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Housing accessibility and its associations with participation among older adults living with long-standing spinal cord injury

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Abstract

Objectives: To describe the housing situation and aspects of participation among older adults living with long-standing spinal cord injury (SCI) with attention to SCI severity, and to examine whether and how objective housing accessibility (based on objectively measurable criteria) is associated with aspects of participation.

Design: Cross-sectional study utilizing the assessment tools Impact on Participation and Autonomy (IPA) and Housing Enabler (HE). Adjusting for demographic, social and injury related data, associations between objective housing accessibility and aspects of participation were analyzed by means of ordinal regression models.

Setting: Home and community settings.

Participants: Older adults (≥ 50 years) ($N=123$), with a traumatic or non-traumatic SCI for at least 10 years. To make comparisons within the sample, three groups of SCI severity were formed using the American Spinal Injury Association (ASIA) Impairment Scale.

Results: Housing adaptations and environmental barriers were common and differed between SCI severity groups; those with AIS D injuries had fewer adaptations and more environmental barriers indoors. A majority of the participants in the total sample perceived their participation as good or very good in most of the IPA activities studied. Accessibility indoors was significantly associated with autonomy indoors ($P=0.009$), family role ($P=0.002$) and participation problems ($P=0.004$); more accessibility problems were associated with less participation and more participation problems.

Conclusion: This study indicates that optimizing the housing environment for older adults with SCI can potentially increase their participation and make them more autonomous. Further studies based on longitudinal data are needed to determine the causality of the associations identified.

Keywords: architectural accessibility, health services for persons with disabilities, environment, occupational therapy, personal autonomy, spinal cord injuries

Introduction

Survival and longevity after a spinal cord injury (SCI) have greatly improved thanks to advances in acute treatment, rehabilitation and physiatric care.¹ Due to such advances after the second World War, persons with SCI age in larger numbers into their 50s, 60s, 70s and older, and life expectancy has increased.^{2,3} The SCI population is diverse and there are considerable differences between aging with SCI acquired many years ago and aging when being an older adult already at the time of the injury. There are also differences according to level and severity of injury.¹ Regardless of these differences, it is important to be able to maintain an independent living while aging with SCI. Housing accessibility as a condition for an independent living and participation as a component of independent living are both affected by a SCI.⁴ Even though research on aging with SCI has increased, little is known about older adults who have lived with SCI for many years. When it comes to housing accessibility and participation among older adults living with SCI for 10 years or more, knowledge is even more limited.

Physical environmental barriers in the home and its immediate surroundings 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.^{5,6} That is, the concept describes the interaction of a personal (P) and an environmental (E) component, both objectively assessed on the basis of detailed instructions and criteria.^{5,7} A recent report from the Swedish government has shown that environmental barriers as objectively observable factors are common in the ordinary housing stock overall.⁸ 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 manage everyday life.⁹ As to the methodology for studies on housing accessibility among people with SCI, to date the majority of the few published studies focusing on aspects of housing relied on participant perceptions.¹⁰⁻¹² That is, studies using assessments capturing accessibility as an objective phenomenon are to a great extent lacking.

Participation is an important goal in rehabilitation¹³⁻¹⁴ and has been found to reduce the risk of mortality related to SCI.¹⁵ Taking environmental factors and social roles into account, in the present study we adopted the definition of participation as stated in the International Classification of Functioning, Disability and Health (ICF), that is, “involvement in a life situation”.¹⁶ 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 operationalization of participation.¹⁷

Knowledge of how to provide aging individuals with an appropriate environment and opportunities that can strengthen autonomy and participation is of interest to improve their situation. In this context accessible housing environments are important in order to support autonomy and participation in later life in the general population,¹⁸⁻²⁰ as well as in sub-groups with specific diagnoses. For older adults with SCI, a life characterized by autonomy, independent activities and participation may be particularly challenging. For example, a recent study with SCI users of powered mobility devices found that objective accessibility problems at entrance doors were significantly associated with restrictions in autonomy.²¹ Without mentioning any specific environmental arena, another study asserted that the physical environment is perceived as limiting participation by people with SCI.⁹ 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.²² Consequently, additional studies are needed to explore environmental impact, housing accessibility and participation among older adults with SCI.

The objective of this study was twofold: 1) to describe the housing situation and aspects of participation among older adults living with long-standing SCI, with attention to SCI severity; 2) to examine whether and how objective housing accessibility is associated with aspects of participation.

Methods

The present study was based on a sub-set of data from the baseline data in the Swedish Aging with Spinal Cord Injury Study (SASCIS)²³. SASCIS aims to increase knowledge of factors associated with healthy aging in older adults with long-standing SCI. The baseline data collection was conducted by two of the authors (L.N. and S.J.) through home visits including structured interviews based on a study-specific questionnaire and seven internationally established assessment tools. In addition, five assessment tools suitable for self-administration were sent to the participants in advance, and were reviewed during the subsequent home visits to minimize missing data. Moreover, information was retrieved from the participants' medical records, including socio-demographic data (e.g., age and sex) and information about the SCI (e.g., cause of injury, level and severity of injury). For further details, see design and methodology overview and descriptive baseline results reported by Jørgensen et al.²³

Participants

Participants were recruited through clinical databases at the SCI unit at Skåne University Hospital, Lund, which has the south of Sweden as catchment area. The current population is approximately 1,770,000 people (out of approximately 9,800,000 people in total in Sweden). All people with SCI that have been in contact with the SCI unit over the four past decades were included in the databases. The main inclusion criteria for SASCIS were: being 50 years of age or older and having a traumatic or non-traumatic SCI for at least 10 years. All non-traumatic injuries were non-progressive. The participants were also required to understand written and oral information in Swedish and reside in the southern part of Sweden (for details, see Jørgensen et al.).²³

A total of 184 people matched the inclusion criteria and were invited to participate. The final study sample consisted of 123 individuals (87 men) with a mean age of 63 years (i.e., a 67% participation rate). The mean time since injury was 24 years and the mean age at the time of injury was 39 years. The motor and sensory impairment was 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).²⁴ 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 ($N=60$).²³ For further sample characteristics, see Table 1.

(Table 1 about here)

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.²³

Data collection tool on housing situation and accessibility

To assess environmental barriers and housing accessibility the Housing Enabler (HE) was used. The HE is a scientifically established instrument for assessing and analyzing housing accessibility problems.^{25,7} 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. Herein, dependence on mobility devices serves as a proxy for more severe mobility limitations. Moreover, by including these items in the personal component, analysis of person-environment (P-E) interactions can be extended to cover problems that may arise from the use of such devices. The P component assessment results in a so-called 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 (present/not present) assessed based on national guidelines and standards for housing design (i.e., specifications for the design of specific housing features). 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 HE uses a computerized scoring matrix, which juxtaposes the functional limitations of an individual with the barriers

found in the housing environment. 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; cases where the individual does not have any functional limitations/dependence on mobility devices score 0. The predefined severity ratings were established by expert panels followed by subsequent revisions based on empirical results, structured rater observations and additional expert panels during a period of 20 years.^{26,7} The HE has demonstrated sufficient inter-rater reliability and construct validity and is being used in cross-national aging research on home, health and disability.²⁷⁻²⁹

Data on other characteristics of the housing situation were: overall housing standard (e.g., amenities according to national specifications, number of rooms), housing adaptations (i.e., individually tailored interventions in the housing environment) and type of housing; that is, one family house or multi-dwelling block (terms used in Sweden for single-family housing and housing with multiple apartments, respectively). These were all captured by means of project-specific questions that were answered by the raters based on observations made during the home visits.

Data collection tool on aspects of participation

Aspects of participation were assessed by using the Impact on Participation and Autonomy questionnaire (IPA), which is a generic self-evaluation assessment tool developed in the Netherlands for adults with chronic conditions.³⁰ The IPA was

developed to be used in research and to evaluate the effects of rehabilitation interventions.³⁰ It consists of 31 items in five domains (each constituting one sub-scale), rated on a five-point ordinal scale (ranging from 0 = 'very good' to 4 = 'very poor').³¹ Based on close inspection of the content at item level as related to the study aims, for the present study we focused on two of the domains, namely autonomy indoors and family role (seven items each). As recommended by the IPA manual, we computed scores for the two domains by assigning the median value of the responses in the respective domain.³² In a few cases with median values between two integer values (only .5 values can occur), we had to round the values to fit the ordinal scale. Based on the distribution of responses we merged 3 (poor) and 4 (very poor) into one category in the regression models (described later). 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. Once again based on close inspection of the content at item level as related to the study aims, we included problem ratings regarding mobility, self-care, family role, financial situation, leisure, and social relations. In a similar way as for the two domains autonomy indoor and family role, a score for participation problems was computed by assigning the median value of the responses (ranging from 0 to 2). Internal consistency and test-retest reliability for the IPA have been found to be good, and convergent and discriminant validity are supported by research. The instrument is considered reliable and valid for use with people with chronic disorders, including SCI.³⁰ The Swedish version of the IPA has been tested among individuals with SCI with satisfying psychometric results.³³

Procedure

Data were collected by two experienced data collectors with expertise in rehabilitation; one is a registered occupational therapist (L. Norin; first author) and the other a licensed physician (S. Jörgensen; fourth author). Prior to the data collection they both underwent project-specific training, including a graduate course in objective accessibility assessment.

Statistical analysis

Descriptive statistics were used to present data on the housing situation and on aspects of participation in the three SCI severity groups. Group differences were analyzed by means of the Kruskal-Wallis test and/or the Mann-Whitney U-test for ordinal variables, and the Chi-square test for nominal variables. Where significant differences were found, post-hoc analyses were carried out applying significance levels adjusted with Bonferroni correction.

To examine the association between accessibility and aspects of participation we used ordinal regression under the cumulative odds model with location parameters only.^{34,35} This model estimates the average odds ratio (OR) of all possible dichotomizations of the ordinal dependent variable. All ordinal dependent variables were coded such that an OR greater than one implied a negative effect. The dependent variables representing aspects of participation were the scores for the domains autonomy indoors, family role and participation problems, respectively. First we carried out univariable regression analyses with indoor, exterior surroundings and entrance accessibility as independent variables.³⁶ The link function for the domain autonomy indoors was the negative log-log and the link function for family role and participation problems was the probit. Thereafter we proceeded with the multivariable regression

analyses. To reduce complexity, we decided to focus the analyses on the indoor subsection of objective accessibility, which showed the most consistent significant associations with all the aspects of participation under study. In these analyses adjustments were made for age (<65/≥65), sex (man/woman), living with partner (yes/no), SCI severity group (Tetraplegia AIS A-C, Paraplegia AIS A-C, All AIS D) and use of assistance (yes/no).

All computations were conducted using IBM SPSS Statistics 22 for Windows (IBM Corporation, Armonk, NY, U.S.). P-values <0.05 were considered to be statistically significant unless Bonferroni correction was applied. The 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).

Ethics approval

The SASCIS was approved by the Regional Ethical Review Board in Lund (No.2010/692). The Helsinki declaration for research on humans was followed. All participants were given both written and oral information about the study and informed about their right to withdraw at any time. Written informed consent was obtained before the start of the data collection.

Results

Housing situation and objective accessibility

Nearly all of the participants (>95% in each group) lived in dwellings that exceeded the lowest acceptable level according to current Swedish housing standard. More than half of the total sample lived in a one-family house (50-58% in the three groups).

The All AIS D group reported significantly less housing adaptations, that is, 60% compared to >90% in the other two groups ($P<0.001$). With respect to the total number of environmental barriers (i.e., in close exterior surroundings, at entrances and indoors), the All AIS D group lived in dwellings with significantly more barriers than those in the Paraplegia AIS A-C group ($P<0.001$), and with significantly more barriers indoors compared to both the Tetraplegia AIS A-C ($P<0.001$) and Paraplegia AIS A-C group ($P<0.001$).

Regarding accessibility problems, the participants in the Tetraplegia AIS A-C group lived in dwellings with significantly more total accessibility problems than those in the Paraplegia AIS A-C group ($P<0.001$). As to the accessibility problem scores for the different housing sections, the Tetraplegia AIS A-C group had significantly more problems in exterior surroundings and indoors than the Paraplegia AIS A-C as well as All AIS D groups. For further details, see Table 2.

(Table 2 about here)

Aspects of participation

A majority of the participants perceived their participation as good or very good in most of the activities studied. In general, the participants rated their participation for the activities in the domain “Autonomy indoors” better than the activities in the domain “Family role”. The participants in the Paraplegia AIS A-C group rated their participation regarding “Getting around indoors when I want” significantly better compared to the All AIS D ($P=0.007$). Regarding “Heavy housework jobs” those in the Tetraplegia AIS A-C group rated their participation better than those in the Paraplegia AIS A-C group. For further details, see Table 3.

(Table 3 about here)

Additionally, a large proportion of the participants perceived either no or minor problems with participation. Mobility (24%), self-care (23%) and leisure (23%) were the sub-domains which reportedly caused the highest frequency of severe problems in the total sample. There were no significant differences between the three SCI severity groups with regard to the participation problem areas. More detailed information is presented in Table 4.

(Table 4 about here)

Associations between objective accessibility and participation

The univariable regression models showed that indoor accessibility was significantly associated with all aspects of participation under study, that is, autonomy indoors ($P=0.006$), family role ($P=0.003$) and participation problems ($P=0.003$). Accessibility in the exterior surroundings was significantly associated with autonomy indoors ($P=0.012$) and family role ($P=0.048$) but not with participation problems. Likewise, entrance accessibility was significantly associated with autonomy indoors ($P=0.008$) and family role ($P=0.013$) but not with participation problems. Total accessibility, where most of the items relate to indoor accessibility, was also significantly associated with all three aspects of participation. All the significant results indicated that living in a dwelling with more accessibility problems was associated with less participation and autonomy and more participation problems.

The multivariable regression models showed that accessibility indoors was significantly associated with autonomy indoors ($P=0.009$), family role ($P=0.002$) and participation problems ($P=0.004$) (see Table 5). That is, living in housing with more accessibility problems was associated with less participation and more participation problems. The three regression models explained 13.5% to 18.1% of the variance. Among other factors that could influence participation, age was significant in relation to autonomy indoors ($P=0.026$) and family role ($P=0.040$). That is, those <65 years of age reported better participation in the two domains. For the domain family role, SCI severity was significant in that the participants in the All AIS D group and the Tetraplegia AIS A-C group perceived better participation compared to the Paraplegia AIS A-C group (reference category). For further details, see Table 5.

(Table 5 about here)

Discussion

The main finding of this study is that more objective accessibility problems are significantly associated with less participation and more participation problems among older adults living with long-standing SCI. Objective accessibility problems indoors are significantly associated with autonomy indoors and family role, which sheds new light on the living situation of older adults with SCI. The findings of the present study also pave the way for more research in this area. While important for health and well-being of older adults and people with disabilities, objective accessibility is still only one out of several aspects with regard to the housing situation that requires attention in research as well as in rehabilitation practice. For example, several perceived aspects of housing deserve further research attention.^{13,21} As discussed by Noreau et al. more than a decade

ago, accessible housing can facilitate activities of daily living, and the possibility to go outside is a necessary condition for several aspects of participation.⁴ Adding to what is already indicated by studies using data on perceived accessibility, the present study increases the knowledge about objective housing accessibility (including details regarding specific housing sections) and participation among older adults living with long-standing SCI.¹⁰⁻¹²

According to the IPA, “autonomy indoors” is about getting around indoors and performing personal activities of daily living like grooming and dressing, while the “family role” is about taking care of the home.²⁹ As described in a recent study, older adults with SCI experience frustration when activities of daily living take precedence over more rewarding activities.³⁷ This suggests that activities such as those included in the IPA domains “autonomy indoors” and “family role” are important and need to run smoothly in an accessible environment 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.³⁸

With advancing age, daily life tends to be more and more focused around the home which also underpins the importance of a well-functioning housing situation.¹⁸ Based on the findings from a study on the perceived influence of the environment on social participation among individuals with SCI, housing was considered the most important physical environmental arena supporting community participation, and the participants considered the lack of accessibility in their homes as an obstacle to participation.⁴ In a previous study using data from the SASCIS, Pettersson et al. found that the more functional limitations an individual had the greater the restriction in autonomy indoors and outdoors.²¹ In order to shed further light on the housing situation as related to participation among older adults with SCI, data on perceived aspects of housing such as

feeling attached to one's home and usability should be included in future studies, not the least in the upcoming follow-up studies of the SASCIS.³⁹

The Tetraplegia AIS A-C group lived in dwellings with more accessibility problems than the other two groups, but this group did not perceive more participation problems. One would assume that they would perceive their participation as poorer and their participation problems as more severe. Even though everyone in the Tetraplegia AIS A-C group and 66% in the Paraplegia AIS A-C group used some kind of assistance, they did not differ in the perceived aspects of participation. In the multivariable regression models we adjusted for use of assistance, but it was not significantly associated with any of the aspects of participation under study. However, in one of the few studies published concerning SCI and participation related to the physical environment, it was found that individuals with tetraplegia considered home care services as a facilitator for participation to a greater extent than those with paraplegia.⁴ Those with tetraplegia also found that environmental facilitators were of a social nature while the main obstacles were physical. Given this complexity, more research is needed to build up the evidence-base required for the development of interventions with the potential to improve participation in different sub-groups of people with SCI.

A plausible explanation for the finding that the All AIS D group had more environmental barriers indoors and fewer housing adaptations than the other groups but did not have the most accessibility problems is that their SCI was less severe. That is, with less complex functional profiles, the accessibility score is lower even if there are a considerable number of environmental barriers. Earlier studies based on general population samples of very old people have indicated that the HE accessibility problem score is predominantly influenced by the P component (i.e., the functional capacity of the individual).⁴⁰ Bearing this in mind, to support the interpretation of this facet of the

findings, we used SCI severity as a proxy for functional capacity in our regression models. The finding that aspects of participation nevertheless are significantly associated with accessibility problems can therefore be interpreted as indicating a more balanced influence between the P and E components on the accessibility problem score in a SCI sample. Hence, there is a need for in-depth methodological studies to substantiate such a conclusion.

The results indicate that a large proportion of older adults with SCI perceive their participation as good. Lundström et al. have studied the experience of participating in everyday activities among people aging with tetraplegia.³⁷ They found that after a number of years living with their SCI, the participants changed their priorities and chose to drop activities which were too demanding in favor of less demanding ones, thus adapting to their situation and capacity.³⁷ Similarly, in a previous study, using a subsample of the SASCIS, focusing on autonomy and objective accessibility among the powered mobility users ($N=48$), Pettersson et al. found that the longer the participants had lived with their injury, the less restrictions they perceived as having regarding autonomy indoors.²¹ Since everyone in our study sample had lived with their injury for at least ten years, adaptation over time could be a reason as to why many of the participants were quite content with their participation and reported few or no participation problems. Nevertheless, a substantial proportion (43%) of them reported severe participation problems in at least one of the areas under study. This finding supports the need for interventions to improve the possibilities for participation. Severe participation problems were mostly reported with regard to mobility, self-care and social relations. As the performance of mobility and self-care activities is related to environmental barriers such as insufficient maneuvering space and equipment/controls difficult to reach, interventions targeting housing design features could be a way to

achieve better participation. Again, this highlights the need for further research considering different aspects of the housing environment.

The reason for focusing on autonomy indoors and family role was that we found those domains of participation the most relevant in relation to the housing environment and therefore also most relevant according to the study aims. Actually, a study on participation after acquired brain injury also using the IPA supports this design strategy, and we consider our decision to select domains which are more closely related to accessibility a methodological strength.⁴¹

Until now, the HE has never been used among people with SCI. Using the instrument for the baseline data collection for the SASCIS, we made observations indicating some validity problems. As a majority of the participants lived in dwellings where individual housing adaptations had been implemented and a substantial proportion used powered wheelchairs, the P and E components of accessibility differed from those of the population in general.²¹ It should be kept in mind that the assessment of the E component is based on dichotomizing whether a design feature meets the current national standards for housing design or not. Since individual housing adaptations typically result in solutions going beyond the requirements posed by the national specifications of housing standards, the HE might not be sufficiently sensitive to environments where extensive housing adaptations have resulted in designs that go far beyond what is stipulated by the official (minimum) standards for housing design. Moreover, modern powered wheelchairs have functions that might compensate for some of the accessibility problems captured by the HE. That is, with only one item intended to cover all kinds of wheelchairs as part of the P component of the instrument, the HE does not optimally capture the diversity of today's variety of powered mobility devices. To some extent the P-E interactions seem to be specific for people with SCI, and the HE

scoring matrix might produce some artifacts that potentially challenge the validity of the resultant accessibility scores. Therefore, the present study and the previous study which focused on the users of powered mobility devices in the present sample constitute the starting-point for further methodological development.²¹

With respect to the limitations related to the sample size and considering our specific interest in housing aspects related to participation, we deliberately chose to compute regression models with rather few variables. Since the intention was to explore relationships hitherto not studied rather than creating prediction models, we consider this a valid analysis approach, even if the variance explained was relatively low. However, a note of caution is in place, as there were warnings for cells with zero frequencies during the analysis. The empty cells are mostly due to the wide range of possible values of the accessibility problem score but also a consequence of the small sample size. The different tests applied (Model Fitting Information, Goodness-of fit, Test of Parallel Lines) show that the multivariable models fit the data well. Nonetheless, in the multivariable model with “family role” as the outcome variable, there was a significant result of the test of parallel lines, i.e. the assumption of an ordinal regression that the slope coefficients are the same across response categories was not fulfilled. In order to investigate this further, we reanalyzed this model with the total sample divided into two groups of SCI severity: All AIS D and Tetraplegia AIS A-C/Paraplegia AIS A-C. We found the same result regarding the significant relationship between indoor accessibility and family role (data not shown), and with non-significant result of the test of parallel lines. With this in mind, we consider the significant test of parallel lines as a minor problem.

Conclusion

The significant associations between accessibility indoors and participation related to autonomy indoors, family role and participation problems identified in the present study indicate the importance of objective housing accessibility for older adults living with long-standing SCI. Considering these results, by optimization of the housing situation for this group there is potentially much to be gained in terms of participation and autonomy. Further studies based on longitudinal data are needed to determine the causality of the associations identified.

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Conflict of Interest: Susanne Iwarsson and Björn Slaug are the copyright holders and owners of the Housing Enabler (HE) assessment tool and software, provided as commercial products. The other authors have no competing interests.

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Table 1. Characteristics of the 123 participants with long-standing spinal cord injury

Variable	Tetraplegia AIS A-C (N=22)	Paraplegia AIS A-C (N=41)	All AIS D (N=60)	Total (N=123)
Sex, % men	68	83	63	71
Age, years Mean, SD	60 ± 7	63 ± 9	65 ± 9	63 ± 9
Age at injury, years Mean, SD	31 ± 13	36 ± 15	45 ± 16	39 ± 16
Time since injury, years Mean, SD	30 ± 9	27 ± 12	20 ± 11	24 ± 12
Cause of injury, %				
Traumatic ^a	82	83	40	62
Non-traumatic ^b	18	17	60	38
Living with partner, %	59	51	45	50
Use of assistance ^c , %	100	66	57	67

^a Traffic/transportation (motor vehicle, train, bicycle), fall, workplace accident, diving accident, gunshot/assault/torture, other traumatic (e.g. sports, leisure activities).

^b Spinal tumor, spinal disc herniation, spinal arteriovenous malformation, spinal infarction, spinal infection.

^c Including personal assistance, home-help service, dependent on next-of-kin/significant other, personal security alarm, help with cleaning/household/maintenance, escort, other.

Table 2. Housing situation and objective accessibility among older adults with long-standing spinal cord injury (N=123)

Housing variable	Tetraplegia AIS A-C (N=22)	Paraplegia AIS A-C (N=41)	All AIS D (N=59) ^a	P-value
Necessary housing standard, (%) ^b	100	95	95	0.586
Housing adaptation,%	95	90	60	<0.001 ^{2,3}
Number of environmental barriers, median (q1-q3) ^c				
Exterior surroundings	9 (7-13)	8 (6-12)	9 (7-11)	0.311
Entrances	10 (7-23)	9 (6-15)	11 (8-17)	0.359
Indoor	42 (40-46)	42 (39-48)	49 (45-54)	<0.001 ^{2,3}
Total	65 (58-78)	61 (54-69)	71 (64-78)	<0.001 ³
Accessibility problem score, median (q1-q3) ^c				
Exterior surroundings	74 (41-96)	46 (21-66)	46 (27-63)	0.028 ^{1,2}
Entrances	75 (38-149)	60 (41-79)	53 (33-77)	0.146
Indoor	205 (169-227)	137 (103-164)	162 (105-208)	<0.001 ^{1,2}
Total	336 (283-429)	231 (182-295)	288 (185-353)	<0.001 ¹
Type of housing, %				
Multi-dwelling block	50	46	42	0.812
One-family house	50	54	58	

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:

¹ Tetraplegia AIS A-C vs Paraplegia AIS A-C.

² Tetraplegia AIS A-C vs All AIS D

³ Paraplegia AIS A-C vs All AIS D

^a Data for one observation missing. ^b According to Swedish National Board of Housing, Building and Planning.

^c According to the Housing Enabler ²⁵.

Table 3. Comparison of participation levels between three SCI severity groups on the Impact on Participation and Autonomy (IPA) questionnaire (N=123)

Participation domain Item	Tetraplegia AIS A-C (N=22)				Paraplegia AIS A-C (N=41)					All AIS D (N=60)					P-value	
	Very good %	Good %	Fair %	Poor %	Very poor %	Very good %	Good %	Fair %	Poor %	Very poor %	Very good %	Good %	Fair %	Poor %		Very poor %
Autonomy indoors																
Getting around indoors where I want	54	27	9	4	0	44	19	29	0	2	28	35	27	5	3	0.055
Getting around indoors when I want	54	14	18	4	4	61	15	29	0	2	30	38	23	3	3	<0.001 ²
Washing, dressing, grooming the way I want	32	23	41	0	0	27	37	22	7	2	33	32	25	2	7	0.947
Washing, dressing, grooming when I want	23	36	36	0	0	29	29	27	5	2	37	30	25	2	5	0.727
Going to bed when I want	27	27	32	2	0	39	17	24	7	7	40	33	15	5	5	0.439
Going to the toilet when I need ^a	23	32	27	0	0	37	29	24	2	2	45	27	12	8	7	0.741
Eating and drinking when I want	54	27	14	0	0	63	17	12	2	0	67	25	5	2	0	0.637
Autonomy indoors score	38	33	29	0		41	31	23	5		39	39	17	5		0.970
Family role																
Contributing to looking after the home	4	32	36	18	4	34	32	7	17	15	22	23	32	17	5	0.597
Minor housework jobs the way I want	36	45	14	0	0	34	34	15	5	7	40	32	22	2	2	0.665
Heavy housework jobs the way I want ^b	18	41	23	9	0	17	15	14	24	22	22	10	28	17	22	0.029 ¹
Getting housework done when I want	32	41	23	0	0	19	37	15	15	10	22	22	35	15	5	0.055
Repairs and upkeep the home ^c	14	27	23	23	0	10	17	19	22	27	15	8	30	17	25	0.081
Fulfilling my role at home	54	23	41	4	0	27	19	29	17	2	22	28	27	15	3	0.760
Spending income as wished	54	23	9	9	0	37	34	15	5	5	32	27	27	8	5	0.100
Family role score	19	48	33	0		26	31	15	28		17	31	39	14		0.377

Note: In Autonomy indoors score and Family role score, Poor and Very poor were merged into one category.

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:

¹ Tetraplegia AIS A-C vs Paraplegia AIS A-C

² Paraplegia AIS A-C vs All AIS D

^a Due to missing data: Tetraplegia AIS A-C N=18. ^b Due to missing data: Tetraplegia AIS A-C N=20. ^c Due to missing data: Tetraplegia AIS A-C N=19.

Table 4. Comparison of participation problems between three SCI severity groups (N=123)

Participation problem item ^a	Tetraplegia AIS A-C (N=22)			Paraplegia AIS A-C (N=41)			All AIS D (N=60)			P-value
	No problems %	Minor problems %	Severe problems %	No problems %	Minor problems %	Severe problems %	No problems %	Minor problems %	Severe problems %	
Mobility	4	73	18	15	58	22	7	65	27	0.596
Self-care ^b	9	54	32	32	44	17	30	45	22	0.103
Family role	27	45	23	27	49	19	22	60	17	0.972
Financial situation	50	32	14	54	27	15	48	33	17	0.818
Leisure	23	45	27	27	46	19	18	57	22	0.700
Social relations	32	50	14	24	61	10	23	47	28	0.237
Problem score	19	57	24	21	62	18	17	56	27	0.630

^a IPA-S: Impact of Participation and Autonomy (Swedish version) ³³.

^b Due to missing data: Paraplegia AIS A-C N=19, All AIS D N=58.

Table 5. Multivariable ordinal regression models with aspects of participation (autonomy indoors, family role, participation problems) as the dependent variables among older adults with long-standing spinal cord injury (N=118)

Independent variable	Autonomy indoors (0-3)		Family role (0-3)		Participation problems (0-2)	
	Odds Ratio (95% CI)	P-value	Odds Ratio (95% CI)	P-value	Odds Ratio (95% CI)	P-value
Accessibility problems indoors	1.00 (1.00-1.01)	0.009	1.00 (1.00-1.01)	0.002	1.00 (1.00-1.01)	0.004
Age						
< 65 years	0.56 (0.34-0.93)	0.026	0.64 (0.42-0.98)	0.040	1.11 (0.71-1.74)	0.644
≥ 65 years	Ref.		Ref.		Ref.	
Sex						
Women	0.72 (0.41-1.26)	0.247	0.91 (0.58-1.42)	0.665	1.51 (0.94-2.44)	0.089
Men	Ref.		Ref.		Ref.	
Living with partner						
Yes	0.67 (0.39-1.13)	0.136	0.91 (0.59-1.40)	0.671	1.01 (0.64-1.60)	0.958
No	Ref.		Ref.		Ref.	
SCI severity						
All AIS D	1.12 (0.54-2.31)	0.755	1.91 (1.03-3.54)	0.041	1.52 (0.79-2.93)	0.208
Tetraplegia AIS A-C	1.30 (0.61-2.77)	0.494	2.01 (1.06-3.79)	0.032	1.39 (0.71-2.71)	0.339
Paraplegia AIS A-C	Ref.		Ref.		Ref.	
Use of assistance ^a						
Yes	1.35 (0.75-2.45)	0.315	1.45 (0.90-2.34)	0.131	1.27 (0.77-2.11)	0.352
No	Ref.		Ref.		Ref.	
Pseudo R-square						
Nagelkerke	0.149		0.181		0.135	

Note: Due to missing data, N=118 in the multivariable regressions. Statistically significant p-values are bolded.

^a Including personal assistance, home-help service, dependent on next-of-kin/significant other, personal security alarm, help with cleaning/household/maintenance, escort, other.