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Research Article

Need and availability of assistive devices to compensate for impaired hand function of individuals with tetraplegia

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Context/Objective: To evaluate the availability and self-declared unmet need of assistive devices to compensate for impaired hand function of individuals with tetraplegia in Switzerland.

Design: Cross-sectional survey.

Setting: Community.

Participants: Individuals with tetraplegia, aged 16 years or older, living in Switzerland.

Interventions: not applicable.

Outcome Measures: The self-report availability and unmet need of 18 assistive devices for impaired hand function was analyzed descriptively. The availability of devices was further evaluated stratified by sex, age, SCI severity, independence in grooming, time since injury, living situation, working status, and income. Associations between availability of devices and person characteristics were investigated using logistic regression analysis.

Results: Overall 32.7% of participants had any assistive device for impaired hand function at their disposal. The most frequent devices were adapted cutlery (14.8%), type supports (14.1%), environmental control systems (11.4%), and writing orthosis (10.6%). In the bivariate analysis several factors showed significant associations with at least one assistive device. Nevertheless, when controlling for potential confounding in multivariate analysis only independence in grooming (adapted cutlery, environmental control systems, type support, speech recognition software), SCI severity (writing orthosis, type support), and sex (adapted kitchenware) remained significantly associated with the availability of the mentioned assistive devices. The self-declared unmet need was generally low (0.7% - 4.3%), except for adapted kitchenware with a moderate unmet need (8.9%).

Conclusion: This study indicates that most individuals with tetraplegia in Switzerland are adequately supplied with assistive devices to compensate for impaired hand function. The availability depends mainly on SCI severity and independence in grooming.

Keywords: Assistive devices, Hand function, Spinal cord injury, Tetraplegia, Need

Introduction

Cervical spinal cord injury (SCI) has extensive consequences on functioning, activities and participation of an individual.¹ Depending on level and severity of the lesion, hand and arm function as well as independence in all activities of daily living (ADL's) can be profoundly restricted.¹⁻³ Research has shown that individuals with tetraplegia rank an improved hand and arm function as one of their highest priorities.^{1,4-6}

Assistive devices, defined as “any item, piece of equipment, or product system, whether acquired commercially,

modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities”,⁷ cannot improve the hand function itself, however, they can compensate for impaired hand function. Article 26 in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) illustrates the importance by claiming the human right of the provision of assistive devices to “enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.⁸

Individuals with tetraplegia can benefit from assistive devices in performing many ADL's,⁹ such as eating and

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drinking,^{1,10} self-care,¹ communication,^{1,11,12} or the use of computers.^{1,10,11,13,14} Thereby they can increase their independence and participation in general,^{15,16} overcome barriers to employability,¹⁷ and enhance their quality of life.^{17,18} In fact, the prescription of appropriate assistive devices is an important aspect of successful and cost-efficient rehabilitation for individuals with SCI.¹⁹ The aim is to prescribe optimal assistive devices to achieve the overall goal of rehabilitation that is to maximize functioning and enable as much independence as possible for the individual with SCI.¹ Thus, the World Health Organization (WHO) declared assistive devices as an important issue in their 'International Perspectives on Spinal Cord Injury'.¹ It highlighted that an unmet need for assistive devices might also affect individuals with SCI in high-income countries and advocated research about access rates.

Despite its important role, there is limited data regarding the patterns of need and provision of assistive devices for impaired hand function of individuals with tetraplegia. Besides, there is a knowledge gap regarding what factors have an impact on the provision of these devices. The most often revealed reasons for non-provision and a subsequent unmet need of assistive devices in general are insufficient information or knowledge about technology,^{20–22} restricted availability,²³ and lack of financing.^{10,20–22,24} However, we do not know whether these problems also apply to Switzerland and specifically to assistive devices for impaired hand function.

The specific aims of this study were (1) to evaluate the availability and self-declared unmet need of assistive devices to compensate for impaired hand function of individuals with tetraplegia in Switzerland and (2) to analyze potential associations between the availability and demographic and disability related factors (sex, age, SCI severity, independence in grooming, time since injury, living situation, working status, income).

Methods

Study design and sample

Cross-sectional data from the first community survey of the Swiss Spinal Cord Injury (SwiSCI) Study were used. SwiSCI is an ongoing nationwide and population-based cohort study including individuals who have been diagnosed with traumatic or non-traumatic SCI, are 16 years or older, and permanently residing in Switzerland. Exclusion criteria are congenital conditions leading to SCI, new SCI in the context of palliative care, neurodegenerative disorders and Guillain-Barré-Syndrome. Details on the study design have been published previously.²⁵

The first community survey consisted of three subsequent modules and was conducted between September 2011 and March 2013.²⁶ A total of 3807 eligible persons were identified and invited to participate through collaboration with three specialized SCI-rehabilitation centers, an organization representing people living with SCI in Switzerland (Swiss Paraplegic Association) and a SCI-specific home care institution (ParaHelp). Participants could choose between a paper- or web-based questionnaire and a telephone interview to complete the survey. 1549 participants (49%) returned the first two modules, containing socio-demographic and socio-economic characteristics and information about the SCI severity and etiology. To reduce the burden, participants who completed the first two modules were assigned to one of the three additional modules using a weighted random generation algorithm.²⁶ The Health Services Research Module (HSR module), including questions about the need and availability of assistive devices for impaired hand function, was completed by 492 out of 580 invited participants (84.8%). Only participants reporting that they suffer from tetraplegia were included in the present study, resulting in a sample of 150 individuals.

Ethics

Ethical approval for SwiSCI was obtained from the ethics committee of the Canton of Lucerne and subsequently endorsed by the ethics committees of the Cantons Zürich, Basel-Stadt and Valais. SwiSCI projects adhere to the applicable guidelines of the Declaration of Helsinki. All participants provided written informed consent.

Measurements

Assistive devices to compensate for impaired hand function

The HSR module comprised information about the availability and the self-declared unmet need of 18 assistive devices to compensate for impaired hand function (adapted cutlery, adapted kitchenware, environmental control system, writing orthosis, forearm support, trackball mouse, joystick mouse, head control device, sip- and puff-control, mouse with external click, special keyboard, type support, mouthstick, touch-screen, document holder, page turner, speech recognition software, onscreen keyboard). Availability was assessed by asking the participants whether they have the respective device. Individuals indicating that they do not have the respective device were asked whether they would need it. The self-declared unmet need for each device was classified as 'Yes', if the participant did not have a

device but reported that he would need it and as ‘No’, if the individual either had the device or indicated that he does not have a need.

Further variables

Information on lesion characteristics included self-reported SCI severity (complete / incomplete tetraplegia), SCI etiology (traumatic / non-traumatic), and time since injury in years (grouped into the categories ≤ 5 , 6-15, 16-25, 26+ based on guidelines of the International Spinal Cord Society (ISCoS)).²⁷ Moreover, we used the Spinal Cord Independence Measure (SCIM) self-care item ‘grooming’, assessed by the SCIM Self-Report,²⁸ to grade differences in functional capacity in hand and arm function. ‘Grooming’ contains four levels of independence (completely independent, assistive devices or specific setting needed, partial assistance needed, total assistance needed) and showed high correlations with the upper extremity motor score (UEMS) and the extended manual muscle test (MMT) as well as various aspects of hand and arm function measured by functional capacity tests in a previous study.²⁹

Socio-demographic and socio-economic characteristics included sex, age (at questionnaire, grouped according the ISCoS guidelines²⁷ into five categories: 16-30, 31-45, 46-60, 61-75, 76+), living situation (living alone / living with someone else), working status (assessed by the question ‘Are you in paid employment at the moment?’: yes / no), and net-equivalent household income. The monthly net-equivalent household income was calculated based on the net-household income, weighted for household size (number of adults and children) according to the Organization for Economic Co-operation and Development (OECD) criteria³⁰ and grouped into the tertiles ‘low’ (≤ 3500 Swiss Francs), ‘middle’ (3501-5250 Swiss Francs) and ‘high’ (> 5250 Swiss Francs).

Data analysis

Descriptive statistics were used to analyze participants’ characteristics, the number of assistive devices participants had at their disposal, the number of devices they reported an unmet need for, and availability and self-declared unmet need of each device in the total sample. For all descriptive analysis frequencies and percentages were reported.

The availability of assistive devices was additionally analyzed stratified by sex, age, SCI severity, independence in grooming, time since injury, living situation, working status, and net-equivalent household income. Fisher’s exact test was used to evaluate group differences

and the significance level for these bivariate analyses was set at $P \leq 0.05$.

Moreover, we performed multivariate logistic regression analyses for devices that were available to at least 5% of the participants. Variables with p-values ≤ 0.15 in the bivariate analyses were included in the logistic regression. To account for potential bias due to item non-response we used multiple imputation (MI). We multiply imputed predictors but not outcomes using chained equations³¹ assuming missing-at-random with the Stata option ‘mi impute chained’. Odds ratios and p-values from the unrestricted fraction missing information (FMI) model test (likelihood ratio test for regressions without missing data) were reported using a significance level of $P \leq 0.05$.

The analysis was pre-specified in a study protocol and approved by the SwiSCI Steering Committee prior to data access. All statistical analyses were performed using STATA® version 14.2 (Stata Corp LP, College Station, Texas, USA).

Results

Participants’ characteristics are shown in Table 1. The total sample consisted of 150 individuals with the majority being male (73.3%). The mean age was 54.3 (± 15.5) years and the mean time since injury was 17.0 (± 14.1) years. Overall, 70% of the participants reported an incomplete tetraplegia and traumatic injury (89.3%) was the predominant etiology. More than half of the participants (58.0%) stated that they are independent in grooming. The remaining individuals needed assistive devices (8.7%), partial (16.0%) or total assistance (17.3%). The mean monthly net-equivalent income was 4363 (± 1733) Swiss Francs.

Roughly two thirds of the participants (67.3%) did not have any assistive devices to compensate for impaired hand function at their disposal (Table 2a). One or two devices were available to 10.0% and 10.7%, respectively. The large majority (85.3%) did not report an unmet need for any of the devices (Table 2b). Some participants declared an unmet for one (8.7%), two (3.3%) or three and more (2.7%) assistive devices.

Table 3 presents the total number of participants having an assistive device or reporting an unmet need for the devices. The availability of devices ranged from 14.8% (adapted cutlery) to 1.4% (sip- and puff-control, mouthstick, page turner). Only four devices (adapted cutlery, environmental control system, writing orthosis, type support) were available to more than 10% of the participants. The self-declared unmet need was rather low for most devices and was highest for adapted kitchenware

Table 1 Participants' characteristics.

	Total (N = 150) n (%)
Sex	150 (100)
Female	40 (26.7)
Male	110 (73.3)
Age (years)	150 (100)
16-30	13 (8.7)
31-45	34 (22.7)
46-60	40 (26.7)
61-75	54 (36.0)
76+	9 (6.0)
SCI severity	150 (100)
Complete tetraplegia	45 (30.0)
Incomplete tetraplegia	105 (70.0)
Independence in grooming (SCIM-SR)	150 (100)
Total assistance needed	26 (17.3)
Partial assistance needed	24 (16.0)
Assistive devices or specific setting needed, but no assistance	13 (8.7)
Completely independent	87 (58.0)
SCI etiology	150 (100)
Non-traumatic	16 (10.7)
Traumatic	134 (89.3)
Time since injury (years)	148 (100)
≤5	43 (29.1)
6-15	41 (27.7)
16-25	25 (16.9)
26+	39 (26.4)
Working status	80 (100)
Not in paid employment	32 (40.0)
In paid employment	48 (60.0)
Living situation	147 (100)
Living with someone else	115 (78.2)
Living alone	32 (21.8)
Net-equivalent household income per month (tertiles)	136 (100)
Low (≤3500 Swiss Francs)	55 (40.4)
Middle (3501-5250 Swiss Francs)	40 (29.4)
High (>5250 Swiss Francs)	41 (30.1)

SCIM-SR: Self-report version of the Spinal Cord Independence Measure (SCIM III).

(8.9%), followed by touchscreen (4.3%), adapted cutlery and environmental control system (4% each).

The bivariate analysis revealed significant association between the provision of assistive devices and

independence in grooming (14 assistive devices), SCI severity (7 devices), time since injury (6 devices), sex, age, and net-equivalent household-income (1 device each) (Tables 4a–d). No significant associations were found for living situation and working status. Except for adapted kitchenware, which was more often available to women, there were no significant differences in the provision of devices between men and women. Age at questionnaire was only significantly related to the availability of onscreen keyboard. All devices, except adapted kitchenware, forearm support, and sip- and puff-control, were predominantly available to individuals with complete lesions. Moreover, there was a tendency that participants with lower levels of independence in grooming (total or partial assistance needed), which implies lower functional capacity in hand and arm function, were more frequently provided with the assistive devices included in this study compared to participants with more independence in grooming (only assistive devices needed or completely independent). People with longer time since injury (16-25 or 26+ years) tended to have higher availability rates for the majority of devices with the highest access rates in the group with a time since injury between 16 and 25 years. The pattern of the availability of the assistive devices regarding income remained somewhat ambiguous. Some devices were more prevalent in the low income group, others in the high income group. However, the only significant difference existed for environmental control systems which were available to 21.1% of participants with high income as compared to 13.3% with low income and 2.7% with middle income.

When controlling the associations found in the bivariate analysis with multivariate logistic regressions, most of the associations were no longer significant (Table 5). Sex (kitchenware), SCI severity (writing orthosis, type support), and independence in grooming (adapted

Table 2a Number of devices available to a participant.

Number of devices available	Total (N = 150) n (%)
0	101 (67.3)
1	15 (10.0)
2	16 (10.7)
3	5 (3.3)
4	3 (2.0)
5	3 (2.0)
6	4 (2.7)
7	1 (0.7)
9	1 (0.7)
15	1 (0.7)

Table 2b Number of devices a participant reports a need and which were not at his disposal (self-declared unmet need).

Number of devices (unmet need)	Total (N = 150) n (%)
0	128 (85.3)
1	13 (8.7)
2	5 (3.3)
3	1 (0.7)
7	2 (1.3)
12	1 (0.7)

Table 3 Availability and self-declared unmet need of assistive devices to compensate for impaired hand function in total.

Assistive device	N	Total	
		Availability n (%)	Unmet need n (%)
Adapted cutlery	142	21 (14.8)	5 (4.0) ^o
Adapted kitchenware	140	9 (6.4)	11 (8.9) ^o
Environmental control system	132	15 (11.4)	5 (4.0) ^o
Writing orthosis	141	15 (10.6)	2 (1.4)
Forearm support	139	3 (2.2)	2 (1.4)
Trackball mouse	139	7 (5.0)	2 (1.4)
Joystick mouse	141	3 (2.1)	2 (1.4)
Head control device for computer	140	3 (2.1)	2 (1.4)
Sip- and puff-control for computer	139	2 (1.4)	1 (0.7)
Mouse with external click	140	11 (7.9)	1 (0.7)
Special keyboard	140	5 (3.6)	1 (0.7)
Type support	142	20 (14.1)	2 (1.4)
Mouthstick	138	2 (1.4)	2 (1.4)
Touchscreen	138	4 (2.9)	6 (4.3)
Document holder	140	6 (4.3)	1 (0.7)
Page turner	139	2 (1.4)	2 (1.4)
Speech recognition software	140	10 (7.1)	2 (1.4)
Onscreen keyboard	139	6 (4.3)	3 (2.2)

^opercentage refers to n = 123 (adapted kitchenware) respectively n = 124 (adapted cutlery and environmental control system), since some participants answered only the question about the availability but not the unmet need of the respective device.

cutlery, environmental control system, type support, speech recognition software) were the only variables that remained significant for the availability of the mentioned assistive devices.

Discussion

This study showed that only about one third of individuals with tetraplegia living in Switzerland had one or more assistive devices to compensate for impaired hand function at their disposal. This number is rather low, nevertheless, over 85% of participants reported that they do not have an unmet need for any of those devices. The most prevalent assistive devices were adapted cutlery, type support, environmental control systems, writing orthoses, mice with external click, and speech recognition software. Except for five devices (adapted kitchenware, touchscreen, adapted cutlery, environmental control system, onscreen keyboard) the self-declared unmet need was only marginal and below 2%. These results suggest that most individuals with tetraplegia in Switzerland are adequately supplied with the necessary assistive devices for impaired hand function. Based on the present data we could not find evidence for a gap in service provision.

The majority of participants suffered from an incomplete tetraplegia and more than half of them reported that they were completely independent without assistive devices in grooming. These findings suggest, that the functional capacity in hand function was rather good in many of the participants and this was presumably the main reason why 67% did not have any assistive device for an impaired hand function.

The availability of assistive devices for an impaired hand function found in this study was lower than observed in previous studies for most of the

Table 4a Proportions of participants having the respective device stratified by sex and age.

Assistive device	N	Sex			Age at questionnaire in years ^o					
		Female n (%)	Male n (%)	P-Value	N	31-45 n (%)	46-60 n (%)	61-75 n (%)	76+ n (%)	P-Value
Adapted cutlery	142	7 (18.4)	14 (13.5)	0.438	142	3 (9.1)	8 (22.2)	10 (19.6)	0 (0.0)	0.156
Adapted kitchenware	140	8 (21.1)	1 (1.0)	<0.001*	140	2 (6.1)	3 (8.3)	4 (8.2)	0 (0.0)	0.940
Environmental control system	132	4 (10.8)	11 (11.6)	1.000	132	6 (18.8)	5 (14.7)	4 (8.5)	0 (0.0)	0.391
Writing orthosis	141	2 (5.3)	13 (12.6)	0.355	141	3 (9.1)	8 (21.6)	3 (6.0)	1 (12.5)	0.124
Forearm support	139	1 (2.7)	2 (2.0)	1.000	139	1 (3.0)	0 (0.0)	2 (4.0)	0 (0.0)	0.764
Trackball mouse	139	1 (2.7)	6 (5.9)	0.675	139	1 (3.0)	5 (13.5)	1 (2.0)	0 (0.0)	0.183
Joystick mouse	141	1 (2.6)	2 (1.9)	1.000	141	0 (0.0)	2 (5.3)	1 (2.0)	0 (0.0)	0.669
Head control device for computer	140	0 (0.0)	3 (2.9)	0.566	140	3 (9.1)	0 (0.0)	0 (0.0)	0 (0.0)	0.084
Sip- and puff-control for computer	139	0 (0.0)	2 (2.0)	1.000	139	2 (6.1)	0 (0.0)	0 (0.0)	0 (0.0)	0.257
Mouse with external click	140	3 (8.1)	8 (7.8)	1.000	140	5 (15.2)	4 (10.8)	2 (4.0)	0 (0.0)	0.291
Special keyboard	140	2 (5.3)	3 (2.9)	0.613	140	3 (9.1)	2 (5.3)	0 (0.0)	0 (0.0)	0.218
Type support	142	5 (13.2)	15 (14.4)	1.000	142	5 (15.2)	9 (23.7)	5 (10.0)	1 (12.5)	0.228
Mouthstick	138	0 (0.0)	2 (2.0)	1.000	138	1 (3.0)	0 (0.0)	1 (2.1)	0 (0.0)	0.812
Touchscreen	138	0 (0.0)	4 (4.0)	0.574	138	1 (3.0)	3 (8.1)	0 (0.0)	0 (0.0)	0.260
Document holder	140	2 (5.3)	4 (3.9)	0.663	140	1 (3.0)	4 (10.5)	1 (2.0)	0 (0.0)	0.415
Page turner	139	0 (0.0)	2 (2.0)	1.000	139	2 (6.1)	0 (0.0)	0 (0.0)	0 (0.0)	0.257
Speech recognition software	140	4 (10.5)	6 (5.9)	0.460	140	5 (15.2)	4 (10.5)	1 (2.0)	0 (0.0)	0.152
Onscreen keyboard	139	1 (2.7)	5 (4.9)	1.000	139	5 (14.7)	1 (2.8)	0 (0.0)	0 (0.0)	0.023*

^oSignificant at the level of P ≤ 0.05.

^oNo participants younger than 31 years.

Table 4b Proportions of participants having the respective device stratified by SCI completeness and independence in grooming.

Assistive device	N	SCI severity			Independence in grooming (measured by the SCIM-SR)					
		Complete tetraplegia n (%)	Incomplete tetraplegia n (%)	P-Value	N	Total assistance n (%)	Partial assistance n (%)	Assistive devices n (%)	Independent n (%)	P-Value
Adapted cutlery	142	8 (18.6)	13 (13.1)	0.444	142	9 (37.5)	6 (26.1)	3 (23.1)	3 (3.7)	<0.001*
Adapted kitchenware	140	1 (2.4)	8 (8.2)	0.278	140	1 (4.5)	1 (4.3)	4 (30.8)	3 (3.7)	0.013*
Environmental control system	132	10 (27.0)	5 (5.3)	0.001*	132	11 (55.0)	2 (8.7)	0 (0.0)	2 (2.6)	<0.001*
Writing orthosis	141	10 (25.0)	5 (5.0)	0.001*	141	3 (13.6)	7 (31.8)	2 (15.4)	3 (3.6)	0.001*
Forearm support	139	0 (0.0)	3 (3.0)	0.559	139	0 (0.0)	2 (8.7)	1 (8.3)	0 (0.0)	0.026*
Trackball mouse	139	3 (7.7)	4 (4.0)	0.401	139	2 (10.0)	3 (13.6)	0 (0.0)	2 (2.4)	0.063
Joystick mouse	141	3 (7.1)	0 (0.0)	0.025*	141	2 (9.1)	1 (4.5)	0 (0.0)	0 (0.0)	0.050*
Head control device for computer	140	2 (5.0)	1 (1.0)	0.196	140	2 (10.0)	1 (4.3)	0 (0.0)	0 (0.0)	0.037*
Sip- and puff-control for computer	139	0 (0.0)	2 (2.0)	1.000	139	1 (5.0)	1 (4.5)	0 (0.0)	0 (0.0)	0.155
Mouse with external click	140	8 (19.5)	3 (3.0)	0.002*	140	4 (20.0)	5 (21.7)	0 (0.0)	2 (2.4)	0.002*
Special keyboard	140	4 (9.8)	1 (1.0)	0.026*	140	4 (19.0)	1 (4.5)	0 (0.0)	0 (0.0)	0.002*
Type support	142	13 (31.7)	7 (6.9)	<0.001*	142	4 (19.0)	9 (37.5)	3 (23.1)	4 (4.8)	<0.001*
Mouthstick	138	1 (2.6)	1 (1.0)	0.487	138	1 (5.0)	1 (4.8)	0 (0.0)	0 (0.0)	0.151
Touchscreen	138	3 (7.7)	1 (1.0)	0.068	138	0 (0.0)	3 (14.3)	1 (7.7)	0 (0.0)	0.006*
Document holder	140	2 (5.0)	4 (4.0)	1.000	140	2 (9.5)	3 (13.6)	0 (0.0)	1 (1.2)	0.028*
Page turner	139	1 (2.6)	1 (1.0)	0.484	139	1 (5.0)	1 (4.5)	0 (0.0)	0 (0.0)	0.155
Speech recognition software	140	6 (15.0)	4 (4.0)	0.032*	140	7 (33.3)	3 (13.6)	0 (0.0)	0 (0.0)	<0.001*
Onscreen keyboard	139	4 (10.3)	2 (2.0)	0.052	139	5 (23.8)	1 (4.8)	0 (0.0)	0 (0.0)	<0.001*

*Significant at the level of P ≤ 0.05.

devices.^{6,11,20,23,32} Some studies examined the availability of computer devices collectively without differentiation of the specific devices. For instance, a study in the U.S. showed that 35% of participants with tetraplegia used assistive devices for computer access such as voice recognition, modified mice, typing splints, or head pointers.¹¹ Another recent study with U.S. veterans reported that about 38% of tetraplegic participants had computer access equipment.⁶ In an Australian sample, ten out of 41 participants with tetraplegia used assistive devices for the computer.²³ When excluding those devices not intended for computer use (environmental control system, writing orthosis, document holder, page turner, adapted cutlery and kitchenware) in our survey only 21% of participants reported to have at least one assistive device for the computer. This number is considerably lower than in the above-mentioned studies. However, due to missing information about what exactly was considered as assistive devices for the computer, it is not possible to compare the

devices and explain the differences in access rates conclusively. Furthermore, a French study investigated the availability of assistive devices separately and found that special mice (50%), voice recognition (13%), and onscreen keyboard (11%) were the most often available computer devices.²⁰ Moreover, almost half of the participants had some kind of environmental control system at their disposal. Unfortunately, while the lesion level was assessed, the severity of lesion was not, making it difficult to draw valid conclusions when comparing with our sample. The high number of participants having a power wheelchair (61%) in the above mentioned study might reflect more severe disabilities on average than in the current sample where only 18% of participants with incomplete and 50% with complete tetraplegia had a power wheelchair.³³ To our knowledge, only one study investigated the provision with assistive devices for an impaired hand function in the kitchen in an SCI population so far.³² With 14% having kitchen tools or cutlery with special handles

Table 4c Proportions of participants having the respective device stratified by time since SCI and living situation.

Assistive device	Time since injury (years)					Living situation				
	N	0-5 n (%)	6-15 n (%)	16-25 n (%)	26+ n (%)	P-Value	N	Living with someone else n (%)	Living alone n (%)	P-Value
Adapted cutlery	140	4 (9.8)	2 (5.0)	6 (28.6)	8 (21.1)	0.035*	139	18 (16.5)	3 (10.0)	0.566
Adapted kitchenware	139	1 (2.5)	1 (2.5)	5 (23.8)	2 (5.3)	0.012*	137	6 (5.6)	3 (10.0)	0.410
Environmental control system	131	4 (10.0)	5 (13.2)	4 (21.1)	2 (5.9)	0.399	129	12 (12.0)	3 (10.3)	1.000
Writing orthosis	140	2 (4.9)	1 (2.6)	4 (16.0)	8 (22.9)	0.016*	138	13 (12.3)	2 (6.2)	0.520
Forearm support	138	2 (5.0)	0 (0.0)	1 (4.3)	0 (0.0)	0.249	136	3 (2.9)	0 (0.0)	1.000
Trackball mouse	138	0 (0.0)	1 (2.6)	1 (4.2)	5 (14.3)	0.026*	136	6 (5.8)	1 (3.1)	1.000
Joystick mouse	140	1 (2.4)	0 (0.0)	1 (4.2)	1 (2.8)	0.786	138	3 (2.8)	0 (0.0)	1.000
Head control device for computer	139	1 (2.5)	0 (0.0)	2 (8.3)	0 (0.0)	0.137	137	3 (2.9)	0 (0.0)	1.000
Sip- and puff-control for computer	138	1 (2.5)	0 (0.0)	1 (4.2)	0 (0.0)	0.542	136	2 (1.9)	0 (0.0)	1.000
Mouse with external click	139	3 (7.7)	1 (2.6)	2 (8.3)	5 (13.5)	0.372	137	9 (8.6)	2 (6.2)	1.000
Special keyboard	139	2 (5.1)	0 (0.0)	2 (8.0)	1 (2.8)	0.319	137	5 (4.8)	0 (0.0)	0.591
Type support	141	3 (7.5)	1 (2.6)	5 (20.0)	11 (29.7)	0.003*	139	17 (15.9)	3 (9.4)	0.566
Mouthstick	137	0 (0.0)	0 (0.0)	1 (4.2)	1 (2.9)	0.343	135	2 (1.9)	0 (0.0)	1.000
Touchscreen	137	0 (0.0)	0 (0.0)	2 (8.3)	2 (5.7)	0.055	135	3 (2.9)	1 (3.1)	1.000
Document holder	139	1 (2.5)	1 (2.6)	2 (8.0)	2 (5.7)	0.662	137	5 (4.8)	1 (3.1)	1.000
Page turner	138	0 (0.0)	0 (0.0)	2 (8.3)	0 (0.0)	0.029*	136	2 (1.9)	0 (0.0)	1.000
Speech recognition software	139	3 (7.5)	0 (0.0)	4 (16.0)	3 (8.6)	0.066	137	9 (8.6)	1 (3.1)	0.452
Onscreen keyboard	138	3 (7.5)	0 (0.0)	2 (8.3)	1 (2.9)	0.235	136	6 (5.8)	0 (0.0)	0.335

*Significant at the level of $P \leq 0.05$.

Table 4d Proportions of participants having the respective device stratified by working status and net-equivalent household income.

Assistive device	Working status				Net-equivalent household income (tertiles)				
	N	Not in paid employment n (%)	In paid employment n (%)	P-value	N	Low income n (%)	Middle income n (%)	High income n (%)	P-value
Adapted cutlery	77	4 (12.9)	5 (10.9)	1.000	128	12 (23.5)	5 (13.2)	3 (7.7)	0.125
Adapted kitchenware	77	2 (6.5)	4 (8.7)	1.000	126	6 (12.2)	3 (7.9)	0 (0.0)	0.058
Environmental control system	71	3 (11.5)	3 (6.7)	0.662	120	6 (13.3)	1 (2.7)	8 (21.1)	0.040*
Writing orthosis	76	2 (6.9)	4 (8.5)	1.000	129	8 (15.1)	4 (10.5)	3 (7.9)	0.616
Forearm support	78	0 (0.0)	1 (2.1)	1.000	126	2 (3.9)	0 (0.0)	1 (2.6)	0.780
Trackball mouse	77	1 (3.3)	3 (6.4)	1.000	126	3 (5.9)	1 (2.7)	3 (7.9)	0.717
Joystick mouse	78	0 (0.0)	0 (0.0)	1.000	128	2 (3.8)	1 (2.7)	0 (0.0)	0.629
Head control device for computer	78	0 (0.0)	1 (2.1)	1.000	127	2 (3.9)	0 (0.0)	1 (2.6)	0.779
Sip- and puff-control for computer	77	1 (3.3)	0 (0.0)	0.390	126	2 (3.9)	0 (0.0)	0 (0.0)	0.336
Mouse with external click	78	2 (6.7)	5 (10.4)	0.701	127	2 (4.0)	2 (5.3)	6 (15.4)	0.160
Special keyboard	77	0 (0.0)	1 (2.1)	1.000	127	3 (5.9)	1 (2.6)	1 (2.6)	0.732
Type support	78	4 (12.9)	8 (17.0)	0.754	129	6 (11.5)	5 (13.2)	7 (17.9)	0.731
Mouthstick	77	0 (0.0)	1 (2.1)	1.000	125	1 (2.0)	0 (0.0)	1 (2.6)	1.000
Touchscreen	77	0 (0.0)	1 (2.1)	1.000	125	2 (4.0)	2 (5.4)	0 (0.0)	0.469
Document holder	77	0 (0.0)	2 (4.3)	0.518	127	5 (9.6)	0 (0.0)	1 (2.6)	0.126
Page turner	77	0 (0.0)	1 (2.1)	1.000	126	1 (2.0)	0 (0.0)	1 (2.6)	1.000
Speech recognition software	77	1 (3.3)	5 (10.6)	0.395	127	6 (11.5)	0 (0.0)	4 (10.5)	0.081
Onscreen keyboard	78	1 (3.3)	2 (4.2)	1.000	126	3 (5.9)	1 (2.7)	2 (5.3)	0.879

*Significant at the level of $P \leq 0.05$.

Table 5 Odds Ratios of the availability of assistive devices to compensate for impaired hand function.

Assistive device	Adapted cutlery	Adapted kitchenware	Environmental control system	Writing orthosis	Trackball mouse	Mouse with external click	Type support	Speech recognition software
Sex								
Female		1						
Male		0.01						
<i>P-value</i>		<i>0.007*</i>						
Age (years)								
16-30				-				
31-45				1				
46-60				2.72				
61-75				0.79				
76+				2.25				
<i>P-value</i>				<i>0.445</i>				
Time since SCI (years)								
≤5	1	1		1	-		1	1
6-15	0.69	14.27		0.52	1		0.34	-
16-25	4.46	124.19		2.99	1.36		2.58	88.52
26+	2.60	5.86		2.49	4.12		3.30	1.38
<i>P-value</i>	<i>0.163</i>	<i>0.127</i>		<i>0.380</i>	<i>0.374</i>		<i>0.124</i>	<i>0.089</i>
SCI severity								
Complete tetraplegia			1	1		1	1	1
Incomplete tetraplegia			0.36	0.26		0.24	0.25	0.46
<i>P-value</i>			<i>0.194</i>	<i>0.043*</i>		<i>0.058</i>	<i>0.020*</i>	<i>0.533</i>
Independence in grooming (SCIM-SR)								
Total assistance	1	1	1	1	1	1	1	1
Partial assistance	0.40	6.29	0.07	3.00	1.34	1.16	2.30	0.05
Assistive devices needed	0.37	45.35	-	1.12	-	-	1.97	-
Completely independent	0.08	10.64	0.04	0.34	0.26	0.16	0.33	-
<i>P-value</i>	<i>0.011*</i>	<i>0.292</i>	<i><0.001*</i>	<i>0.087</i>	<i>0.227</i>	<i>0.077</i>	<i>0.047*</i>	<i>0.028*</i>
Net-equivalent household income								
Low	1	1	1					1
Middle	0.44	0.12	0.24					-
High	0.26	-	1.41					3.63
<i>P-value</i>	<i>0.167</i>	<i>0.112</i>	<i>0.351</i>					<i>0.328</i>

Logistic regression analyses using multiple imputation to account for item non-response.

The analysis includes devices that were available to at least 5% of the participants and variables with p-values ≤ 0.15 in the bivariate analyses.

A dash (-) denotes that there were no observations with the respective device in this group / *Significant at the level of P ≤ 0.05.

SCIM-SR: Self-report version of the Spinal Cord Independence Measure (SCIM III).

the number seems to be comparable to our results. However, it has to be considered that their sample consisted of individuals with para- and tetraplegia to almost equal shares.

Despite the comparatively small number of participants having the assistive devices available, only a minority of 22 people (15%) stated that they had an unmet need for any of the devices. Three of these participants claimed an unmet need for 7 or 12 devices respectively. This means that their self-declared unmet need already accounted for half of the total reported unmet need of

52 assistive devices. While a need for multiple devices can be reasonable, it remains questionable whether an unmet need for 7 to 12 devices can be objectively justified, because many of the devices are for the same task (e.g. different keyboards or mice) or for different levels of functional capacities. Moreover, similar to our findings a previous study found only few individuals with an unmet need for special mice and onscreen keyboards (2% each) but a much higher unmet need for speech recognition software (13%) and environmental control systems (20%).²⁰ In addition, although our

findings revealed a generally low self-declared unmet need, a substantial unmet need (9%) was found for adapted kitchenware. Further investigations should examine the reasons behind with the aim to reduce the unmet need for this device.

While several significant associations between the provision of assistive devices and independence in grooming, SCI severity, time since injury, sex, age, and income were found in the bivariate analyses, most of them disappeared when controlling for other factors in a regression analysis. Significant associations remained for the availability of adapted cutlery, environmental control systems, type supports, and speech recognition software with the independence in grooming. The availability of writing orthoses and type supports stayed significantly associated with SCI severity and the availability of adapted kitchenware with sex. Apart from the association with sex, the remaining significant factors for the availability of devices (SCI severity and independence in grooming) probably reflect the limitations in functioning as a result of the tetraplegia. Our results are in line with previous findings where the availability of assistive devices for an impaired hand function was associated with lesion level (high vs. low tetraplegia),^{20,23} but not with age or time since injury.²⁰ Furthermore, the fact that income was no longer associated with the availability of devices in the multivariate analysis indicates that the provision system in Switzerland is sufficient and the financial position presumably is not limiting the acquisition of assistive devices for impaired hand function of individuals with tetraplegia.

A major limitation of this study is its relatively small sample size. Due to the very low share of individuals with a self-declared unmet need we were only able to conduct stratified analyses for availability but not for the unmet need. It could be argued that people with the most limited hand function and consequently the highest need for the included assistive devices were less likely to participate in the survey. To reduce this potential non-response bias participants were offered the option to participate in a telephone interview instead of filling out a questionnaire. However, a previous analysis of the total SwiSCI community study sample showed that the probability of participating in the survey of people with tetraplegia did not significantly differ from people with paraplegia.²⁶ A further limitation is the reliance on self-report data, which could in particular affect the unmet need. The unmet need found in this study could be overestimated if participants reported an unmet need for devices which are not appropriate for them from an objective point of

view. The opportunity to try the assistive devices and practice is important to find the optimal device. On the other hand, the unmet need could also be underestimated due to a lack of information or knowledge of the participants on which devices would be beneficial for them. Additionally, the exact lesion level was not assessed and we used the SCIM item 'grooming' instead to grade the participants according to their functional capacity. Despite the fact that the functional abilities are well reflected with this item, lesion level should be included in future studies to meet the recommendations of ISCoS²⁷ for standardization and better comparability. In Switzerland the financing of assistive devices is covered by different types of insurances. Depending on factors like age or etiology of SCI the responsible insurance is determined according to federal law.³⁴ In general, only devices that follow the principle "simple and appropriate" are financed by the insurances.^{35,36} Because information about the type of insurance paying for the devices was not collected, we could not investigate potential differences in availability or unmet need between the insurances.

This study focused on the need and availability of devices, however, it was not assessed whether the devices were used and how the satisfaction with the available assistive devices was. In general, non-use of assistive devices is rather common.³⁷ Conversely, the study of Brochard *et al.* showed very high using rates of devices comparable to those included in our study in a population with tetraplegia.²⁰ In order to maximize the benefit for the individuals and contribute to an efficient allocation of resources, future studies should investigate factors associated with the satisfaction and use of assistive devices for an impaired hand function.

Conclusion

The current study was the first evaluating the availability and self-declared unmet need of a large variety of assistive devices to compensate for impaired hand function of individuals with tetraplegia. The analyses showed that only a minority (32.7%) of individuals with tetraplegia in Switzerland had assistive devices for an impaired hand function at their disposal. Nevertheless, the self-declared unmet need was marginal for most of the devices. When controlling for potential confounding factors, the availability of writing orthoses and type supports was still associated with SCI severity, whereas the availability of adapted cutlery, environmental control systems, type supports, and speech recognition software was associated with independence in grooming. These associations suggest that the level of

functioning is the main reason for the provision with those assistive devices.

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Disclaimer statements

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Ethics approval The SwiSCI study was approved by the ethics committee of the Canton of Lucerne (the location of the main study center) and subsequently endorsed by the ethics committees of the Cantons Zürich, Basel-Stadt and Valais.

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