 2015). Even small changes in functioning can have far-reaching consequences for performance and engagement in everyday life (Thompson & Yakura, 2001). Moreover, the interaction with the surrounding physical and social environment considerably impacts disability of people with SCI (Molton & Jensen, 2010; Kemp et al., 2004).

Still, it is largely unknown what to expect of daily life as an older adult with long-standing SCI when it comes to environmental challenges in the dwelling. What environmental barriers that are common to encounter as an older adult with SCI is valuable information both to the person and on a societal level in planning housing provision or housing adaptations. The lack of research regarding SCI and housing accessibility is of great concern. If OTs in primary healthcare and the municipalities are to provide efficient interventions for older adults with SCI, more research in this area is needed.

## **Older adults with long-standing SCI, participation and environmental factors**

Enhancing participation is another central focus in occupational therapy (Law, 2002), an important goal in rehabilitation (Heinemann, 2010) and has been found to reduce the risk of mortality related to SCI (Krause et al., 2015). There are several definitions of participation. In a systematic review Imms and colleagues (2015) investigated how researchers defined participation in intervention research, and found that attendance and involvement were core concepts. This is also recognised in WHO's well-known and frequently used definition "involvement in a life situation" (WHO, 2001), which is the definition chosen for this thesis. More specifically, participation is a complex construct embracing different aspects, such as family role, interaction with others and autonomy (literally meaning "self-rule"). Autonomy is crucial for the implementation of participation (Cardol, De Jong & Ward, 2002). Providing aging individuals with an appropriate environment and opportunities that can strengthen autonomy and participation are of interest in improving their situation. In this context accessible housing environments are important in order to support autonomy and participation in later life in the general population, (Cardol et al., 2002; Haak, Fänge, Iwarsson & Dahlin Ivanoff, 2007; Oswald et al., 2007) as well as in sub-groups with specific diagnoses. For older adults with SCI, attaining a life characterised by autonomy, independent activities and participation may be particularly challenging. For example, a study on SCI users of powered mobility devices found that objective accessibility problems at entrance doors were significantly associated with restrictions in autonomy (Pettersson, Brandt, Lexell, & Iwarsson, 2015). Without mentioning any specific environmental arena, another study asserted that the physical environment is perceived as limiting participation by people with SCI (Chaves, Boninger, Cooper, Fitzgerald, Gray, & Cooper, 2004). Yet, a previous literature review found only weak and in part conflicting evidence of environmental impact on participation in this sub-group of the population (Reinhardt & Post, 2010). Consequently, additional studies are needed to explore environmental impact, housing accessibility and participation among older adults with SCI.

## **Understanding the interaction between the person and the environment**

Over time, a number of theories and models addressing person-environment transactions have been developed. The concept of occupational performance is central in occupational therapy, and always takes place in an environmental context (Baum, Bass & Christiansen, 2015). Theories, models and frameworks serve as a



cornerstone in research, and a tool for systematic information gathering, explanation and development (Bengtson & Settersten, 2016; Baum et al., 2015), and has a vital role within occupational therapy practice and research. Models within occupational therapy have some common characteristics, influenced by theories at the environment level, and all include the person, the environment and occupation in different ways. I will briefly describe the most common model used within occupational therapy to give an overview of the differences and similarities between them.

The Model of Human Occupation, MOHO (Kielhofner, 2008) is one of the most common models used, and is a person-centred model of occupational performance that conceptualises how individuals choose and create patterns and perform occupations meaningful to them (i.e., participation). This process of participation is supported by volition, habituation and performance capacity. It was designed to organise concepts to guide occupational therapy practice. In the Canadian Model Enabling Occupation, CMOP-E, (Townsend & Polatajko, 2007), occupational performance is explained as the result of the interaction and interdependence between the person, the environment and the person's occupations, and puts the person in a social environmental context. The Person-Environment-Occupation-Performance model, PEOP (Christiansen et al., 2005) was conceived to guide occupational therapy practice. The model focuses on the person's characteristics and his/her living environment. The understanding of how the person and the environment interacts to effect occupational performance is the core in both the model and occupational therapy practice.

Different models serve different purposes and elucidate the core concepts to different degrees. Focusing on the physical environment and its meaning for accessibility and participation, this thesis project is grounded in environmental theory. Although the aforementioned models are very prominent within occupational therapy, one of the environmental theories that has influenced occupational therapy, the Ecological Theory of Aging (ETA) (Lawton & Nahemow, 1973) will serve as the framework for this thesis.

## **The Ecological Theory of Aging**

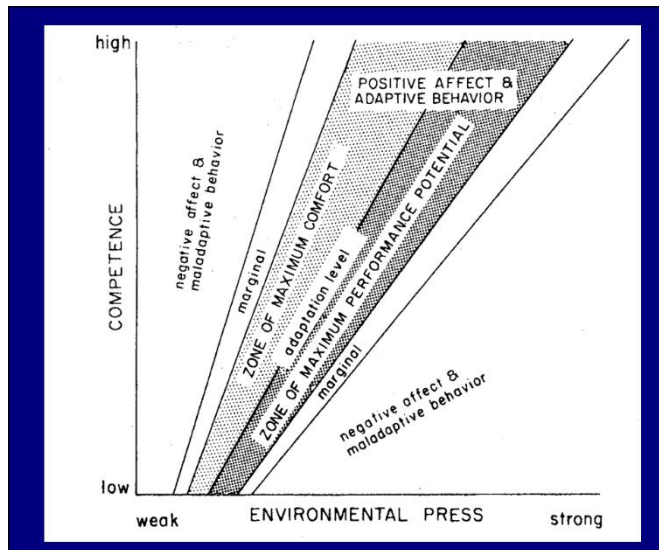
The ETA is considered classic work and the foundation of other theories (Wahl & Oswald, 2016), also known as the competence-press model or the person-environment fit (P-E fit) model, originally targeting older adults, especially vulnerable individuals (Scheidt & Norris-Baker, 2003). In the ETA, the environment is not restricted to the physical environment, but means the environment at large (socially, economically etc.). By contrast, in the context of this thesis the physical environmental dimension is in focus. More specifically, I focus

on the dwelling and immediate surroundings as this is where older people spend the majority of their time (Wahl & Oswald, 2016).

The ETA highlights the influence the environment has on human behaviour. The person holds a set of personal *competences* (biological health, sensory and motor skills, cognitive function). The environment affects the person through demands or supporting qualities, that is, *environmental press*. The greater the competence a person holds, the greater environmental press can be managed. A balance between the person and the environment (i.e., P-E fit) can be achieved by altering one or both of the components. An environment that exceeds the competence just a little (the zone of maximum performance potential, Figure 2) may encourage development also in old age (Wahl & Oswald, 2016). As an illustration of the ETA; a low kitchen worktop may be considered an obstacle for convenient cooking for people in general. A way to improve the conditions would be to complement the worktop with a table of suitable height or to sit down while working, and thereby decrease the environmental demand. Another option would be to engage in physical exercise aiming to increase strength and range of motion to improve the person's capacity. A low kitchen worktop is usually an obstacle for people in general, while it may be a prerequisite for performing household chores for a wheelchair dependent person. The same environmental demand holds different implications depending on the capacity of the person, and emphasises the important interplay between the person and the environment.

The ETA includes the environmental docility hypothesis (Lawton & Simon, 1968), which suggests that with decreased competence the individual is more likely to be controlled by environmental factors. That is, the lower the competence of the individual, the more vulnerable s/he is to environmental press. Older adults with long-standing SCI experience decreased competence both due to the SCI itself and the aging process. According to the docility hypothesis, they are thus more vulnerable to environmental press than older people in general. The need for a housing adaptation is an indication of an imbalance in P-E fit, and a confirmation of the docility hypothesis.

As the ETA has been around for a long time, it has also gained some criticism over the years, not the least from Lawton himself (Lawton, 1985). Aging is an ongoing process, and a weakness of the ETA is the lack of the time perspective, as personal competence and environmental press can change over time (Lawton & Nahemow, 1973). Another limitation is the lack of the view on the environment as a supportive resource and not only creating demands, something Lawton did address in his later work through the concept of 'environmental proactivity' (Lawton, 1989). A housing adaptation can be seen as a way to implement proactivity by providing resources for overcoming disability.



**Figure 2:**  
 The competence-press model (Lawton & Nahemow, 1973, p 661). Copyright © 1973 by the American Psychological Association (APA). Reprinted with permission from the APA

## Accessibility

Environmental press can be represented by physical environmental barriers in the home and its immediate surroundings. These constitute an objectively observable factor that can be assessed based on national standards and guidelines for good housing design. With Lawton and Nahemow’s ecological model and the docility hypothesis as the theoretical base, a well-cited definition of accessibility describes it as the relationship between the person’s functional capacity and the demands of the physical environment (Iwarsson & Ståhl, 2003; Lawton & Nahemow, 1973). That is, the concept describes the interaction of a personal and an environmental component, both objectively assessed on the basis of detailed instructions and criteria (Iwarsson et al., 2012; Iwarsson & Ståhl, 2003).

As the design of the physical environment is important in order to facilitate meaningful and independent activities in people with SCI, accessible housing may be critical to independently managing everyday life (Chaves et al., 2004).

## **Assessment of the housing environment**

To ensure accessibility, there is a need to survey the environment for environmental barriers related to the functional capacity of the individual or a group. To generate valid housing accessibility data per definition (Iwarsson & Ståhl, 2003), it is crucial to refer to specified standards for housing design according to available national guidelines. There are several assessment instruments which address or incorporate the environment in different ways (Fougeyrollas 1995; Gray, Hollingsworth, Stark, & Morgan, 2008; Keysor, Jette, & Haley, 2005;). Those assessing housing environments often focus on safety (Chandler, Duncan, Weiner, & Studenski, 2001; Chiu et al., 2006; Fisher et al., 2008;), a specific diagnosis (Gitlin, Schinfeld, Winter, Corcoran, Boyce, & Hauck, 2002) or are based on self-report (Fougeyrollas, 1995; Gray et al., 2008; Keysor et al., 2005; Sanford, Pynoos, Tejral, & Browne, 2001). It is worth noting that there is a lack of generally accepted instruments (Whiteneck & Dijkers, 2009) for standardized housing assessments (Chibnall, 2011). Instruments addressing the physical home environment objectively are few, but they are nevertheless important tools for OTs.

### *Reliability and validity*

Reliability and validity is crucial for the applicability and credibility of an assessment instrument. Reliability is a broad concept, and main aspects of concern are to what extent an assessment is free from measurement error, to what extent true variation is detected, and to what extent data obtained under similar conditions are stable and consistent, across different raters (inter-rater reliability) and occasions (intra-rater reliability) (Mokkink et al., 2010). An instrument can be generic with a wide target group, or specific for a certain diagnosis, depending on what it is intended to capture. The target population is very important as the heterogeneity of the population influences the reliability parameters (De Vet et al., 2011). Hence, the reliability of an instrument may be jeopardized when used in a different population to the original target population.

Validity refers to to what extent an instrument captures the construct/s it intends to measure (Mokkink et al., 2010). There are different types of validity, and relevant for this thesis are content validity and construct validity. Content validity addresses whether the items in an instrument are sufficient to cover the domain of interest, without any irrelevant items (Streiner et al., 2015). Construct validity is provided by hypothesis testing based on the underlying construct, to determine whether the instrument validly measures the construct it purports to measure. (De Vet et al., 2011).

### *The Housing Enabler instrument*

The Housing Enabler (HE) (Iwarsson & Slaug, 2010) is a method and assessment instrument targeting housing accessibility, developed for and mainly used with older

adults. The HE is one of few research-based instruments by which a quantitative measure of P-E fit is yielded and which can be used reliably, validly and systematically by professionals, addressing accessibility in ordinary housing. By assessing whether the design of a dwelling complies with national guidelines and standards for housing design, a quantitative measure of accessibility, or P-E fit, is generated. The assessment also provides a specific, individual combination of functional limitations, a functional profile. Mobility devices are included in the personal component in the HE instrument, unlike in the ICF (WHO, 2001), where mobility devices are considered part of the environment (WHO, 2001). The reasons for inclusion in the HE is that dependence on mobility devices is a very concrete indicator of the significance of the functional limitation. Moreover, the person and the mobility device can be seen as an entity, interacting with the physical environment. People with SCI are often dependent on assistive technology in daily life, yet our knowledge of the P-E dynamics among older adults with long-standing SCI is practically non-existent.

To establish the construct validity of the HE, the instrument was based on the ETA (Lawton & Nahemow, 1973) and Swedish legislation on guidelines and standards for housing design (Svensson, 2015). The definition proposed by Iwarsson & Ståhl (2003), describing accessibility as the relationship between the individual's functional capacity and the demands generated by the design of the environment, underlies the instrument. This is in line with the ETA, including the much-cited notion of P-E fit (Lawton & Nahemow, 1973). The HE has demonstrated construct validity (Fänge & Iwarsson, 2003) and overall moderate to good inter-rater reliability (Iwarsson Nygren, & Slaug, 2005). The instrument has also been tested for inter-rater reliability in occupational therapy practice in a cross-Nordic setting, with a mean percentage agreement of paired raters exceeding 80% for both components (Helle et al., 2010). The HE has been used in research in various national contexts (Helle, Brandt, Slaug, & Iwarsson, 2011; Lien, Steggell, Slaug, & Iwarsson, 2016; Oswald et al., 2007), but until now mostly with general population samples of older adults (see e.g., Iwarsson et al., 2007; Kylén, Ekström, Haak, Elmståhl, & Iwarsson, 2014).

While the HE rests on extensive research, the reliability and validity of the instrument when used in populations with specific diagnoses of severe disabilities has not been scrutinised previously. As an instrument can only produce valid scores in the context and population it has been tested for (De Vet et al., 2011), the results of previous methodological studies on the HE may not apply for populations with specific diagnoses displaying severe disability. In such situations, additional studies are needed (Streiner et al., 2015).

## **Assistive devices and housing adaptations**

There are different ways to achieve accessibility in the physical environment for people with severe disability, for example, by providing mobility devices or adapting the housing environment. With a powered wheelchair, steep gradients and distances can be manageable, and a ramp or lift are options to access a building even if there are steps at the entrance.

Provision of assistive devices is an important component in occupational therapy practice as a means to compensate for functional limitations. In Sweden, the provision of assistive devices is mainly regulated by the Health Care Act (Hälsö- och sjukvårdslag, SFS 2017:30), the Patient Safety Act (Patientsäkerhetslag, SFS 2010:659) and the Patient Act (Patientlag, SFS 2014:821). Regions, county councils and municipalities have a shared responsibility for provision of assistive devices (Socialstyrelsen, 2017), although the exact sharing of the responsibility is not regulated by law and differs within the country. Different professions are prescribers for various assistive devices, for example, physiotherapists, nurses and occupational therapists.

A housing adaptation is an individually tailored intervention to facilitate the performance of daily activities, based on individual needs. In Sweden, housing adaptations are governed by the Housing Adaptation Act (Lag (2018:222) om bostadsanpassningsbidrag), and the municipalities have the financial and administrative responsibility for such grants. The purpose of the grant is to provide people with disabilities with the possibility of leading an independent life in their own accommodation. The applicant is responsible for the application which, apart from the formal application, is usually accompanied by a certificate stating the need for the housing adaptation, most commonly issued by an OT. Written consent by the owner of the dwelling that the interventions may be carried out is also needed. The municipality may request that the applicant complete the application with a copy of a tender/quotation or cost estimate, along with plans and layout drawings. Once an application is made, a housing adaptation grant manager at the local authority processes the application and makes the formal decision of approval or rejection. If approved, it lies with the applicant to carry out the intervention, and when finalised and approved by the applicant, the granting authority will pay out the grant. After the certification, the OT is still involved in the housing adaptation as an intervention as such, although not formally involved in the implementation, as the housing adaptation process is between the applicant and the granting authority. Once a housing adaptation is accomplished, long-term follow-up is rare, mainly because it is not obvious whose obligation this is, the OT or the granting authority (Malmgren Fänge, Lindberg, & Iwarsson, 2013).

Relevant to this thesis, housing adaptations and mobility devices intend to improve the performance of daily activities in the home for the person, and you would thus

expect the results of accessibility assessments to reflect this. As community-living people with SCI typically receive housing adaptation early on after their injury, it is largely unknown how their housing situation is after many years living with SCI, both with regard to housing adaptations and accessibility issues. This thesis contributes with new knowledge on housing accessibility, environmental barriers and housing accessibility assessments among older adults with long-standing SCI.

# Rationale

While aging with a SCI is a prioritised research area (van Middendorp et al., 2016), the physical environment and its relation to health tends to receive little attention. Previous research has indicated that despite living in countries with high housing standards and well-developed welfare systems, people with SCI experience restrictions in participation due to environmental barriers (Norin, Slaug, Haak, Jörgensen, Lexell, & Iwarsson, 2017; Reinhardt, Ballert, Brinkhof, & Post, 2016). As longevity increases among older adults with long-standing SCI (Savic & Charlifue, 2015), and more time is spent at home with increasing age (Gitlin, 2003), there is a need for increased knowledge about housing accessibility for this group.

Housing adaptations and provision of assistive devices are very common in clinical occupational therapy practice, and not the least important for OTs is receiving more scientific support for their interventions. More knowledge about the housing accessibility situation, associations between accessibility and participation, and reliable and valid accessibility assessments can be used to plan, provide and evaluate interventions to meet the needs among older adults with SCI in an optimal way.





# Aims

The overarching aim of this thesis project was to examine housing accessibility and its associations with participation among older adults with long-standing SCI in Sweden. An additional aim was to deepen the methodological knowledge on accessibility assessments.

## Specific aims

In a sample of older adults aged 50 years or older at least 10 years after SCI:

- describe their housing situation and aspects of participation, with attention to injury severity.
- examine whether and how housing accessibility is associated with aspects of participation.
- investigate whether the Housing Enabler instrument adequately and validly reflects accessibility problems in ordinary housing when used in this specific population.
- investigate housing adaptations and current accessibility problems in their dwellings.



# Method

The four studies in this thesis apply a cross-sectional design, utilizing sub-sets of the baseline data from the Swedish Aging with Spinal Cord Injury Study, SASCIS (N=123). This section starts with a description of SASCIS in terms of design, participants and data collection. After that there follows a description of the selected data and assessment instruments used in this thesis, the data management and analyses.

## Research design







### **Swedish Aging with Spinal Cord Injury Study, SASCIS**

The SASCIS is a longitudinal cohort study focusing on people aged 50 or older, at least 10 years post injury. The SASCIS is the first study of its kind in a northern European perspective, and the overarching aim is to deepen the understanding of aging with long-standing SCI in Sweden by increasing the knowledge of personal and environmental factors affecting daily life and health. The SASCIS had just started when I got involved, and I took an active part in recruiting the participants, planning and performing the data collection, creating the database and performing the data quality controls. The baseline data was collected in 2011/2012 and the first follow-up, involving 78 people (out of 101 still living) from the original study sample, was completed in October 2018 (S. Jørgensen, personal communication, November 5, 2018).

# Thesis overview

For an overview of the four studies in this thesis and how they build upon each other, see Table 2.

**Table 2.**  
Thesis overview

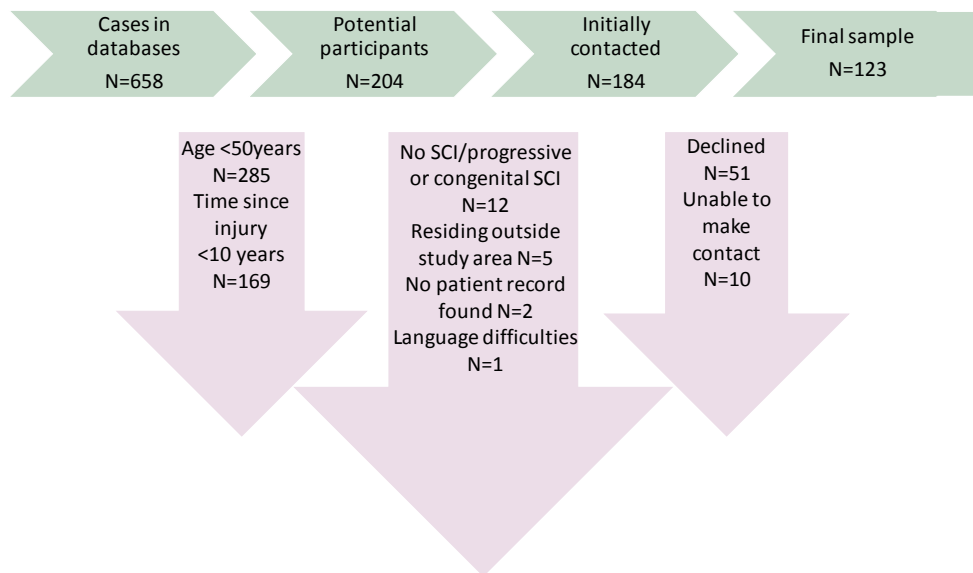
Study	Design	Data collection methods	Data analysis	Analysis objective
Baseline N=123 	Study protocol Descriptive Cross-sectional	Study-specific questionnaire Medical records	Descriptive statistics	Describing SASCIS (sample characteristics, design, data collection) <sup>a</sup> 
Participation N=123 	Descriptive Exploratory Quantitative Cross-sectional	Rater assessments by means of HE and IPA	Ordinal regressions	Describing and examining the housing situation, participation and associations between them 
Psychometric N=122 	Descriptive Quantitative Exploratory Psychometric	Rater assessments by means of HE; field notes	Iterative evaluation procedure, analytic statistics	Identifying and evaluating potential threats to validity and reliability of HE in a SCI sample context 
Accessibility N=122	Descriptive Quantitative Cross-sectional	Rater assessments by means of HE; field notes	Descriptive and analytic statistics	Investigating the housing accessibility situation applying lessons learned from the Psychometric Study

<sup>a</sup> In this thesis, the findings of the Baseline Study is part of the Method section, i.e. Participants and Table 3.

## Participants

Participants were recruited through the clinical databases at the SCI Unit at Skåne University Hospital, Sweden. The recruitment included all former patients who had been in contact with the SCI unit during the past four decades at the time of recruitment (2011). Main inclusion criteria were being 50 years of age or older and having a traumatic or non-traumatic SCI for at least 10 years. There were several motives for the main inclusion criteria 50 years of age or older. The lower age limit of 50 years captured the initial phases of age-related decline, rendered the possibility of recruiting a larger sample and allowed the participants to both participate and have the possibility to benefit from longitudinal studies. All aetiologies of SCI were of interest, and a stable post-injury phase was desired. Further requirements were understanding oral and written information in Swedish, and being resident in the southern part of Sweden. The hospital databases comprised a total of 795

individuals, whereof 658 still living. A total of 184 individuals matched the inclusion criteria and were invited to participate in the study. The final sample consisted of 123 individuals (67% response rate). A flow chart of the recruitment procedure is presented in Figure 3.



**Figure 3.**  
The recruitment procedure for SASCIS

In the SASCIS baseline sample, men were in the majority (71%). The mean age of all participants was 63 years (50-89), and they were on average 39 years old (7-74) at the time of injury. The mean time since injury was 24 years (10-56). A majority had sustained a TSCI (62%), and the most common cause was transport-related accidents. A vast majority used some form of mobility device indoors (76%) and/or outdoors (88%). The motor and sensory impairment of the SCI were classified according to the American Spinal Injury Association Impairment Scale, AIS, into one of five categories ranging from “A” (complete injury with loss of motor and sensory function in the sacral segments) to “E” (normal neurological function) (Kirshblum et al., 2011). Thereafter, the sample was divided into three SCI severity groups: i) Tetraplegia AIS A-C (N=22; 15 AIS A, four AIS B and three AIS C); ii) Paraplegia AIS A-C (N=41; 23 AIS A, eight AIS B and ten AIS C); and iii) All AIS D (N=60). The most common type of injury was Paraplegia AIS D (28%). The All AIS D group were more likely to have a NTSCI, were older at time of injury, had a

shorter time since injury and were less likely to use mobility devices. The most common functional profile in the total sample was poor balance, incoordination, limitations of stamina, difficulty in moving head, reduced upper extremity function, reduced fine motor skills, loss of upper extremity function, reduced spine and/or lower extremity function, dependence on walking aids and dependence on wheelchair. Further background data is presented in Table 3.

A drop-out analysis was conducted, showing no significant differences between the participants (N=123) and the non-participants (N=61) with respect to sex, chronological age, age at injury, time since injury, cause of injury, SCI severity and injury level.

**Table 3.**

Socio-demographics and injury characteristics among 123 older adults with long-standing spinal cord injury in southern Sweden

<b>Variable</b>	<b>N (%); mean <math>\pm</math>SD; median, min-max</b>
Sex	
Men	87 (71)
Women	36 (29)
Age (years)	63 $\pm$ 9; 63, 50-89
Age at injury (years)	39 $\pm$ 16; 38, 7-74
Time since injury (years)	24 $\pm$ 12; 22, 10-56
<i>Cause of injury</i>	
Traumatic	76 (62)
Non-traumatic	47 (38)
<i>Level and severity of injury</i>	
Tetraplegia AIS A-C	22 (18)
Paraplegia AIS A-C	41 (60)
All AIS D	60 (49)
Co-habiting	61 (50)
Use of assistance	83 (67)
<i>Use of mobility devices indoors</i>	
Powered wheelchair	18 (15)
Manual wheelchair	60 (49)
Walking device	15 (12)
No mobility device	30 (24)
<i>Use of mobility devices outdoors</i>	
Powered wheelchair	51 (54)
Manual wheelchair	39 (32)
Walking device	18 (15)
No mobility device	15 (12)

## Data collection

Data was collected through home visits and from medical records. All of the home visits were carried out during periods of time between May 2011 and December 2012, by myself together with a licensed physician, S. Jörgensen. The visits lasted approximately two hours, and we performed two or three visits a day. The home visits comprised structured interviews based on a study specific questionnaire, and four diagnosis specific and eight generic assessments. The assessment instruments were chosen so as to cover all components of the ICF: Functioning and disability: Body functions and structures, activity and participation; Contextual factors: environmental factors, personal factors. Five of the instruments were mailed to the participants prior to the home visit, and reviewed and collected at the visit, to reduce the length of the visit and the burden on the participant. I conducted all of the HE assessments. An overview of the assessment instruments is presented in Table 2.

**Table 4.**

Assessment instruments used in the Swedish Aging with Spinal Cord Injury Study (SASCIS).

Assessment instrument	Used in this thesis	Used in Jörgensen's thesis
<i>Generic</i>		
Housing Enabler (HE)	X	
Impact on Participation and Autonomy (IPA) <sup>1</sup>	X	
Craig Hospital Inventory of Environmental Factors (CHIEF) <sup>1</sup>		
15-item Geriatric Depression Scale (GDS-15)		X
Life Satisfaction Questionnaire (LiSat-11) <sup>1</sup>		
Satisfaction With Life Scale (SWLS) <sup>1</sup>		X
13-item Sense of Coherence Scale (SOC-13)		X
Wheelchair User's Shoulder Pain Index (WUSPI) <sup>1</sup>		
<i>Spinal cord injury-specific assessment instruments</i>		
Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI)		X
Spinal Cord Independence Measure, third version (SCIM III)		X
Spinal Cord Injuries Quality of Life Questionnaire (SCI QL-23)		
Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ)		X

<sup>1</sup> Assessment instruments mailed in advance

## Data and assessment instruments

### *Study-specific questionnaire*

Selected data from the study-specific questionnaire was used to describe socio-demographics, injury characteristics and housing situation.



### *Impact on Participation and Autonomy (IPA)*

Aspects of participation were assessed by using the Impact on Participation and Autonomy questionnaire (IPA), which is a generic self-evaluation assessment instrument developed in the Netherlands for adults with chronic conditions (Cardol, de Haan, van den Bos, de Jong, & de Groot, 1999). The instrument was one of the five instruments mailed in advance for self-assessment prior the home visit. The IPA is based on the ICF domain of participation and constructed to measure participation in general, not highlighting any specific dimension. The instrument is intended for use in research and to evaluate the effects of rehabilitation interventions (Cardol et al., 1999). IPA consists of 31 items in five domains (each constituting one sub-scale), with each item rated on a five-point ordinal scale (ranging from 0 = 'very good' to 5 = 'very poor'); lower scores indicate better participation (Cardol, de Haan, de Jong, van den Bos, de Groot, 2001). In addition to the domains, the IPA provides a rating of participation problems in nine areas (mobility, self-care, family role, financial situation, leisure, social relations, helping people, work and education). These problems (one item for each area) are rated on a three-point scale (from 0 = 'no problems' to 2 = 'severe problems') and treated as a separate subscale; lower scores indicate fewer problems. Based on close inspection of the content of the IPA at item level as related to the study aims for the Participation Study, we focused on two of the domains, namely autonomy indoors and family role. As for the problem ratings we also made a selection, and included six of the problem ratings, namely mobility, self-care, family role, financial situation, leisure, and social relations.

The instrument is reliable and valid in people with chronic disorders, including SCI (Cardol et al., 2001). Internal consistency and test-retest reliability are good with Cronbach's alpha >0.81 (Cardol et al., 1999, Cardol et al., 2001) and ICC between 0.83 and 0.91, and there is support for convergent and discriminant validity (Cardol et al., 2001). A Swedish version has been tested among individuals with SCI (Larsson Lund, Fisher, Lexell, & Bernspång, 2007). One item (helping and supporting other people, in the social life and relationship subscale), has been added to the original IPA, thus comprising 32 items. The current Swedish version of IPA (32 items) was used in SASCIS and has in addition been used in people with late effects of polio (Larsson Lund & Lexell, 2008).

### *Housing Enabler (HE)*


To assess environmental barriers and housing accessibility the HE was used. The HE is a scientifically established instrument for assessing and analysing housing accessibility problems (Iwarsson & Slaug, 20010; Iwarsson et al., 2012). The HE assessment results in an objective measure of person-environment fit (P-E fit) which captures accessibility problems in a systematic manner. The assessment procedure is performed by a trained rater and consists of three steps. First, the personal (P)

component of accessibility is dichotomously (present/not present) assessed, based on the occurrence of functional limitations (12 items) and dependence on mobility devices (two items) for the individual. The P component assessment results in what is called a “functional profile”. Second, in the environmental (E) component assessment 161 environmental barriers in the exterior surroundings (28 items), in the entrance (46 items) and in the indoor environment (87 items) are dichotomously assessed (present/not present) based on national guidelines and standards for housing design. Importantly, the E component assessment is administered based on observations of design features as they appear at the time of the assessment, no matter if they were part of the original design of the dwelling or the result of individual housing adaptations. In the third step the case-specific accessibility problems are calculated. The accessibility problem score in the HE is built up from two nominal scales (functional limitation present or not and environmental barrier present or not) and then juxtaposed into a new scale using a computerized scoring matrix. In each intersection between a functional limitation/dependence on mobility device item and an environmental barrier registered as present, the matrix provides predefined severity ratings (0-4). These ratings are summed to a total accessibility problem score, representing a quantification of the magnitude of accessibility problems predicted by the objective P and E component assessments. A higher score (theoretical maximum = 1,844) indicates more accessibility problems. An absence of functional limitations results in a score of zero regardless of the number of environmental barriers present. The predefined severity ratings were established by expert panels followed by subsequent revisions based on empirical results, structured rater observations and additional expert panels over a period of 20 years (Iwarsson & Slaug, 2000; Steinfeldt, 1979).

### *Field notes*

Documentation of housing adaptations were not a formal part of the study specific questionnaire, but the need to make field notes already emerged as obvious and immediate at the very first home visit. The design of the housing adaptations did not comply with the items in the assessment protocol, which made the assessment situation challenging, (see Figure 4). I felt an urge to document my observations to have the possibility to ponder on the design and the assessment afterwards. The detailed field notes contained descriptions of housing adaptations present, perceived assessment challenges and types of mobility devices used. The notes were sometimes supplemented with photographs (with permission from the participant) to support the documentation. I conducted the field notes, and as an experienced OT and trained HE rater, the details and extent of the field notes was considered adequate and of good quality. All housing adaptations and mobility devices recorded in the field notes were coded and added to the SASCIS dataset.

Lifts.	
B26. Lift does not stop at the same level as building floor (difference in level of more than 15 mm). <i>The width of the lift door is rated at B1.</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B27. Wide gap between the lift and the building floor (max. 3 cm).	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B28. Heavy doors without automatic opening.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B29. Automatic opening on swing doors.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B30. Doors that do not stay in open position or close quickly.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B31. Doors that cannot be fastened in open position (locking device required).	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B32. Lift stops abruptly.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B33. No handrail in lift.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated
B34. No seat in lift.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not rated



**Figure 4.**

Example of when the assessment protocol and assessment situation contrast. According to the Housing Enabler assessment protocol, a lift is supposed to be placed in the entrance and have the design of a 'box' with doors, that you enter. In the assessment situation, the lift might be located in the dining room, and have a platform design.

## Data management and analyses

All data were entered into a database and underwent quality control procedures to ensure that the database accurately and completely represented the data collected. The IBM SPSS Statistics for Windows, version 22 (IBM Corporation, Armonk, NY, USA), was used for the Baseline and the Participation Study. The Housing Enabler software (Veten & Skapen HB and Slaug Enabling Development, Lund and Staffanstorp, Sweden), was used for the Participation, the Psychometric and the Accessibility Studies and in addition the SAS software (SAS Institute Inc., Cary, NC, USA) version 9.4, was used for the Accessibility Study.

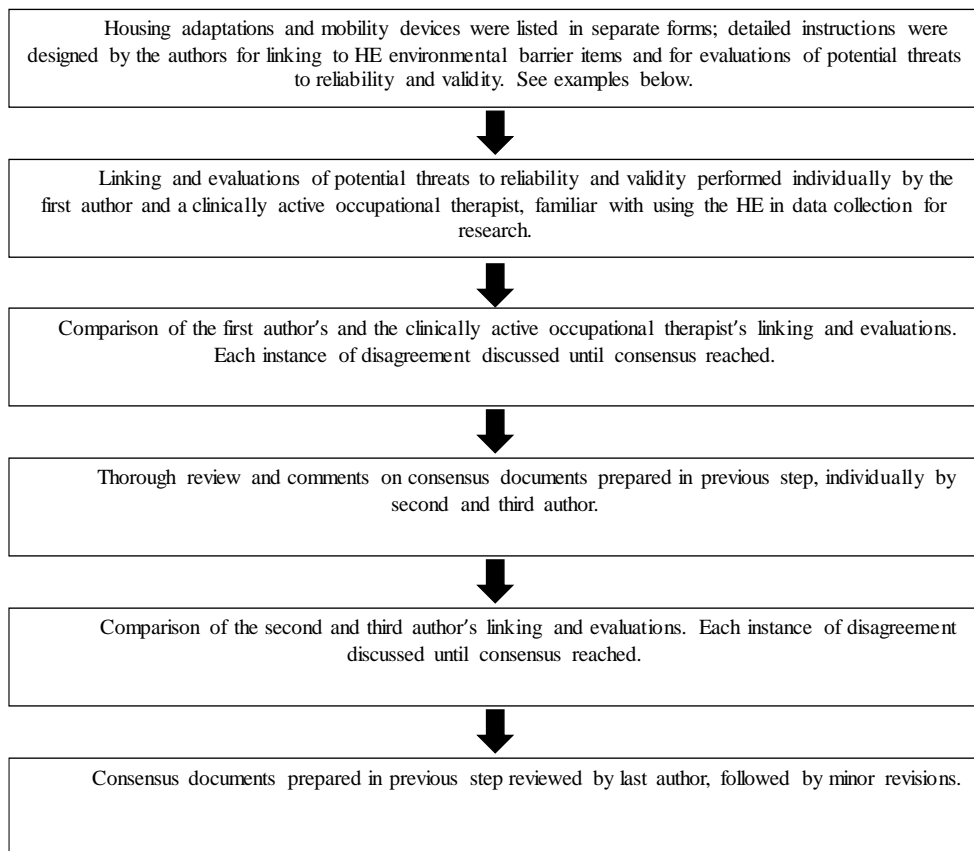
### Statistical analyses

Descriptive statistics were used to present data on socio-demographics, injury characteristics, housing situation and aspects of participation. Differences between groups were analysed using the Kruskal-Wallis test, the Mann-Whitney U-test or the Chi-square test, where appropriate.

To examine the association between accessibility and aspects of participation we used ordinal regression under the cumulative odds model with location parameters only (Armstrong & Sloan, 1989; Mc Cullagh, 1980). To reduce complexity, we decided to focus the analyses on the indoor sub-section of objective accessibility, which showed the most consistent significant associations with all the aspects of participation under study. P-values < 0.05 were considered to be statistically significant. The Bonferroni corrected significance level was set to  $0.05/3=0.0166$  (i.e. three post-hoc pairwise tests were carried out for each group difference found).

### **Psychometric analyses**

The potential effect on the reliability and content validity of the HE instrument was qualitatively considered and reviewed in an iterative evaluation procedure. Housing adaptations and mobility devices were listed and then linked to the items in the HE. The linking was made in a form designed for the purpose, with detailed written instructions. The instructions were based on which items would be relevant to assess for each housing adaptation or mobility device and why an item would be difficult to apply. Potential threats to reliability, content and construct validity were then evaluated. The evaluation procedure is illustrated in Figure 5.



**Figure 5.**  
The iterative evaluation procedure.

After the evaluation procedure, we analysed the potential effect on construct validity through simulations adjusting accessibility problem scores for housing adaptations and use of mobility devices. We hypothesised that if the construct was still to be considered as valid, it should not significantly change the accessibility problem score when accounting for the particular housing adaptations and mobility devices observed in the SASCIS sample. Two alternative accessibility problem scores were produced; one with the scoring adjusted for the presence of certain housing adaptations (water tap on front of kitchen sink, ceiling lift bedroom, ceiling lift bathroom, mirror at angle, toilet elevated, platform lift indoors, chairlift indoors, lift indoors, light switch with touch control and remote-controlled window opening), and another adjusted for the use of certain mobility devices (rollators and powered wheelchairs). Thereafter, the Wilcoxon's signed rank test was used to test for statistically significant differences ( $p < 0.05$ ) between the accessibility problem score produced by the existing HE matrix and the two adjusted scores.

## **Mapping housing adaptations and current accessibility problems**

The occurrence of housing adaptations and environmental barriers generating accessibility problems in the sample was descriptively analysed and mapped by section in the dwelling. The accessibility problem scores were adjusted for the presence of housing adaptations and mobility device use, as described above.

The ranking of environmental barriers according to the magnitude of accessibility problems they generated, was produced by using the accessibility scores for each of the 161 environmental barriers. An average score for the sample was computed for each item, then the barriers were sorted in descending order based on the average score.



# Ethical considerations

All research concerning humans has to be carried out with great respect for the person and his/her integrity; this implies that the individual's well-being must be given precedence over the needs of society and science (Vetenskapsrådet [VR], 2017).

Formal ethical approval for the baseline data collection in SASCIS was obtained from the regional Ethical Board in Lund (No.2010/692), following the principles of the Helsinki Declaration (World Medical Association, 2009). All participants were given both oral and written information about the project and had the opportunity to ask questions before enrolment. They were assured anonymity and informed that participation in the study was voluntary, and that they are entitled to withdraw their participation at any time without any consequences. Written informed consent was received from all participants before the data collection started. The SASCIS is registered as a person register and kept in a database in accordance with current legislation (Lag (2018:218) med kompletterande bestämmelser till EU:s dataskyddsförordning).

The potential participants were initially contacted by mail, with a letter containing information about the study, and a written informed consent form, S. Jörgensen being responsible for this. Those who returned the form were contacted by phone either by me or Mrs Jörgensen; any questions they had were answered and arrangements for a home visit were made. To ease the burden of questions during the visit, five questionnaires were mailed to each participant in advance.

Home visits are a special situation, and it is a challenge as a researcher collecting data to balance the role of being a guest and also leading the visit. Great efforts were made to make each participant as comfortable as possible in this situation. At the beginning of the visit, we presented ourselves and outlined the structure of the visit. The pre-sent questionnaires were reviewed and collected, and the participant was given the opportunity to ask questions. Each visit lasted for approximately two hours, and the participant was offered breaks according to his/hers needs and wishes. A much appreciated coffee break was often initiated by the participant. Some of the questions gave rise to emotions and memories that needed attention, and the participant was then given time to reflect before proceeding with the assessments.



The burden of questions may have been challenging, but they were well received. The participants' body weight was recorded by using a portable scale for wheelchairs. The use of the scales was appreciated; a majority of the participants did not know their own body weight since scales for wheelchair dependents are rare. Many of the participants were surprised by the number of participants in the study, as a majority expressed that they felt alone in their situation. Overall, the impression was that the participants were eager to share their experiences in order to contribute to better understanding of their situation.

# Results

Results from the Baseline Study are presented in the Method-section under the heading 'Participants', and in Table 3.

## Housing situation and aspects of participation

### Housing situation and accessibility

Nearly all the participants (96 %) lived in dwellings with necessary housing standard as specified by the Swedish National Board of Housing, Building and Planning (Boverket, 2008). More than half of the total sample (67%) lived in a single-family house. The vast majority of the participants (77%) lived in dwellings with housing adaptations. The All AIS D group lived in dwellings with significantly less housing adaptations and more environmental barriers indoors, compared to the other two groups. Further information is provided in Table 5 and 6.

**Table 5.**  
Housing situation among 122 older adults with long-standing spinal cord injury in southern Sweden

Variable N, (%)	Total (N=122)	Tetraplegia AIS <sup>1</sup> A-C (N=22)	Paraplegia AIS A-D (N=41)	All AIS D (N=59)
Necessary housing standard <sup>2</sup>	118 (96)	22 (100)	39 (95)	57 (95)
<i>Type of housing</i>				
Multi-dwelling block	55 (45)	11 (50)	19 (46)	25 (42)
Single-family house	67 (55)	11 (50)	22 (54)	34 (58)
<i>Residential location</i>				
Urban stad	77 (63)	18 (82)	20 (49)	39 (66)
Rural land	45 (37)	4 (18)	21 (51)	20 (33)
Housing adaptation	92 <sup>3</sup> (77)	21 <sup>3</sup> (100)	37 (90)	34 <sup>3</sup> (60)

<sup>1</sup> AIS= American Spinal Injury Association (ASIA) Impairment Scale.

<sup>2</sup> According to Boverket, 2008.

<sup>3</sup> 1-3 missing.

Regarding accessibility problems overall, the Tetraplegia AIS A-C group lived in dwellings with the most accessibility problems, significantly more than the Paraplegia AIS A-C group ( $P<0.001$ ). The Tetraplegia AIS A-C group also had significantly more accessibility problems in their dwellings as to the areas exterior surroundings ( $P=0.028$ ) and indoors ( $P<0.001$ ) than the other two groups, see Table 6.

**Table 6.**

Housing accessibility according to the Housing Enabler among older adults with long-standing spinal cord injury, N=122

Housing variable	Total N=122	Tetraplegia AIS A-C N=22	Paraplegia AIS A-C N=41	All AIS D N=59	P-value
No. of environmental barriers, median (q1-q3)					
<i>Exterior surroundings</i>	9 (7-12)	9 (7-13)	8 (6-12)	9 (7-11)	0.311
<i>Entrances</i>	10 (8-17)	10 (7-23)	9 (6-15)	11 (8-17)	0.359
<i>Indoor</i>	45 (41-50)	42 (40-46)	42 (39-48)	49 (45-54)	<b>&lt;0.001</b> <sup>2,3</sup>
<i>Total</i>	67 (59-76)	65 (58-78)	61 (54-69)	71 (64-78)	<b>&lt;0.001</b> <sup>3</sup>
Accessibility problem score, median (q1-q3)					
<i>Exterior surroundings</i>	47 (28-74)	74 (41-96)	46 (21-66)	46 (27-63)	<b>0.028</b> <sup>1,2</sup>
<i>Entrances</i>	56 (35-81)	75 (38-149)	60 (41-79)	53 (33-77)	0.146
<i>Indoor</i>	156 (115-205)	205 (169-227)	137 (103-164)	162 (105-208)	<b>&lt;0.001</b> <sup>1,2</sup>
<i>Total</i>	280 (193-353)	336 (283-429)	231 (182-295)	288 (185-353)	<b>&lt;0.001</b> <sup>1</sup>

Note: Bolded P-values indicate a significant result of the test between the three groups.

Post-hoc pair-wise comparisons that were significant are indicated as follows:

<sup>1</sup> Tetraplegia AIS A-C vs Paraplegia AIS A-C.

<sup>2</sup> Tetraplegia AIS A-C vs All AIS D

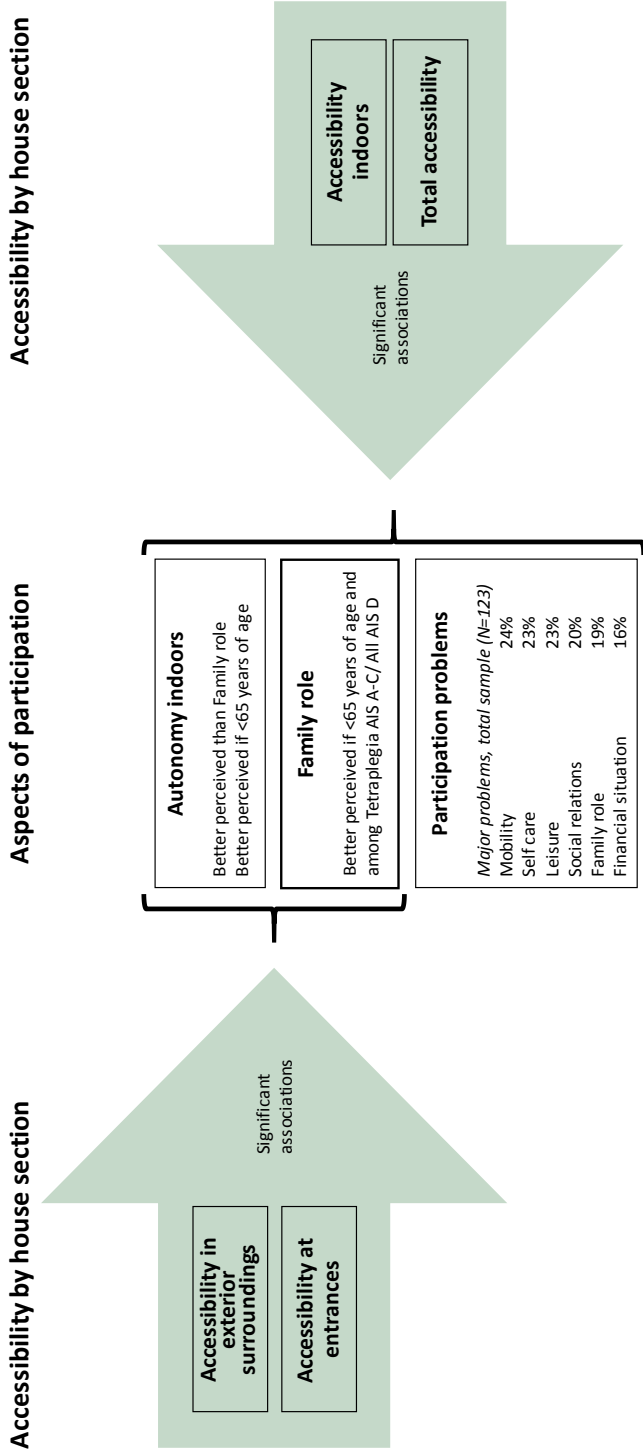
<sup>3</sup> Paraplegia AIS A-C vs All AIS D

## Associations of housing and participation

The majority of the participants perceived their participation as good or very good in most of the activities studied. The domain 'Autonomy indoors' containing items concerning indoor mobility and personal care was rated as perceived as better than the other domain investigated, 'Family role', which mainly concerns household chores. The investigated sub-domains that were reported to cause the highest frequency of severe problems in the total sample were mobility (24%), self-care (23%) and leisure (23%). There were no significant differences between the three severity groups regarding participation problem areas.

Both the univariable and multivariable regression models showed that accessibility indoors was significantly associated with all of the studied aspects of participation.

All the significant results indicate that living in housing with more accessibility problems was associated with less participation and autonomy and more participation problems. Applying lessons learned from the Psychometric Study, we have later re-run the multivariable regression analyses using the accessibility problem score adjusted for use of mobility devices and presence of housing adaptations; the associations between accessibility indoors and participation were still found to be statistically significant. Participation and associations between accessibility and participation are presented in Figure 6. Detailed results can be found in Table 3-5 in the Participation Study (see Appendix, Paper II).



**Figure 6.** Aspects of participation and associations between accessibility and participation among older adults with long-standing spinal cord injury.

# The Housing Enabler instrument in a SCI sample

## Threats to reliability and validity

Thirty-six (out of 61 housing adaptations in total) posed a threat to the reliability and/or validity of the HE instrument. The other 27 adaptations were features covered by existing environmental barrier items in the HE, and did not cause any doubt in the assessment situation; they were thus excluded from further analyses. All housing adaptations observed are presented in Table 7.

**Table 7.**

All housing adaptations observed distributed on severity group in order of the most common in the total sample

Housing adaptation measure	Frequency of housing adaptations			
	Total N=122	Tetraplegia AIS A-D N=22	Paraplegia AIS A-D N=41	All AIS D N=59
Ramp at entrance	29	8	12	9
Wheelchair accessible stovetop	17	6	7	4
Ceiling lift in bedroom	16	13	3	0
Wheelchair accessible kitchen sink	14	4	7	3
Wheelchair accessible kitchen worktop	12	2	7	3
Wall-mounted adjustable kitchen cabinets	12	3	6	3
Remote-controlled door-opening (own dwelling)	12	6	3	3
Stove in accessible height	11	3	5	3
Angle-adjustable washbasin	10	3	6	1
Adjustable kitchen worktop	9	2	4	3
Remote-controlled door-opening (in stairwell)	9	5	2	2
Thresholds removed (indoors in general)	8	2	2	4
Washbasin extended from wall	8	3	3	2
Low kitchen worktop	7	1	5	1
Wall-mounted toilet armrest	7	1	6	0
Chairlift indoors	6	0	3	3
Wall-mounted kitchen cupboards placed low	6	1	4	1
Platform lift outdoors, entrance	5	0	2	3
Adjustable stovetop	5	1	2	2
Adjustable kitchen cupboards, whole section	5	2	3	0
Oven with side-hung hatch	4	0	1	3
Adjustable washbasin	4	0	2	2
Wall-mounted kitchen cupboards with jalousie/sliding door	4	1	2	1
Adjustable kitchen sink	4	1	2	1
Automatic door-opening (in stairwell)	4	2	1	1
Washbasin immersed in large countertop	3	2	1	0
Platform lift indoors	3	2	1	0
Ceiling lift bathroom	3	3	0	0

Shower with seating	2	0	1	1
Toilet elevated	2	0	2	0
Lift indoors	2	0	2	0
Lift indoors, own design	2	0	2	0
Remote-controlled window-opening	2	0	2	0
Remote-controlled garage door	2	0	2	0
Platform lift entrance (indoors)	2	1	1	0
Kitchen worktop with grab-bar	2	1	1	0
Sliding door bathroom	1	0	0	1
Mirror at angle	1	0	0	1
Mirror placed low	1	0	0	1
Light-switch with touch control	1	0	0	1
Fuse box placed low	1	0	0	1
Wall-mounted corner cupboard with turnable unit	1	0	0	1
Water tap on front of kitchen sink	1	0	0	1
Washing machine elevated	1	0	0	1
Wash basin with grab-bar	1	0	1	0
Wash basin placed low	1	0	1	0
Automatic door-opening indoors	1	0	1	0
Door-openings widened	1	0	1	0
Threshold eliminator	1	0	1	0
Ramp indoors	1	0	1	0
Kitchen sink placed low	1	0	1	0
Wheelchair accessible oven	1	0	1	0
Lift in garage	1	0	1	0
Threshold eliminator sitting-out place	1	0	1	0
Cleaning cupboard without base	1	0	1	0
Wardrobe without base, with pullout interior	1	0	1	0
Threshold eliminator entrance	1	1	0	0
Threshold eliminator (own front door dwelling)	1	1	0	0
Remote-controlled door-opening lift	1	1	0	0
Automatic door-opening lift	1	1	0	0
Wall-mounted kitchen cupboards with adjustable shelves	1	1	0	0

■ = Housing adaptation posing a threat to reliability and/or validity of the HE instrument.

■ = Housing adaptation not posing a threat to reliability and/or validity of the HE instrument.

Ten of the 15 most common housing adaptations were found to threaten the reliability and/or validity of the HE, and are presented in Table 8.

**Table 8.**

The 10 of the 15 most common housing adaptations posing a threat to reliability and validity in the HE, and their location in the dwelling

Location	Housing adaptation	Frequency in total sample N=122 N (%)	Reliability affected	Content validity affected	Construct validity affected
Entrance	Remote-controlled door-opening (in stairwell)	9 (7)	a <sup>1</sup>		
	Remote-controlled door-opening (own dwelling)	12 (10)	a <sup>1</sup>		
Kitchen	Wheelchair accessible stovetop	17 (14)	a <sup>2</sup>	b <sup>1</sup>	
	Wheelchair accessible kitchen sink	14 (11)	a <sup>2</sup>	b <sup>1</sup>	
	Wall-mounted adjustable kitchen cupboards	12 (10)	a <sup>3</sup>		
	Stove at accessible height	11 (9)	a <sup>2</sup>	b <sup>1</sup>	
	Adjustable kitchen worktop	9 (7)	a <sup>3</sup>		
	Low kitchen worktop	7 (6)		b <sup>3</sup>	c
	Hygiene area	Angle-adjustable wash-basin	10 (8)	a <sup>3</sup>	
Dwelling in general	Ceiling lift bedroom	16 (13)		b <sup>1</sup>	c

a<sup>1</sup> Compensating for environmental barriers, the specifications and assessment instructions for the HE environmental barriers items related to the housing adaptation were unclear

a<sup>2</sup> The recorded design feature was not completely and clearly described in the HE environmental barrier items

a<sup>3</sup> Represented in the HE but a threat to reliability

b<sup>3</sup> The housing adaptation was considered an environmental barrier according to the HE

b<sup>1</sup> The design feature was not described at all in the HE environmental barrier items

c Compensating for environmental barriers, thus resolving potential accessibility problems and possibly compromising the score contribution

Twenty-nine housing adaptations were evaluated as posing a threat to the reliability of 42 of the 161 HE environmental barrier items, either exclusively or in combination with content validity, construct validity, or both. Examples of housing adaptations posing a threat to reliability were mainly flexible and/or wheelchair accessible bathroom and kitchen features, remote-controlled door-openers and indoor lifts.

Seventeen housing adaptations were evaluated as posing a threat to the content validity of 31 of the 161 HE environmental barrier items, always in combination with construct validity, reliability, or both. Examples of housing adaptations posing a threat to content validity were mainly ceiling lifts and wheelchair accessible kitchen features, lifts of different design and/or location to those assumed in the HE, and low kitchen worktop.



Neither reliability nor content validity were considered to be threatened by the use of mobility devices.

Eleven housing adaptations were evaluated as posing a threat to construct validity in 77 of the 161 HE environmental barrier items, either exclusively or in combination with content validity, reliability, or both. Six of the 77 items were affected by both housing adaptations and use of mobility devices. Examples of housing adaptations posing a threat to construct validity were mainly different kinds of lifts.

Two kinds of mobility devices, powered wheelchair and rollator, were evaluated as posing a threat to the construct validity of 29 environmental barrier items in the HE.

### **Adjusted housing accessibility problem score**

The differences between the accessibility problem score produced by the existing HE matrix and the adjusted scores for housing adaptations and use of mobility devices were modest, albeit statistically significant ( $P < 0.001$ ). When adjusting the accessibility problem score for presence of housing adaptations, 19 % of the cases got a lower accessibility problem score, ranging from 6 to 58 points in difference. With similar adjustment for use of mobility devices, 54 % of the cases got a lower score, ranging from 3 to 39 points in difference.

## **Housing adaptations and current housing accessibility problems**

### **Housing adaptations by house section**

The most common housing adaptations recorded were ramp at entrance (24%), wheelchair accessible stovetop (14%), and ceiling lift in bedroom (13%), see Table 7 and Figure 7. Housing adaptations were frequent in entrances (42%), in kitchens (31%) and hygiene areas (25%), see Figure 8. Seven of the 15 most common housing adaptations were located in kitchens, three in entrances and three in hygiene areas (see Table 7).



**Figure 7. The three most common housing adaptations. Top: Ramp at entrance; Bottom left: Wheelchair accessible stovetop; Bottom right: Ceiling lift in bedroom.**

### **Accessibility problems by house section**

Wall-mounted cupboards and shelves placed high in the kitchen were the environmental barriers generating the most accessibility problems, affecting 69% of the sample. Inaccessible supplementary storage area outside the dwelling affected 70% of the participants, and lack of grab bar in hygiene area 40% (see Table 7).

Four environmental barriers at the entrance generated together an accessibility problem score of 20.8, three barriers in the kitchen 20.7, and the two barriers in the hygiene area generated 11.4. Further information is provided in Table 9.

**Table 9.**

The 10 environmental barriers generating most accessibility problems, N=122

Location	Environmental barrier	N <sup>a</sup>	%	Average accessibility problem score <sup>b</sup>	Rank order
Outside dwelling	Irregular/uneven surface	106	87	4.8	10
Entrance	High thresholds and/or steps	81	66	5.8	4
	Doors cannot be fastened in open position	90	74	5.6	5
	Doors do not stay in open position/close quickly	66	54	5.0	9
Kitchen	Wall-mounted cupboards and shelves placed high	84	69	10.8	1
	Controls in inaccessible position	117	96	5.6	6
Hygiene area	No grab bar in shower/bath and/or toilet	50	41	6.0	3
	Controls in inaccessible position	105	86	5.4	8
Dwelling in general	Controls in inaccessible position	106	87	5.4	7
Supplementary facilities	Storage areas can only be reached via stairs/threshold/other level difference	86	70	6.3	2

Note. Iwarsson & Slaug, 2010.

<sup>a</sup> No. for whom the barrier generates problems. <sup>b</sup> Adjusted for housing adaptations and/or use of mobility device (Norin et al., 2018), min-max = 0-35.

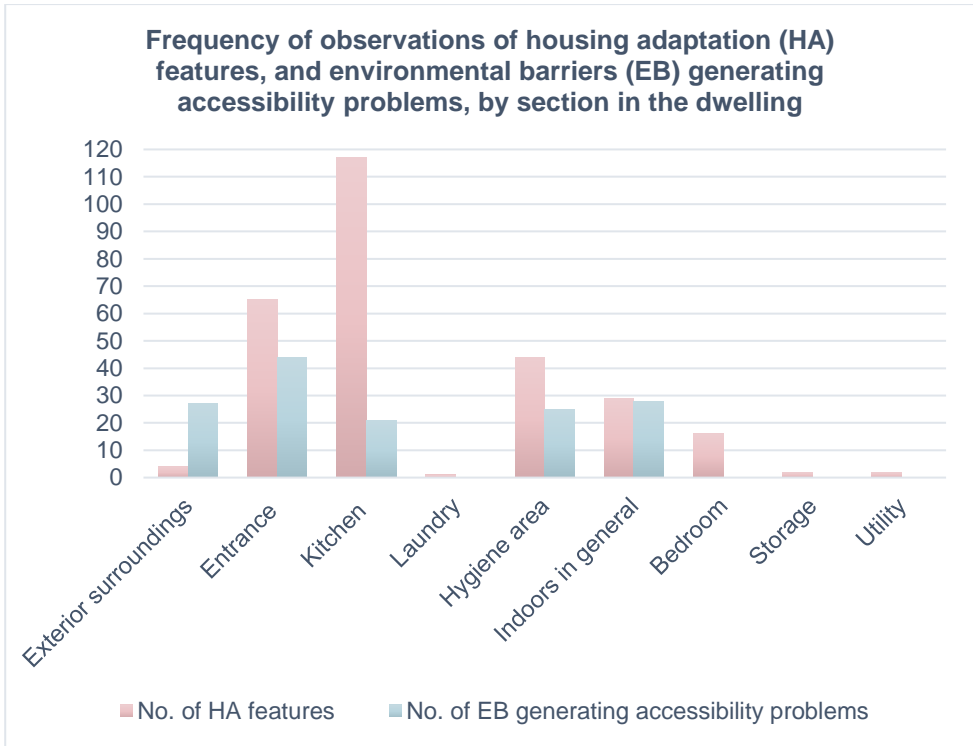
Environmental barriers and housing adaptations were found in the same sections of the dwelling; the most common housing adaptations were solutions for the most common environmental barriers, see Table 10.

**Table 10.**

The most common environmental barriers generating accessibility problems and the most common housing adaptations potentially resolving the barrier

Location	Environmental barrier Total sample N=122 N (%)	Housing adaptation Total sample N=122 N (%)
Entrance	Doors do not stay in open position/close quickly 66 (54)	Remote-controlled door-opening (in stairwell and own dwelling) <sup>1</sup> 19 (16)
Kitchen	Wall-mounted cupboards and shelves placed high 84 (69)	Wall-mounted adjustable kitchen cupboards 12 (10)
		Wall-mounted kitchen cupboards placed low 6 (5)
		Controls in high/inaccessible position 117 (96)
		Wheelchair accessible stovetop 17 (14)
		Wheelchair accessible kitchen sink 14 (11)
		Stove at accessible height 11 (9)
Hygiene area	No grab bar at shower/bath and/or toilet 50 (41)	Wall-mounted toilet armrests 7 (6)

<sup>1</sup>19 individuals had remote-controlled door-opening, whereof 2 had both in stairwell and own dwelling



**Figure 8.**

# Discussion

Investigating and describing housing accessibility and its associations with participation among older adults with long-standing SCI in Sweden, this thesis adds unique knowledge to the existing body of research targeting this group. Moreover, this project contributes with deepened methodological knowledge on accessibility assessments in terms of reliability and validity threats when using a well-established instrument in a population with specific characteristics and housing situations.

The major findings show that more extensive housing accessibility problems are associated with lower perceived participation and that accessibility problems are substantial despite frequent housing adaptations. Assessing housing accessibility among individuals with complex and specific functional profiles, frequent use of mobility devices and dwellings with a substantial occurrence of housing adaptations is complex, and places high demands on both instruments and raters. There are considerable reliability and validity threats to the HE when using the instrument in the presence of extensive housing adaptations and/or use of mobility devices. Environmental barriers often have the same location as housing adaptations, indicating that the accessibility in their dwellings does not meet the requirements of older adults with long-standing SCI.

**More accessibility problems is associated with less participation and autonomy and more participation problems. Can other health-related aspects be associated with housing accessibility?**

The fact that housing accessibility affects participation, and not only has to do with the physical environment is worth some attention. This is in line with the knowledge that the surrounding environments affect health, achievement and well-being, which is fundamental within neurodesign (Sjövall & Gospic, 2016). According to this scientific field, the surroundings affect people physiologically and psychologically, which my findings on associations between accessibility and participation support. The association between accessibility problems and perceived participation was significant, and severe participation problems were mostly reported with regard to mobility, self-care and social relations (see Appendix, Paper II, Table 4). That is, mobility and the performance of self-care activities are related to environmental barriers such as insufficient manoeuvring space and equipment/controls difficult to reach, which were among the most common environmental barriers generating

accessibility problems. As described in another study from Sweden, older adults with SCI experience frustration when activities of daily living take precedence over more rewarding activities (Lundström, Lilja, Gray, & Isaksson, 2015). This suggests that activities such as those included in the IPA domains “autonomy indoors” and “family role” (Cardol et al., 1999) are important and need to run smoothly in accessible environments to allow time and energy to be spent on more meaningful activities. Thus, an accessible environment is important in several different ways to enable activity (Gilbert, Hagerty, & Taggert, 2012) which is supported by my results.

**Housing adaptations and use of mobility devices are found to threaten the reliability and validity of the HE. Further optimization is necessary to capture P-E fit in populations with specific characteristics**

Use of mobility devices affects the accessibility problem score in more cases than presence of housing adaptations, while housing adaptations causes more uncertainty in the assessment situation. A majority of the housing adaptations poses a threat to reliability and validity in a majority of the items in the HE, however, at the individual level, mobility devices are more problematic as they affect the accessibility problem score more in individual cases. Both housing adaptations and use of mobility devices are common among older adults with long-standing SCI as well as among older adults with complex profiles of functional limitations due to other diagnoses. This indicates that further optimization of the HE is necessary to capture P-E fit in populations with specific characteristics.

Based on extensive research (Iwarsson et al., 2012), the HE was designed for and has been used mainly in general populations of older adults. As the data for this thesis were collected in a sample with complex functional profiles (see Jörgensen, Iwarsson, Norin, & Lexell, 2016), many housing adaptations and frequent use of mobility devices, reliability and validity issues related to the HE not recognized previously became obvious. Use of mobility devices is taken into consideration in the HE instrument as they serve as a sign of more severe mobility limitations. Despite this, the results of the Psychometric Study show that use of mobility devices threatens the construct validity of the instrument. One reason for this is that as a term, “mobility devices” include a broad variety of products, from a simple walking stick to a very advanced powered wheelchair with multiple special functions. Among people with SCI, more advanced mobility devices are more common, and they have the capacity to support the individual to overcome environmental barriers, thus influencing P-E fit. Still, the simulated analysis targeting construct validity shows that even though the presence of housing adaptations and/or mobility devices affects the accessibility problem score, the overall impact is modest; on group level

the score difference is comparatively small. However, in individual cases, the overestimation reflected in the score is substantial, and an adjustment of the accessibility problem score on the individual level is necessary for reliable and valid results.

The results that use of mobility devices affects the construct validity of the HE raises questions regarding use of other assistive devices. Use of hygiene devices like mobile shower commodes and bowel and bladder-related assistive devices is common among people with SCI, and investigation of whether the use of hygiene devices threatens reliability and validity of the HE would elicit further knowledge to strengthen the psychometric properties of the instrument.

Further along this line of reasoning, with advanced technology when many functions are possible to control remotely in various ways, the design of fixed controls in dwellings such as light-switches, door-handles etcetera becomes less important. On an individual level, certain design features may then be of minor importance and not that vital to assess in terms of accessibility. Accordingly, the development of advanced technology must be considered if the HE is to remain as a reliable measure of P-E fit.

A systematic approach to environmental assessments is valuable to OTs who often meet clients with complex functional profiles and housing adaptations. In practice settings, OTs need reliable and valid information to form the base for individual interventions, and among the housing assessments available the HE is considered a useful measure of housing accessibility (Weeks, Lamb, & Pickens, 2010). Every new context for an instrument demands re-establishment of the psychometric properties (Streiner et al., 2015), and the findings reported in the Psychometric Study suggest further studies to safeguard reliable and valid use of the HE in populations where housing adaptations and use of mobility devices is common. This thesis contributes with an identification of needs for optimisation in the HE as well as suggestions for further improvement.

**Accessibility assessments should be complemented with additional assessments capturing other aspects of housing**

The HE provides an objective measure of P-E fit and does not take any individual goals or desired outcomes into account. Accessibility was considered the most important aspect of housing to target based on the overarching scope and ambition of SASCIS, and no additional housing-related data (e.g., on usability and other perceived aspects of housing, see Oswald, Schilling, Wahl, Fänge, Sixsmith, & Iwarsson, 2006) was collected. However, current research shows that perceptions about the home are important for health and well-being (Kylén, 2018). Accordingly, to complement the knowledge about aspects of housing and health among older



adults with long-standing SCI, instruments capturing perceived aspects of home constitute a valuable complement in this field of research. One single instrument may not fulfil all requests, and diverse instruments can complement each other to provide a wider picture (Mokkink et al., 2016). For example, the Usability in My Home (UIMH) questionnaire (Fänge & Iwarsson, 1999) captures to what extent the physical environment supports performance of daily activities in the home, and the Meaning of Home (MOH) questionnaire (Oswald & Wahl, 2005) concerns the individual's subjective meanings in relation to home. Adding information on such aspects of the housing situation of older adults with long-standing SCI would provide OTs with a strong starting-point for client-centred discussions targeting housing-related interventions.

**The high prevalence of housing adaptations among older adults with long-standing SCI supports the Ecological Theory of Ageing and confirms the docility hypothesis.**

The finding that the lower the competence of the individual, which in the present sample is represented by complex profiles of functional limitations following SCI, the more frequent are housing adaptations, is consistent with the ETA. According to the ETA, lowering of environmental press is a way to attain the adaptation level (in terms of behaviour; ADL performance is one facet of behaviour). For the Tetraplegia AIS A-C group, the rater observed more housing adaptations and accessibility problems in total than for the Paraplegia AIS A-D and All AIS D groups, indicating that their greater severity of injury requires lower environmental press. In correspondence to that, in the All AIS D group significantly less housing adaptations were observed ( $P < 0.001$ ) than in the other two groups, and more environmental barriers, indicating that individuals with higher competence can manage greater environmental press. The docility hypothesis (Lawton & Simon, 1968) implying that decreased competence makes the individual more liable to be controlled by environmental factors, also holds true by these results. With lower competence in terms of functional capacity, the Tetraplegia AIS A-D group is likewise more susceptible to environmental press than the other two groups, which is confirmed by the findings of the Participation Study.

**P-E fit is a dynamic, not a static relation. Regular follow-ups of housing adaptations are necessary to maintain accessibility, not the least as accessibility also affect participation.**

Overall, the findings presented in this thesis underpin the importance of P-E fit as a dynamic, and not a static relation. An imbalance between the person and the environment in the dwelling is common after a SCI, and a housing adaptation is a probable solution. The current prevalence of environmental barriers despite housing

adaptations indicate that the P-E fit has changed since the housing adaptation was implemented. This is, however, at odds with ETA which has been criticized for the treatment of P-E fit as a static relation. Functional limitations do increase with age and generate increasing accessibility problems even if the physical environment does not change, and this lack of the time dimension in ETA is another criticism to the theory. Although a housing adaptation based on the assessment of the functional capacity of the individual was implemented at the time of the SCI, P-E fit changes over time. Studying very old people in the general population, Granbom, Iwarsson, Kylberg, Pettersson, & Slaug (2016) found that due to functional decline over time, accessibility did not improve although very old adults moved to dwellings with fewer environmental barriers. The environmental press did decrease, but so did the individuals' capacity, resulting in persisting accessibility problems. Changes in P-E fit is one possible explanation for the magnitude of current accessibility problems found in this thesis project. As stated in the introduction, follow-up of housing adaptations is not self-evident, although regular follow-up would be beneficial for maintaining P-E fit despite declining functional capacity following increasing age. Further research is warranted to investigate to what extent accessibility problems among older adults with long-standing SCI are attributed to the injury itself, or to the ageing process – or maybe both.

**The most common housing adaptations mirror the complex functional profiles of older adults with long-standing SCI and differs from the most common housing adaptations in Sweden.**

The fact that ramp, wheelchair accessible stovetop and ceiling-lift in bedroom were the most common housing adaptations and that they differ from the most common housing adaptations among the population in general (threshold elimination, montage of grab-bar, and ramp) (Boverket, 2016), reflects the special characteristics of older adults with SCI. However, the sections in the dwelling with the most frequent housing adaptations are in line with those found in the general population, and the results on the top-ten environmental barriers (see Table 9) are similar to findings in a previous study on very old people living in ordinary housing (Granbom et al., 2016). In that study irregular/uneven surface in exterior surroundings, high thresholds and/or steps at the entrance and inaccessible storage areas were also among the top-ten environmental barriers regardless of functional profile or type of house (single-family house or multi-dwelling block). Consequently, very old people in general face similar accessibility problems as those with SCI. If the ageing population in general (both with and without specific diagnoses), are facing accessibility problems, this indicates shortcomings of the ordinary housing stock containing environmental barriers that generates problems to older people.

Ramp at the entrance is a common housing adaptation both in Sweden in general (Boverket, 2016), among persons with SCI in Sweden (Norin, Slaug, Haak & Iwarsson, 2018) as well as internationally (Hertig-Godeschalk, Gemperli, Arnet, Hinrichs, & SwiSCI study group, 2017). A way to address the design of the environment is through the universal design concept, which can be defined as ‘a process that enables and empowers a diverse population by improving human performance, health and wellness, and social participation’ (Steinfeld & Maisel, 2012). Consequently, already existing constructions can be made accessible, while the universal design concept can be advantageously applied to new construction. Universal design, (also called ‘design for all’ in Europe, or ‘inclusive design’ in the United Kingdom) is not a new concept, and it is currently gaining ground both in Sweden and internationally. As long as there is a paucity of dwellings constructed based on the universal design paradigm, an individually granted housing adaptation is a viable option to make the dwelling accessible. To date, housing design, building traditions and legislation have not taken accessibility accommodating the needs of the ageing population (in particular people ageing with disability) sufficiently into account. With today’s knowledge, politics and new regulations, a ramp is hopefully not among the most common housing adaptations in the future.

Although the accessibility in the Swedish housing stock has improved over the years (Granbom, Slaug, Kylberg, Pettersson, & Iwarsson, 2015), automatic door-opening and ramps in multi-family blocks made up > 11% of the housing adaptation grants in Sweden in 2015 (Boverket, 2016). The lack of accessible entrances is supported by findings in this thesis, as fifty-five participants (45%) lived in multi-dwelling blocks, whereof only four buildings had automatic door-opening at the entrance; subsequently, nine participants had remote-controls for door-opening. As a housing adaptation is an individually granted intervention where the individual owns the adaptation (and thus is entitled to bring it with her/him in case of relocation), accessibility problems in communal areas can be challenging to address considering that other people also uses the premises. An individually granted housing adaptation is a reasonable solution in a single-family house, although in multi-dwelling blocks other solutions may be considered. For example, the owner of a multi-dwelling block could invest in door-automation for everyone to use. When major refurbishments of multi-dwelling blocks are being planned, accessibility interventions beneficial for people in general should also be considered.

A recurrent theme in the results are that environmental barriers are present in the dwellings where older adults with long-standing SCI live, despite housing adaptations addressing such environmental barriers (see Table 9, 7 and 10), particularly in entrances, kitchens and hygiene areas. Accordingly, there is room for design improvement, and the complexity of P-E fit and the diversity of needs within the population deserves explicit attention in housing policy and housing provision. This thesis contributes with an understanding of what environmental challenges

older adults with SCI can face, thus highlighting the important role of the design of the physical environment.

**Inaccessible positions of objects/functions are recurrent environmental barriers, indicating that housing standards do not meet the needs of older adults with long-standing SCI.**

Inaccessible position of objects (e.g., letterbox, cupboards, shelves) or functions (e.g., different types of controls) were recurrent environmental barriers in all housing sections and affected practically the total sample in terms of accessibility problems (see Table 9 and 10). The discrepancy between the accessibility standards and the housing adaptations is interesting. As a housing adaptation often is reaching beyond the standards one would assume that the results of the accessibility assessments would have reflected this. The extent and frequency of current environmental barriers suggest that national standards for housing design are not sufficient for individuals with SCI. This is in fact true also for older adults in general, as found in a study addressing validation of housing accessibility standards (Helle, Iwarsson, & Brandt, 2014). The participants in that study performed well-known household activities in a kitchen setting designed according to current standards for accessible housing. There were three groups of participants (participants not using mobility devices/rollator users/manual wheelchair users), and all three encountered substantial accessibility problems, captured by means of observations as well as self-reports. In another study on standards for accessible housing, Helle and co-workers highlighted the need for development of research-based definitions to ensure that standards actually improve accessibility for the target population (Helle et al., 2011). The results in this thesis support the need for improved housing accessibility to better meet the needs of the ageing population, and contributes with knowledge on the housing accessibility situation among older adults with SCI.

## Methodological considerations, strengths and limitations

This thesis builds upon selected data from the SASCIS. Great efforts were made to provide a comprehensive base of information about the life situation of older adults with long-standing SCI. The data collection instruments were carefully selected to reflect all components of the ICF, a specific study protocol was designed and the data was collected through home visits. Home visits are resource intensive, but well worth the effort with advantages such as a high response rate (67%) and minimal missing data. Moreover, visiting people in their home provides a unique understanding of each individual's life situation. Besides the privilege to have met

all the participants in person, it was very helpful to have the real persons to relate the quantitative variables to when setting up the database. This helped me to find inconsistencies in the data that I would not have noticed otherwise.

The main characteristics of the SASCIS sample (sex, cause of injury), are consistent with previous studies (DeVivo, 2012). As there were no significant differences between the participants and the non-participants regarding age, age at injury, time since injury, injury level, completeness and cause of injury, the SASCIS sample is likely to represent the population of older adults with long-standing SCI in southern Sweden.

With today's aging population and the increasing number of years lived with disability (Vos et al., 2015), it may seem inappropriate to include individuals 50 years of age in research concerning 'older adults'. Seen from a psychosocial perspective, 50 years of age is not considered old, and people lead active lives far into advanced age (Agahi & Parker, 2002). However, as stated already in the introduction, life expectancy is lower and premature ageing is probable as a consequence of the SCI (Frontera & Molett, 2017). In addition, the human body has its peak of maximum functional status around 25 years of age, and thereafter the capacity starts to decline (Frontera & Molett, 2017). After a SCI there is an accelerated functional decline in the body, after which the ageing process continues at a normal pace (Frontera & Molett, 2017). Thus, at least from a biological perspective, it is highly relevant to include individuals at the age of 50 years in research on older adults with SCI. As the data used data is cross-sectional, no conclusions about the ageing process of people with SCI can be drawn. With a recently completed follow-up of the SASCIS sample, there will be possibilities to investigate changes over time, and thus identify causal relationships and shed light on the ageing process of older adults with long-standing SCI.

The most common functional limitations in the sample (e.g., reduced function in upper and/or lower extremity, incoordination) are found in older adults in general as well. This implies that although SCI is a specific diagnosis, the results of this thesis may also be applicable to people with other diagnoses.

One person (me) performed all the HE assessments. The inter-rater reliability of the HE when used in samples of the general ageing population is moderate to good, but with all the HAs to relate to in the SASCIS sample, I believe that the one-person performance was beneficial for the consistency in the assessments. In addition, the amount of data collection alerted me to the challenges regarding reliability and validity that motivated the Psychometric study. With more persons involved, these important aspects might have remained unnoticed.

This is the first time the HE has been used systematically with a sample with a certain diagnosis with complex functional limitations such as the consequences of a

SCI. It is also the first time the HE has been used in a sample with such an extensive frequency of dwellings with housing adaptations and prevalent use of mobility devices. Using well-established, research-based and internationally available instruments is a strength, and provides possibilities for similar studies and comparative research. Moreover, using an assessment instrument out of its original context is challenging, but also necessary for continuous optimization and development.

A limitation of the thesis is that the need for extended housing-related information such as structured collection of data on housing adaptations was not identified beforehand. Consequently, I had to stay with the detailed field notes mainly containing descriptive information of the observed adaptations, recorded at the home visits. Specific details on the housing adaptations, like date of implementation and type of financing (private/grant), would have required additional ethical permit and contacts with many local authorities (municipalities) to collect the necessary data. However, such data would be valuable for a follow-up study on the housing situation of the SASCIS sample and is possible to retrieve for future studies.

The sample size is also worth a comment. The sample size is small in general terms, but considering the number of eligible participants (N=184) and the high response rate (67%), it is nevertheless substantial. Furthermore, SCI studies often focus on only one of the injury severity groups, although in SASCIS all SCI aetiologies are included. It is interesting to compare severity groups, as are comparisons with other studies, but with small sub-groups it would not be valid to draw any solid conclusions of such analyses.

## Future perspectives

This thesis contributes with new knowledge on housing accessibility and participation among older adults with long-standing SCI. Further research along these lines should be carried out in other parts of Sweden as well as in other national contexts, to enhance our understanding of the housing situation of this population and provide a base for evidence based, tailored, interventions.

As housing accessibility is associated with perceived participation, it would be interesting to investigate whether accessibility is associated with other health-related aspects, such as quality of life or physical activity. This would widen our understanding of what impact the physical environment has on health.

We have objective information on what environmental barriers generate the most accessibility problems for this population, although we do not know whether this is in compliance with the opinion of the individuals. Interviews with a sub-sample of

the participants to explore their perceptions of accessibility and other aspects of housing would provide a better understanding of the housing situation of older adults with long-standing SCI.

# Conclusions

This thesis contributes with new knowledge on the housing accessibility situation and its associations with participation among older adults with long-standing SCI, as well as new knowledge on accessibility assessments in this population.

- Older adults with longstanding SCI perceive their participation as good or very good in general, which is positive considering that a majority of older adults with longstanding SCI have severe injuries and complex functional limitations.
- Living in housing with more accessibility problems is related to less participation and autonomy, and more participation problems. Hence, improved housing accessibility may also affect perceived participation, but any causal relations remain to be investigated and confirmed.
- Housing adaptations and use of mobility devices are found to threaten the reliability and validity of the HE. Further optimization of the HE is necessary to capture P-E fit in populations with specific characteristics.
- Critical and informed choices are crucial for choice of assessment methods. Use of assessment instruments out of its original context requires special attention to what the instrument is targeting, what context it was designed for and what the instrument is based on. Additional instruments may be considered to cover the housing situation in a broader sense.
- Housing adaptations and accessibility problems are common among older adults with long-standing SCI, and appear to be more common the greater the severity of injury, which can be expected. This facet of the results supports the Ecological Theory of Ageing, including the docility hypothesis.
- Kitchens, entrances and hygiene areas often hold a frequent number of housing adaptations as well as a frequent number of environmental barriers. Consequently, to arrive at well-functioning solutions these areas need special attention in accessibility assessment and housing adaptation situations.
- Regardless of the comprehensive welfare system and high housing standards in Sweden, this thesis shows that there are still housing



accessibility issues to address. Aiming at accommodating the needs of the population at large, rather than spending public funding on individually tailored housing adaptations should be considered both in refurbishments and in new construction.

# Practical implications

The findings in this thesis may serve as a foundation for occupational therapists and other professionals when planning, and evaluating interventions concerning housing accessibility and participation targeting older adults with long-standing SCI.

- As housing accessibility also affects participation and not only concern the physical environment, the housing accessibility situation of older adults with long-standing SCI should be routinely followed up to ensure optimal accessibility over time and possibly support additional aspects of health.
- Until recommendations for how to ensure reliability and validity when assessing cases with extensive housing adaptations and use of mobility devices are made, the HE should be used with caution under such circumstances. To support the analysis of collected data, detailed documentation of housing adaptations and use of mobility devices is recommended.
- In particular, kitchens, entrances and hygiene areas should be thoroughly evaluated when planning and implementing housing accessibility interventions for older adults with long-standing SCI. This knowledge is valuable for the OT in the housing adaptation process.



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