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Research article

# Availability and need of home adaptations for personal mobility among individuals with spinal cord injury

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**Objective:** To identify the availability and unmet need of home adaptations (HAs) among the Swiss population with spinal cord injury (SCI).

**Design:** Cross-sectional study.

**Setting:** Swiss Spinal Cord Injury Community Survey 2012.

**Participants:** Individuals aged 16 or older with chronic SCI living in Switzerland.

**Interventions:** Not applicable.

**Outcome measures:** The availability of ten HAs (self-report) was analyzed by sex, age, living situation, indoor mobility, SCI severity, SCI etiology and time since SCI. The unmet need (self-report of not having a HA but needing it) of HAs was analyzed by financial hardship.

**Results:** Among the 482 study participants (mean age 55.2 years, standard deviation 15.0 years, 71.6% males), 85.1% had at least one HA. The most frequent HA was a wheelchair accessible shower (62.7%). Availability of HAs markedly varied with indoor mobility (e.g. 38.4% of participants using a wheelchair had a stair lift compared to 17.4% of those walking) and with SCI severity (e.g. 54.8% of those with complete paraplegia had a wheelchair accessible kitchen worktop compared to 26.0% of those with incomplete paraplegia). Unmet need was highest for adjustable kitchen worktops (78.7% of those with a need) and adjustable kitchen cabinets (75.7%) and lowest for wheelchair accessible showers (9.4%) and grab bars next to the toilet (8.5%). No significant differences in unmet need were found when stratifying for financial hardship.

**Conclusion:** Availability of HAs is dependent on indoor mobility and SCI severity. There is a considerable degree of unmet need for selected HAs, which couldn't be explained by financial hardship.

**Keywords:** Architectural accessibility, International Classification of Functioning, Disability and Health (ICF), Mobility limitation, Spinal cord injury, Disability

## Introduction

Optimal mobility refers to the ability to move around safely and freely.<sup>1</sup> Mobility is an important element of human wellbeing<sup>1</sup> and capacity<sup>2</sup> and has shown to be relevant for community reintegration,<sup>3</sup> self-management,<sup>4</sup> quality of life<sup>5</sup> and self-esteem<sup>6</sup> among individuals with spinal cord injury (SCI). A recent review found that restoring mobility after injury was one of the highest priorities among individuals with a newly acquired SCI.<sup>7</sup> Mobility barriers within the home setting can lead to

limitations involving restricted health self-management<sup>4</sup> and less participation or integration in the home, social and community area.<sup>1,8,9</sup>

Home adaptations (HAs) for disabled individuals can be defined as “any permanent alteration to a building carried out with the intention of making the building more suitable for a disabled person.”<sup>10</sup> Adaptations of the built home environment can improve daily functioning<sup>11,12</sup> and restore the optimum level of an individual's mobility after facing a SCI.<sup>8</sup> Suitable HAs can lead to an improved feeling of safety, e.g. when taking a shower, and an overall restoration of life, e.g. improved mobility inside the house and access to the outside

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world.<sup>10</sup> The health status of other members of the household may also improve both mentally and physically.<sup>10</sup> An adequately adapted home can reduce costs by allowing individuals to leave high-cost institutions like hospitals or rehabilitation centers.<sup>11</sup> Moreover, earlier hospital discharge may reduce levels of depression and anxiety among individuals with SCI.<sup>13</sup>

Previous research has shown that the provision of HAs lacks a systematic approach.<sup>14</sup> The knowledge of which HAs are being used most often and which HAs are characterized by a high unmet need could be used to improve the provision of HAs. Improved provision could be achieved by increasing funding for HAs, adapting building policies, raising the number of accessible housing facilities<sup>11</sup> and educating health professionals (including therapists, nurses and social workers) about distribution and use of HAs.<sup>15</sup>

The WHO has reported that unmet needs concerning accessible housing for disabled individuals encompass a global problem, and is a field with only limited availability of data.<sup>11</sup> In Switzerland the reimbursement of HAs after facing a SCI, is based on an individuals' earnings, work capacity and health insurance coverage.<sup>16</sup> Disability insurance reimburses the provision of HAs when work or functional capacity is expected to improve by at least 10% due to the adaptation.<sup>17</sup> However, if an individual requests a HA that is not included in the reimbursement scheme<sup>16</sup> or if work capacity is not expected to improve by at least 10% due to the HA, out of pocket funding is required. Accordingly, provision can be limited for individuals with a lower (before injury) income or for individuals who were unemployed before injury.<sup>16</sup> The Swiss Paraplegic Foundation supports individuals with financial difficulties to obtain HAs.<sup>16</sup>

To our knowledge there are no studies available that evaluate the availability and unmet need of HAs for individuals with SCI living in Switzerland. Therefore, the current study addresses this knowledge gap. The first aim of the study is to evaluate which HAs individuals have available (the self-reported availability of HAs). The second aim is to identify the usage patterns of the different HAs, by computing a measure for combined availability of the HAs. The third aim is to assess which HAs individuals currently don't have at their disposal, but which they indicate they need (the self-perceived unmet need of HAs).

## Method

### *Study design and population*

Self-declared availability and unmet need of HAs was retrieved from a questionnaire of the Swiss Spinal Cord Injury (SwiSCI) Community Survey, distributed between

September 2011 and March 2013.<sup>18</sup> The design of the SwiSCI study has been described previously.<sup>19</sup> Potential participants were identified through cooperation with three SCI rehabilitation centers, the national association for individuals with SCI (Swiss Paraplegics Association) and a SCI-specific home care organization (ParaHelp). The study included residents of Switzerland aged 16 or older with chronic SCI. Exclusion criteria were: congenital conditions leading to SCI, new SCI in context of palliative care, and neurodegenerative disorders.

The survey was distributed in consecutive modules. The first two modules were returned by 1549 individuals (49% response rate) and included questions on socio-demographic and socioeconomic characteristics, SCI characteristics and mobility independence. Individuals were randomly assigned to one of three additional modules; 580 individuals were invited to participate in the module containing questions about HAs, thereof 492 responded (85%).<sup>18</sup> For the present study individuals who were living in an institution (n=10) were excluded, leading to a total study population of 482 individuals.

The responsible regional research ethics committees formally approved the study. All participants provided written informed consent.

## Measurements

### **Home adaptations**

Based on the explanations given by the International Classification of Functioning, Disability and Health (ICF) for "building products and technology of buildings for private use" (code e155), we defined HAs as architectural changes to the homes of participants that enable entering and exiting the home, and accessing facilities inside the home.<sup>20</sup> The following ten HAs were investigated: stair lift, ramp, automatic door opener, grab (support) bar outside bathroom or toilet, grab (support) bar next to toilet, wheelchair accessible shower, adjustable kitchen worktop, adjustable kitchen cabinets, wheelchair accessible kitchen worktop and wheelchair accessible kitchen sink. The self-reported availability of HAs was assessed by asking study participants if they had the adaptation available to them at the time of the questionnaire. The (self-perceived) unmet need for a HA was assessed by asking participants who indicated not to have a certain adaptation, whether they needed it. Open questions were used to assess the availability and need of other HAs not specified in the questionnaire. Furthermore, participants were asked a general question on how well needs concerning 'living without barriers at home' were currently covered (six response options: 'my needs are covered

completely', 'largely', 'for a certain part,' 'for a small part', 'not at all' or 'I don't have such needs').

### Participant characteristics

The following socio-economic characteristics of the participants were collected: sex, age (categorized into five groups<sup>21</sup>: 16–30, 31–45, 46–60, 61–75 or 76+ years), living situation ('living with someone else' or 'living alone'), housing and formal support or care ('living without formal support or care in a non-adapted home', 'living without formal support or care in an adapted home', 'living with formal support or care in an adapted home', 'living with formal support or care in a community home'). Additionally perceived financial hardship was assessed with the question 'Did you experience financial difficulties that restricted your everyday life (participation) over the past four weeks?' and was dichotomized into<sup>22</sup> 'no financial difficulties' ('not applicable' or 'had no impact') or 'some or severe financial difficulties' ('has complicated my life somewhat' or 'has complicated my life massively'). The following SCI characteristics were collected: SCI etiology ('traumatic' or 'non-traumatic'), SCI severity (assessed by questions on lesion level and lesion completeness, combined into four groups<sup>23</sup>: 'incomplete paraplegia', 'complete paraplegia', 'incomplete tetraplegia' or 'complete tetraplegia'), time since injury (categorized into four groups<sup>21</sup>: 0–5, 6–15, 16–25 or 26+ years). Indoor and outdoor mobility were assessed by the self-report version of the Spinal Cord Independence Measure (SCIM-SR, items 12 and 13).<sup>24</sup> The respective items were dichotomized into<sup>25</sup> 'using a wheelchair' ('I use a wheelchair. To move around...' '...I need total assistance', '...I need an electric wheelchair or partial assistance to operate a manual wheelchair' or 'I am independent in a manual wheelchair') or 'walking' ('I walk...' '...and I need supervision while walking', '...with a walking frame or crutches, swinging forward with both feet at a time', '... with crutches or two canes, setting one foot before the other', '...with one cane', '...with a leg orthosis only' or '...without aids').

### Statistical analyses

Participant characteristics were analyzed by sex. Results are presented descriptively using absolute numbers and percentages. The availability of HAs was analyzed stratified by all participant characteristics. Results are reported using proportions and accompanying 95% confidence intervals (CIs). The limits of the CIs were computed using a logit transformation. P-values from chi-square tests were compared against a significance level of  $P \leq 0.0007$  (following a Bonferroni correction for 70 tests with a global significance level of 0.05).<sup>26</sup>

Cluster analysis<sup>27</sup> was used to assess the combined availability of the different HAs stratified by indoor mobility. First, a similarity measure between all pairs of HAs was calculated and transformed into a single measure of mutual relation between pairs of HAs, using the binary Lance-Williams nonmetric dissimilarity measure.<sup>28</sup> Next, the similarity matrix was mapped onto a two-dimensional coordinate system via multidimensional scaling<sup>29</sup> and displayed in a bubble plot. A closer proximity between two or more bubbles indicates an increased joint disposability of the respective products. The size of the bubble was set proportional to the number of participants who have the particular product available to them.

The number of participants indicating not to have a HA but needing it (the self-declared unmet need) was compared with the total need (those having the HA available plus those who don't have the HA and declare a need) using absolute numbers, proportions and 95% CIs. The limits of the CIs were computed using a logit transformation. Furthermore, results were stratified by financial hardship and analyzed by chi-square tests with a significance level of  $P \leq 0.005$  (following a Bonferroni correction for 10 comparisons with a global significance level of 0.05).

All analyses were conducted using Stata version 14 (Stata Corp, College Station, Texas, USA).

### Results

The mean age of participants (N=482, 71.6% male) was 55.2 years (standard deviation 15.0, median 44, interquartile range (IQR) 20.0–57.0 years) (Table 1). Most participants were living in an adapted home (62%). Mean time since injury was 16.2 years (standard deviation 13.2, median 12, IQR 5–25 years).

Of the participants who answered all of the questions concerning HAs (n=255), 14.9% reported to have no HAs at all, 34.1% had one to two HAs, 32.9% had three to four HAs and 18.0% had five or more HAs. The median number of HAs was 3 (IQR=0–9).

The most frequently reported HA among the entire study population was a wheelchair accessible shower (62.7%), followed by a grab bar next to the toilet (56.7%) and a ramp (45.0%). There were no significant differences in proportion of available HAs between males and females (Table 2a). With increasing age more individuals had a grab bar outside the bathroom or toilet and fewer individuals had a wheelchair accessible shower, although this finding was not statistically significant (Table 2a). There were no statistically significant differences in proportions of available HAs by living situation, however those participants who were living with someone else reported to have less HAs in

**Table 1** Participants' characteristics

	Total (N=482) n (%)	Male (N=345) n (%)	Female (N=137) n (%)
Age (years)	482 (100.0)	345 (100.0)	137 (100.0)
16–30	28 (5.8)	21 (6.1)	7 (5.1)
31–45	103 (21.4)	77 (22.3)	26 (19.0)
46–60	148 (30.7)	108 (31.3)	40 (29.2)
61–75	171 (35.5)	119 (34.5)	52 (38.0)
76+	32 (6.6)	20 (5.8)	12 (8.8)
Living arrangement	473 (100.0)	340 (100.0)	133 (100.0)
Living with someone else	363 (76.7)	266 (78.2)	97 (72.9)
Living alone	110 (23.3)	74 (21.8)	36 (27.1)
Housing and formal support/care	439 (100.0)	315 (100.0)	124 (100.0)
Without formal support/care in a non-adapted home	166 (37.8)	113 (35.9)	53 (42.7)
Without formal support/care in an adapted home	129 (29.4)	95 (30.2)	34 (27.4)
With formal support/care in an adapted home	136 (31.0)	100 (31.8)	36 (29.0)
With formal support/care in a community home	8 (1.8)	7 (2.2)	1 (0.8)
Indoor mobility	468 (100.0)	339 (100.0)	129 (100.0)
Using a wheelchair	273 (58.3)	202 (59.6)	71 (55.0)
Walking	195 (41.7)	137 (40.4)	58 (45.0)
Outdoor mobility (10 to 100 meters)	457 (100.0)	328 (100.0)	129 (100.0)
Using a wheelchair	266 (58.2)	194 (59.2)	72 (55.8)
Walking	191 (41.8)	134 (40.9)	57 (44.2)
Financial hardship	467 (100.0)	334 (100.0)	133 (100.0)
No financial difficulties	349 (74.7)	250 (74.9)	99 (74.4)
Some or severe financial difficulties	118 (25.3)	84 (25.1)	34 (25.6)
SCI etiology	477 (100.0)	342 (100.0)	135 (100.0)
Traumatic	366 (76.7)	284 (83.0)	82 (60.7)
Non-traumatic	111 (23.3)	58 (17.0)	53 (39.3)
SCI severity	478 (100.0)	341 (100.0)	137 (100.0)
Incomplete paraplegia	190 (39.7)	124 (36.4)	66 (48.2)
Complete paraplegia	143 (29.9)	109 (32.0)	34 (24.8)
Incomplete tetraplegia	103 (21.5)	72 (21.1)	31 (22.6)
Complete tetraplegia	42 (8.8)	36 (10.6)	6 (4.4)
Time since SCI (years)	352 (100.0)	259 (100.0)	93 (100.0)
0–5	8 (2.3)	4 (1.5)	4 (4.3)
6–15	143 (40.6)	100 (38.6)	43 (46.2)
16–25	88 (25.0)	69 (26.6)	19 (20.4)
26+	113 (32.1)	86 (33.2)	27 (29.0)

SCI: Spinal Cord Injury

the kitchen area compared to those participants living alone (Appendix, Table A1a, available in Supplementary material). Significant differences in availability of HAs were found when stratifying by indoor mobility (using a wheelchair versus walking) for the following HAs: stair lift, ramp, wheelchair accessible shower, wheelchair accessible kitchen worktop and wheelchair accessible kitchen sink. All of these HAs were available more often to participants using a wheelchair. Statistically significant differences in availability were also found by SCI severity, with higher availability of HAs among individuals with complete lesions (Table 2b). No significant differences in proportions of available HAs were identified by cause of injury or time since injury (Appendix, Table A1b, available in Supplementary material).

A total of 89 participants (18.5%) answered at least one of the open questions on availability (81 answers) and unmet need (44 answers) for HAs that were not

assessed in the questionnaire. Frequently mentioned available HAs were a wheelchair accessible parking lot or garage (seven of the 81 answers on availability, i.e. 8.6%) and a wheelchair accessible garden or balcony (seven answers, 8.6%). Six participants (7.4%) indicated to have a family member who is taking care of kitchen tasks, making access to the kitchen unnecessary. Regularly mentioned needed HAs were electrically controllable blinds, windows, doors, etc. (six of the 44 answers on need, i.e. 13.6%), access to the balcony or garden (five answers, 11.4%) and kitchen appliances (fridge, dishwasher, oven, etc.) (four answers, 9.1%).

Figures 1a and 1b depict combinations of HAs that participants have available, stratified by indoor mobility. Among participants using a wheelchair (Fig. 1a), a cluster of adaptations that is often available in combination is formed between a wheelchair accessible shower, a stair lift, a grab bar next to the toilet and a ramp. Another cluster that is close in proximity to this first

**Table 2a** Proportions of participants having the respective adaptation available, in total and stratified by socio-demographic characteristics

Home adaptation	Total		Sex			P-value	Age at questionnaire (years)					P-value	
	N	% (CI)	N	Male % (CI)	Female % (CI)		N	16–30 % (CI)	31–45 % (CI)	46–60 % (CI)	61–75 % (CI)		76+ % (CI)
Stair lift	319	31.3 (26.3–36.8)	319	35.0 (29.0–41.5)	22.9 (15.6–32.4)	0.0332	319	50.0 (30.2–69.8)	20.0 (12.2–31.0)	35.3 (26.7–45.0)	31.8 (23.7–41.2)	27.8 (12.1–51.9)	0.0719
Ramp	322	45.0 (39.5–50.6)	322	41.6 (35.3–48.1)	53.1 (43.2–62.9)	0.0571	322	50.0 (29.4–70.6)	37.5 (27.1–49.2)	52.0 (42.3–61.5)	43.9 (34.8–53.4)	38.1 (20.3–59.8)	0.3683
Automatic door opener	304	22.4 (17.8–27.5)	304	23.2 (18.0–29.4)	20.4 (13.4–29.8)	0.5903	304	10.5 (2.6–33.7)	23.5 (14.9–35.0)	25.5 (17.9–35.0)	22.3 (15.3–31.4)	12.5 (3.1–38.6)	0.5509
Grab bar outside bathroom or toilet	304	18.1 (13.9–22.9)	304	16.4 (12.0–21.9)	22.2 (14.8–32.0)	0.2251	304	10.5 (2.6–33.7)	13.6 (7.3–24.2)	13.4 (7.9–21.7)	24.0 (16.8–33.2)	33.3 (15.8–57.1)	0.0792
Grab bar next to toilet	344	56.7 (51.3–62.0)	344	57.0 (50.7–63.1)	55.9 (46.1–65.2)	0.8452	344	61.9 (40.2–79.7)	48.5 (36.9–60.3)	52.7 (43.4–61.9)	64.8 (56.1–72.7)	50.0 (29.4–70.6)	0.1652
Wheelchair accessible shower	367	62.7 (57.5–67.6)	367	65.1 (59.1–70.7)	56.9 (47.5–65.8)	0.1361	367	81.0 (58.8–92.7)	65.0 (54.0–74.6)	63.2 (54.0–71.5)	59.2 (50.6–67.3)	54.5 (34.1–73.5)	0.3455
Adjustable kitchen worktop	306	4.2 (2.3–7.2)	306	2.8 (1.2–6.0)	8.0 (3.8–15.8)	0.0411	306	0.0	7.2 (3.0–16.3)	5.0 (2.1–11.5)	2.9 (0.9–8.6)	0.0	0.4593
Adjustable kitchen cabinets	305	5.6 (3.3–8.8)	305	3.7 (1.9–7.2)	10.2 (5.4–18.5)	0.0241	305	0.0	7.5 (3.1–16.7)	5.1 (2.1–11.6)	5.8 (2.6–12.4)	6.2 (0.9–33.5)	0.7884
Wheelchair accessible kitchen worktop	330	38.8 (33.5–44.3)	330	34.7 (28.9–41.0)	48.9 (39.0–58.9)	0.0170	330	15.0 (4.9–37.6)	48.6 (37.3–60.0)	42.9 (34.0–52.2)	36.6 (28.2–45.9)	7.1 (1.0–37.0)	0.0056
Wheelchair accessible kitchen sink	327	33.3 (28.2–38.7)	327	30.0 (24.5–36.2)	41.5 (32.0–51.7)	0.0469	327	15.0 (4.9–37.6)	43.8 (33.0–55.3)	38.2 (29.6–47.6)	29.1 (21.4–38.2)	0.0	0.0034

CI: 95% confidence interval

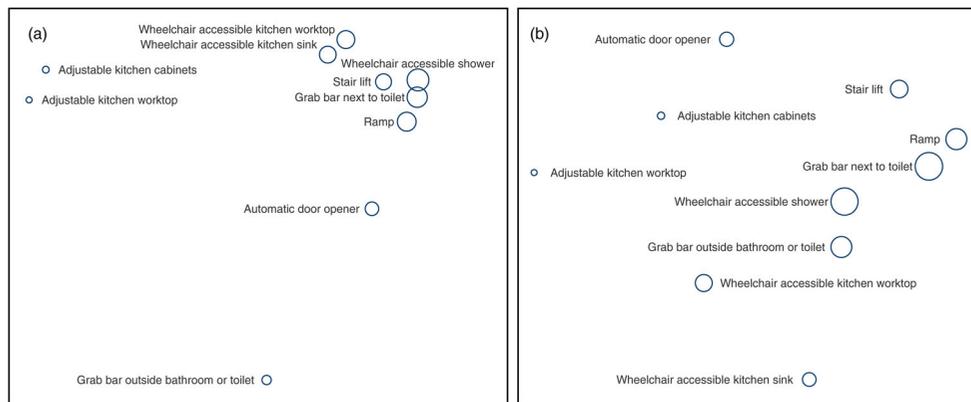
P-values are derived from  $\chi^2$  tests\*Significant at the level of  $P \leq 0.0007$  (using the Bonferroni method to correct for 70 comparisons with a global significance level of  $P \leq 0.05$ )

**Table 2b Proportions of participants having the respective adaptation available, by indoor mobility and SCI severity**

Home adaptation	Indoor mobility				SCI severity					
	N	Using a wheelchair % (CI)	Walking % (CI)	P-value	N	Paraplegia incomplete % (CI)	Paraplegia complete % (CI)	Tetraplegia incomplete % (CI)	Tetraplegia complete % (CI)	P-value
Stair lift	313	38.4 (32.7–44.4)	17.6 (11.4–26.3)	0.0002*	317	25.5 (18.2–34.4)	38.7 (30.1–48.1)	19.7 (11.5–31.5)	48.6 (32.7–64.7)	0.0042
Ramp	316	53.9 (48.0–59.7)	25.3 (17.7–34.7)	<0.0001*	320	33.0 (24.6–42.6)	56.6 (47.4–65.5)	48.5 (36.9–60.3)	38.9 (24.6–55.4)	0.0046
Automatic door opener	301	27.8 (22.3–34.1)	11.5 (6.5–19.5)	0.0016	302	11.2 (6.3–19.1)	24.5 (17.1–33.8)	24.6 (15.7–36.5)	40.5 (26.1–56.8)	0.0022
Grab bar outside bathroom or toilet	298	13.1 (8.3–20.2)	25.0 (17.5–34.4)	0.0102	302	17.5 (11.3–26.0)	19.6 (13.0–28.5)	23.4 (14.7–35.3)	3.0 (0.4–18.6)	0.0888
Grab bar next to toilet	336	62.2 (56.1–67.9)	43.4 (34.3–53.0)	0.0013	341	54.7 (45.6–63.5)	67.5 (58.6–75.3)	51.5 (39.7–63.1)	36.1 (22.3–52.7)	0.0050
Wheelchair accessible shower	360	72.1 (65.9–77.6)	42.2 (33.3–51.6)	<0.0001*	365	48.7 (39.9–57.7)	70.2 (61.9–77.4)	61.8 (50.5–72.0)	79.5 (64.0–89.4)	0.0005*
Adjustable kitchen worktop	301	5.4 (1.8–15.3)	2.0 (0.5–7.8)	0.1767	304	2.0 (0.5–7.6)	6.6 (3.2–13.2)	6.6 (2.5–16.2)	0.0	0.1655
Adjustable kitchen cabinets	300	7.0 (2.9–15.7)	3.0 (1.0–9.0)	0.1657	303	3.0 (1.0–8.9)	8.5 (4.5–15.5)	8.1 (3.4–18.0)	0.0	0.1254
Wheelchair accessible kitchen worktop	325	48.2 (42.4–54.1)	16.5 (10.4–25.2)	<0.0001*	328	26.0 (18.4–35.2)	54.8 (46.0–63.4)	31.2 (21.1–43.5)	33.3 (20.0–50.0)	<0.0001*
Wheelchair accessible kitchen sink	321	42.7 (37.0–48.7)	10.6 (5.8–18.7)	<0.0001*	325	23.5 (16.3–32.7)	48.4 (39.6–57.2)	28.1 (18.5–40.3)	21.6 (11.2–37.6)	0.0002*

CI: 95% confidence interval

P-values were derived from  $\chi^2$  tests\*Significant at the level of  $P \leq 0.0007$  (using the Bonferroni method to correct for 70 comparisons with a global significance level of  $P \leq 0.05$ )



**Figure 1. Combination of home adaptations by indoor mobility, with a) using a wheelchair and b) walking**

The bubble size is proportional to the frequency of availability of the respective home adaptation. A closer spatial proximity between home adaptations is related to higher frequency of combination of the respective home adaptations.

cluster is formed by the wheelchair accessible kitchen worktop and sink. The adjustable kitchen cabinets and worktop form a cluster of niche products among wheelchair users. Among participants who are walking when moving around inside the home (Fig. 1b), no apparent clustered combinations of HAs exist.

The most frequent combinations of two HAs among those who answered all of the questions concerning HAs ( $n=255$ ) were a grab bar next to the toilet combined with a wheelchair accessible shower (32.2%), and a wheelchair accessible shower combined with a wheelchair accessible kitchen worktop (25.5%).

The most frequently reported unmet needs were related to two HAs in the kitchen: adjustable kitchen worktop (78.7%) and adjustable kitchen cabinets (75.7%) (Table 3). There were no significant differences in unmet needs by financial hardship. However, for some of the more expensive HAs (including a stair lift, an automatic door opener and a wheelchair accessible shower) the unmet need was higher among participants that indicated to have some or severe financial difficulties.

The general question on how well needs concerning 'living without barriers at home' were covered, was answered by 472 participants. Of these participants 169 (16.7%) stated that they didn't have such needs. Of the remaining 393 participants, 43% stated to have their needs completely covered, 35.9% indicated to have their needs mostly covered, 14.5% reported to have their needs covered for a certain part, 4.1% for a small part and 2.5% reported to not have their needs covered at all.

## Discussion

This study found that at least one HA is available in the homes of 85% of individuals with SCI living in Switzerland. Most participants have three HAs, with a wheelchair accessible shower being the most frequent

HA. Indoor mobility and SCI severity showed significant differences in availability for some of the HAs. There is a considerable unmet need for certain HAs, with an especially high unmet need for the adjustable kitchen worktop and cabinets.

The availability of HAs identified in this study is comparable to the findings of a Dutch study among participants with SCI, where 90% of the participants had a HA.<sup>30</sup> Other studies reported lower numbers, with 66% in a study among Swedish individuals with SCI,<sup>31</sup> 61% among a Greek SCI population<sup>6</sup> and 60% in a study among an American SCI population.<sup>32</sup> Of the participants that had HAs in our study, only 18% had five or more. This is considerably lower as compared to results found in a study with Danish participants.<sup>15</sup> In this study, 44% of the participants had five or more HAs or home aids, although a larger range of HAs was assessed. In the current study, most HAs were available in the bathroom, with a wheelchair accessible shower (63%) and a grab bar next to the toilet (57%) being the most common HAs. Furthermore, a ramp was reported to be available among 45% of the participants. Biering-Sorensen *et al.* (2009) found that 41% of their Danish study population had a grab bar next to the toilet, while 23% reported not to have HAs outside their bathroom or kitchen.<sup>15</sup> Post *et al.* (1997) found adaptations to the toilet and/or bathroom were most common (71%) in their Dutch sample.<sup>30</sup> HAs most often implemented for individuals with SCI in the United States (US) were ramps (83%) and a reconstruction of the bathroom (46%).<sup>33</sup> Analogous results were found in another US study where ramps were the most common (44%) modification among all SCI impairment groups, followed by grab bars at 22%.<sup>32</sup>

No significant differences between sexes or age groups were found in the availability of the different HAs. However, a tendency towards a higher availability of

**Table 3 Unmet need for home adaptations, by financial hardship**

Home adaptation	All		Financial hardship			P-value
	Total need <sup>1</sup> N	Unmet need % (CI)	Total need <sup>2</sup> N	No financial difficulties	Some or severe financial difficulties	
				Unmet need % (CI)	Unmet need % (CI)	
Stair lift	119	16.0 (10.4–23.7)	117	14.8 (8.8–23.8)	20.7 (9.6–39.0)	0.3985
Ramp	161	9.9 (6.2–15.6)	160	10.1 (5.8–16.9)	9.8 (3.7–23.3)	0.6545
Automatic door opener	91	25.3 (17.4–35.2)	90	21.2 (13.0–32.7)	33.3 (17.6–53.9)	0.1382
Grab bar outside bathroom or toilet	69	20.3 (12.4–31.4)	69	20.4 (11.7–33.2)	20.0 (6.6–47.0)	0.8452
Grab bar next to toilet	213	8.5 (5.4–13.0)	212	8.8 (5.3–14.2)	7.7 (2.9–18.8)	0.8344
Wheelchair accessible shower	254	9.4 (6.4–13.7)	251	8.6 (5.4–13.7)	12.1 (6.2–22.4)	0.2244
Adjustable kitchen worktop	61	78.7 (66.7–87.2)	60	79.1 (64.4–88.7)	76.5 (51.4–90.9)	0.4301
Adjustable kitchen cabinets	70	75.7 (64.4–84.3)	68	75.5 (61.7–85.5)	73.7 (50.2–88.6)	0.4602
Wheelchair accessible kitchen worktop	172	25.6 (19.6–32.6)	170	23.8 (17.3–31.9)	27.5 (15.9–43.2)	0.4883
Wheelchair accessible kitchen sink	155	29.7 (23.0–37.3)	152	26.7 (19.5–35.5)	33.3 (20.0–50.0)	0.3240

<sup>1</sup>The sum of participants who have the home adaptation available (i.e. "met need") plus those who don't have the home adaptation available but state that they would need it (i.e. "unmet need")

<sup>2</sup>The sum of participants who provided information about financial hardship and have the home adaptation available (i.e. "met need") plus those who don't have the home adaptation available but state that they would need it (i.e. "unmet need")

CI: 95% confidence interval

P-values were derived from  $\chi^2$  tests

\*Significant at the level of  $P \leq 0.005$  (using the Bonferroni method to correct for 10 comparisons with a global significance level of  $P \leq 0.05$ )

grab bars in the older age groups was found, which might indicate changes in functionality during the ageing process of individuals with SCI.<sup>25</sup> A study among disabled individuals living in rural areas of the United Kingdom (UK), reported a significantly higher availability of home adaptations among elderly individuals.<sup>34</sup> However, the study also concluded that the needs of younger individuals were less recognized by service providers which might be indicating that older individuals were more visible (to professionals) considering their recognition of need.<sup>34</sup> Some participants mentioned in the open questions that they let their spouses prepare dinner and therefore did not need access to the kitchen area. This was reflected in the availability of the HAs within the kitchen area, which was lower among participants living with somebody else as compared to participants living alone. Although this difference was not statistically significant, it stresses the influence of living arrangement on the HAs that are required. Similar results were found in a study among a population of older people.<sup>35</sup> Participants using a wheelchair when moving around indoors reported to have a significantly higher availability for five of the HAs (stair lift, ramp, wheelchair accessible shower, wheelchair accessible kitchen worktop and wheelchair accessible kitchen sink), as compared to participants walking. These differences in availability of HAs when stratifying for indoor mobility were also noticeable in

the multidimensional scaling figures. For the participants using a wheelchair, some distinct clusters of HAs were identified. However, there were no apparent clusters in the availability of HAs among participants walking. This highlights the role of indoor mobility when planning the provision of HAs for individuals with SCI. Consistent with previous findings<sup>15,30</sup> the availability of HAs varied between the different groups of SCI severity, with the highest availabilities reported among those with a complete lesion. To state an example, the highest availability of ramps and of kitchen adaptations was observed among individuals with a complete paraplegia, which are findings that are supported by previous research.<sup>30</sup>

Although the major part of the provision of HAs in Switzerland is financially supported, the current study still found a relatively high (self-perceived) uncovered need concerning barriers inside the home. Of the participants, 48% reported to have at least some uncovered need. Another study found a slightly higher proportion of participants (55%) indicating not to have a sufficiently adapted home.<sup>30</sup> Administrative barriers have been shown to lead to difficulties in obtaining assistive technologies among individuals with SCI living in high-income settings.<sup>11</sup> In the present study, we found unmet needs for all of the assessed HAs, ranging from relatively low (9% for a grab bar next to the toilet) to high (79% for a wheelchair accessible kitchen

worktop) proportions. Of the participants of a Dutch study, 38% indicated to not having received all the requested HAs.<sup>30</sup> Similar results were found in a Australian study among participants with disabilities, where 45% reported to have unmet needs concerning HAs.<sup>2</sup> A UK study reported that 39% of the participants were in need of one or more adaptations, with a highest need for adaptations related to the kitchen, the bathroom or accessing the home.<sup>36</sup> Another study reported that only 18% of their participants had no access to home aids that were needed.<sup>15</sup> As supported by a previous study,<sup>30</sup> we found a high unmet need for HAs in the kitchen area. Unmet need was assessed subjectively in our study, without including the perception of professionals. A previous study found that disabled individuals reported a much higher need for adaptations as compared to professionals.<sup>37</sup> One possible reason for the discrepancy is the lack of a clear definition of 'need'.<sup>37</sup> But the finding also highlights the need for a close involvement of disabled individuals in the planning and installation of home adaptations.<sup>36</sup> Consequences of unmet need for home adaptations have scarcely been studied. In a study of wheelchair users, Allen *et al.* (2006) showed that home accommodations were inversely associated with the receipt of unpaid help.<sup>38</sup> An interventional trial of frail older adults showed that targeted provision of home adaptations and assistive technology reduced the decline in functional status and decreased the costs for in-home services compared to "usual care services".<sup>39</sup>

The current study found no significant differences in unmet need between participants experiencing no financial hardship as compared to participants experiencing at least some financial hardship. Possibly the Swiss reimbursement system and the previous-mentioned financial safety net for individuals acquiring a SCI allows for equity between different economic classes within the area of architectural needs. Still, some of the more costly HAs showed higher proportions of unmet need among those reporting at least some financial difficulties. Priebe *et al.* (2007) mentioned that HAs are not always included in estimated expenses of individuals with SCI.<sup>40</sup> Since these modifications are often costly, improper budgeting can lead to financial difficulties for individuals with SCI. Having a higher income has been found to be associated with a decreased likelihood of unmet needs concerning accessing the house among stroke survivors.<sup>41</sup>

The current study was subject to the following limitations. First, the study has a cross-sectional design and therefore no causal relationships could be identified. It might also be that some HAs were already in place

before the SCI, for instance among those participants who got injured at an older age. The study also did not assess whether participants moved to an adapted house after their SCI, which could influence the findings. Longitudinal studies are needed to tackle these limitations and to study changes in HAs over time. Second, data was gathered using self-reported questionnaires and had a focus on the lived experience of participants, which could lead to response bias. For instance, unmet need could be overestimated when participants indicate to have an unmet need for an adaptation they do not actually need to have. Future studies could include the assessment of needed HAs by a professional, like an occupational therapist,<sup>10</sup> to help reduce bias. In a different survey among the SwiSCI population, 1,762 participants reported on their primary problems in functioning as a response to an open-ended question.<sup>42</sup> The main problems (20–25% reports) identified in the thematic analysis were related to body functions, including pain and urinating functions. Still, a relatively large number of answers directly addressed HAs for personal use (5%). Third, due to the moderate number of respondents and an analysis requiring numerous subgroups, the number of participants among the different analyzed sub-categories was relatively low. This increases the level of uncertainty of the (stratified) findings, which is also visible in the considerably large confidence intervals that were found. However, the sample of the SwiSCI survey can be considered representative of the Swiss SCI population.<sup>18</sup> Fourth, certain 'modern' adaptations, including systems that allow for central management and/or control of adaptations inside homes, were not assessed. In the future these so-called environmental control systems are likely to become more prevalent<sup>15</sup> and should be included in the assessments.

## Conclusion

This study provides reliable data about the availability and unmet need of HAs among individuals with SCI living in Switzerland. It has been shown that although most participants already had some HAs available, unmet need for HAs was high. Availability of HAs was dependent on indoor mobility and SCI severity. Unmet need was not significantly different between individuals with and without financial hardship.

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### Supplementary material

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