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Published in:
Spinal Cord

DOI:
10.1038/s41393-020-00580-7

Publication date:
2021

Spinal Cord
https://doi.org/10.1038/s41393-020-00580-7

ARTICLE

SwiSCI 360° Perspective – Results from the Swiss SCI Survey 2017

Change in environmental barriers experienced over a 5-year period by people living with spinal cord injury in Switzerland: a prospective cohort study

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Received: 28 February 2020 / Revised: 27 September 2020 / Accepted: 29 September 2020

Abstract

Study design Cohort study with two measurement occasions.

Objectives To investigate change in environmental barriers experienced by people living with spinal cord injury (SCI) over a 5-year period.

Setting Community, Switzerland.

Methods Data were from the Swiss spinal cord injury (SwiSCI) survey. Main outcome measure was the Nottwil Environmental Factors Inventory-Short Form. Random-effects Poisson regression featuring between-within estimation was used to examine predictors of the number of environmental barriers and of its change over time.

Results One thousand five hundred and forty-nine persons participated in Survey 2012 and 1530 participated in Survey 2017; 761 participated in both surveys. In both surveys most participants reported at least three barriers. Leading issues were unfavorable climate, inaccessibility of buildings and public spaces, and lack of or insufficiently adapted means of transportation. Reporting of barriers related to climate, finances, and state services declined over time. Between subjects, having more health problems, lesser physical independence, poorer mental health, and a lower household income were related to a higher number of barriers experienced. Within subjects, improvements in income, physical independence, and mental health over time were related to a reduction in barriers.

Conclusions Inaccessibility of buildings and places and problems with transportation remained major barriers over a 5-year period and should be priorities of Swiss disability policy. People with reduced mental and physical health, and those with lower income are vulnerable groups deserving specific attention. Policies targeting income and life-long rehabilitation targeting health promotion and maintenance may be suitable means to reduce the experience of environmental barriers.

Introduction

Disability cannot be reduced to being a consequence of health conditions such as spinal cord injury (SCI) but develops in interaction with the environment. Environmental barriers can make it difficult for people to perform activities as they would like to and to participate in society on an equal basis with others [1–3]. Environmental barriers are potential

Supplementary information The online version of this article (https://doi.org/10.1038/s41393-020-00580-7) contains supplementary material, which is available to authorized users.

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Published online: 23 November 2020

determinants of lower self-rated health [4], injury [5], mortality and (co-)morbidity [6], and mental health [7]. While environmental barriers may severely impede the lives of people with SCI, the good news is that many environmental barriers can be addressed with appropriate interventions.

It is therefore important to understand how persons living with SCI experience environmental barriers. Encountering barriers can be stressful and make it difficult for people to participate in valued life situations [8]. The experience of environmental barriers can be influenced by time-invariant and time-variant factors. Regarding time-invariant factors, it has for instance been demonstrated that people with complete SCI experience more barriers than those with incomplete lesions [9, 10]. Time-variant factors include age, time since injury, and health status. While those predictors have been included in cross-sectional studies of environmental barriers, longitudinal studies of the impact of change in these predictors on the experience of environmental barriers among people with SCI are absent to date.

The Swiss Spinal Cord Injury (SwiSCI) community survey is part of the Swiss Learning Health System and International Learning Health System for SCI initiative [11, 12]. Utilizing data from this longitudinal study, we investigated environmental barriers experienced over a 5-year period by people living with SCI. We aimed to compare reported barriers across two measurement occasions and to analyze the effect of time-invariant and time-variant predictors on the number of barriers and its change over time.

Methods

Design

The SwiSCI community survey is a prospective cohort study that started in 2011 and is scheduled to be repeated every 5 years. Participants from previous measurement occasions are followed up, while at the same time new participants are recruited at each successive time point [13–15]. Data from two measurement occasions of the SwiSCI survey were available at the time of this study and analyzed. Ethical approval was granted by the responsible Ethics Committees in Switzerland. Written informed consent was obtained from all participants.

Participants and data collection

Eligible for the survey were community-dwelling persons aged over 16 years with traumatic or non-traumatic SCI living in Switzerland. Persons with congenital SCI, neurodegenerative disorders, and Guillain-Barré syndrome were excluded [13–15]. Eligible participants were identified through databases of the Swiss organization representing people with SCI, a home care institution for individuals with SCI, and specialized SCI centers in Switzerland. Participants were invited by postal mail. Data were collected between September 2011 and March 2013 (in the following referred to as Survey 2012), and between March 2017 and March 2018 (in the following referred to as Survey 2017). Questionnaires were available in three languages (German, French, Italian), with the option to return them by postal mail or complete them online. Administration using telephone or face-to-face interview was available if needed. Further details on the study protocol and data collection procedures are available elsewhere [13–15].

Included in the present study were people who participated in either of the two surveys. A total of 1549 persons participated in Survey 2012, 1530 in Survey 2017, and 761 in both. Details about non-respondents and those lost to follow-up are available elsewhere [13, 15].

Measures

All measures are from questionnaires of the SwiSCI community survey [16].

Outcome measure

The Nottwil Environmental Factors Inventory-Short Form (NEFI-SF) was used to measure experienced environmental barriers [8, 17]. The English reference version of NEFI-SF is available in Electronic Appendix (EA) 1. NEFI-SF comprises 14 items relating to unfavorable climate, inaccessibility of public and private spaces, lack of or insufficient devices for moving around over short distances and lack of or insufficiently adapted long-distance transportation, negative attitudes and lack of supports, lack of or insufficient services, and problems with resources such as finances and medical supplies. All items can be rated as: "not applicable"; "no influence"; "made my life a little harder"; or "made my life a lot harder". For most analyses in this study we dichotomized the NEFI-SF items so that 1 indicated a barrier ("made my life a little harder" or "made my life a lot harder") and 0 indicated no barrier ("not applicable" or "no influence"). For cases with less than four missing items, a count index of all reported barriers (range: 0–14) was calculated as a measure of the extent of barriers experienced [18]. Loss to follow-up in 2017 was not related to NEFI-SF scores in 2012 (OR = 0.98, 95% confidence Interval (CI) 0.95–1.01).

Predictors

Time-invariant predictors included gender, age at injury, traumatic etiology (vs. not), tetraplegia (vs. paraplegia), complete lesion (vs. incomplete). Time-variant predictors included age, being married or in registered partnership (vs. not), years of formal education completed at time of the survey, having a nominal household income above 6000 Swiss Francs per month (vs not), mental health status measured with the Medical Outcomes Short-Form-36 mental health subscale (SF-36 MH) [19], physical independence measured with the Spinal Cord Independence Measure-Self Report (SCIM-SR) [20], and an index of the number of reported health problems derived from the Spinal Cord Injury Secondary Conditions Scale [21] ranging from 0 to 15. The SF-36 score was calculated as per the manual [22] and ranged from 0 (worst mental health) to 100 (best mental health). A SCIM-SR score ranging from 0 (completely dependent) to 100 (completely independent) was established based on a transformation table derived from a previous Rasch analysis [23].

Analysis

Data analysis (also see supplemental information in EA 2) was performed with Stata 14.0 (College Station, Texas, USA). Descriptive statistics are provided for (1) the full 2012 vs. the full 2017 sample, and (2) for respondents who solely participated in Survey 2012 vs. those who solely participated in Survey 2017 vs. those who participated in both surveys. For categorical variables percentages are reported, for continuous variables means and standard deviations (SDs). Cramer's V (categorical variables) and Cohen's d (continuous variables) are provided as measures of effect size for differences between (1) samples and (2) respondent groups. P values for tests of differences between (1) samples and (2) respondent groups were derived from chi-squared tests (categorical variables), and independent sample's t tests or F tests.

We report means and SD of the number of barriers reported in 2012 and 2017 for the full sample and the longitudinal cohort. For the longitudinal cohort, a p value for the mean difference from a paired t-test, and standardized mean change (SMC) [24] is also given. Change in the number of reported barriers for participants of both surveys is further illustrated with a bubble plot of the number of barriers reported in 2012 against 2017 with bubble size indicating the number of participants for each particular coordinate. A histogram of change in the number of reported barriers is provided with marks indicating mean (SD) and median (Q1, Q3). Corresponding histograms for the four different samples (full and longitudinal, Survey 2012 and Survey 2017) are available in EA 3. For comparing the endorsement of particular barriers in 2012 and 2017, proportions of participants reporting to have experienced these barriers with 95% CIs are provided for the full sample and the longitudinal cohort. These CIs were calculated with robust standard errors using a clustered sandwich-estimator [25] (cluster variable: subject ID) from log-linear Poisson regression [26] of the endorsement of each barrier on a binary variable indicating the survey wave. Risk ratios with 95% CIs and p-values for the endorsement of barriers in Survey 2017 vs. Survey 2012 are given in the EA 4. In addition, 3×3 contingency tables comparing ratings for each particular barrier between 2012 and 2017 with Discordant Proportions Ratio Sum (DPRS) as effect size, p-values from exact Bowker tests of symmetry, and proportions of participants changing their rating are available in EA 5.

For time-variant independent variables, we estimated average unit (continuous variables) and percent (binary variables) change between 2012 and 2017 with 95% CIs. We used SMC as measure of effect size for both continuous and binary variables [24]. P values from paired t-tests are also reported. We furthermore provide proportions for each combination of statuses in 2012 and 2017, DPRF and p values from exact McNemar tests of symmetry for 2×2 contingency tables of categorical variables and the range of change as 10th and 90th percentile for continuous variables.

We used random-effects (RE) Poisson regression [27, 28] with Gamma-distributed random intercept for participant to estimate the effect of time-invariant and time-variant independent predictors on the number of barriers experienced in 2012 and 2017, including only cases with less than four missing NEFI-SF items (at least 11 items answered). The number of non-missing NEFI items (ranging from 11–14) was used as exposure variable. To ease interpretation, some of the predictor variables were rescaled; we rescaled age and age at injury so that one unit change reflected a five-year interval and the SF-36 MH score and SCIM-SR score were rescaled so that one unit change reflected a ten point interval of the score. Model selection was as specified in EA 2.1.

We employed within-between estimation to model time-variant predictors [29, 30] separating inter-individual variation (between-subject effects) and intra-individual change (within subjects effects). For further explanation and examples see EA 2.2. Unadjusted estimates from univariable models and adjusted estimates from a multivariable model simultaneously including all predictors are provided. Coefficients are displayed in the form of Incidence Rate Ratios (IRRs). IRRs represent the factor with which the expected count of barriers is multiplied if the predictor in question increases by one unit. Examples for the interpretation of IRRs are provided in EA 2.3. Standard errors for confidence intervals were estimated by bootstrap with 1000 repetitions.

Missing values

Primary analysis was based on complete observations only. Listwise deletion of observations with missing values yielded a sample size of 1706 participants with 2214 observations for the fully adjusted RE Poisson model. Sensitivity analysis based on multiple imputation (MI) was performed as described in EA 2.4.

Table 1 Demographic and spinal cord injury characteristics of participants by survey year and survey participation.

	By survey year				By survey participation+				
	2012 ($n = 1549$)	2017 ($n = 1530$)	Effect size*	$P^{‡}$	2012 only ($n = 788$)	2017 only ($n = 769$)	Both surveys ($n = 761$)	Effect size§	P&
Demographics									
Gender			<0.01	0.001				0.01	0.90
Female, *n* (%)	442 (28.5)	438 (28.6)			228 (28.9)	224 (29.1)	214 (28.1)		
Male, *n* (%)	1107 (71.5)	1092 (71.4)			560 (71.1)	545 (70.9)	547 (71.9)		
Age in years									
Mean (sd)	52.3 (14.8)	56.5 (14.7)	0.29	<0.001	53.4 (16.6)	56.4 (15.8)	51.2 (13.4)	0.02	<0.001
Marital status			0.06	0.002				0.04	0.18
Married/registered partnership	815 (53.0)	893 (58.6)			404 (51.7)	432 (56.3)	411 (54.4)		
Not married	722 (47.0)	632 (41.4)			378 (48.3)	335 (43.7)	344 (45.6)		
Years of formal education,									
Mean (sd)	13.6 (3.3)	14.5 (3.5)	0.26	<0.001	13.3 (3.3)	14.1 (3.7)	13.3 (3.2)	0.01	<0.001
Household income			0.08	<0.001				0.07	0.006
CHF 6000 and higher	606 (41.7)	578 (49.7)			279 (38.7)	264 (47.2)	327 (44.6)		
Below CHF 6000	848 (58.3)	585 (50.3)			442 (61.3)	295 (52.8)	406 (55.4)		
SCI characteristics									
SCI level			<0.01	0.881				0.04	0.115
Paraplegia	1066 (69.2)	1040 (69.4)			522 (69.9)	498 (67.6)	544 (71.5)		
Tetraplegia	475 (30.8)	458 (30.6)			258 (33.1)	239 (32.4)	217 (28.5)		
SCI severity			0.06	0.001				0.16	<0.001
Complete	646 (42.0)	486 (36.0)			315 (40.3)	150 (25.3)	331 (43.7)		
Incomplete	894 (58.0)	865 (64.0)			467 (59.7)	443 (74.7)	427 (58.3)		
Etiology			0.07					0.12	
Traumatic	1,301 (84.7)	1,200 (79.2)			658 (84.8)	564 (74.7)	643 (84.5)		
Non-traumatic	236 (15.4)	316 (20.8)			118 (15.2)	191 (25.3)	118 (15.5		
Age at injury in years									
Mean (sd)	35.4 (17.4)	37.9 (17.8)	0.14	<0.001	37.2 (18.5)	42.8 (18.6)	33.6 (15.9)	0.04	<0.001
Time since SCI in years									
Mean (sd)	16.8 (12.7)	18.9 (13.2)	0.16	<0.001	16.1 (12.3)	14.2 (11.6)	17.6 (13.0)	0.13	<0.001

CHF Swiss Francs, *Q1* first quartile, *Q3* third quartile, sd standard deviation, *SCI* spinal cord injury, *SCIM-SR* Spinal Cord Injury Independence Measure-Self Report, *SF-36 MH* Medical Outcomes Short Form-36 Mental Health subscale.

+Information in the column for participants of both surveys is from the first measurement occasion. *Effect size is Cramer's V for categorical variables, and Cohen's *d* for continuous variables. ‡*P* values are from chi-squared tests for categorical variables and *t*-tests for independent samples for continuous variables. §Effect size is Cramer's *V* for categorical variables, and eta-squared for continuous variables. &*P* values are from chi-squared tests for categorical variables and *F*-tests for one-way analysis of variance for continuous variables.

Results

Sample description

Table 1 provides demographics and SCI characteristics stratified by sample and survey participation. A majority of respondents had paraplegia and incomplete injuries of traumatic origin. People who participated in both surveys were younger and were more often employed in 2012. Participants newly recruited for Survey 2017 had more often incomplete lesions and non-traumatic etiology.

Environmental barriers across samples and their change over time

Participants in Survey 2012 reported a mean of 4.1 barriers (SD = 3.1) and participants in Survey 2017 experienced 3.8 (SD = 3.2) barriers on average. People who participated in

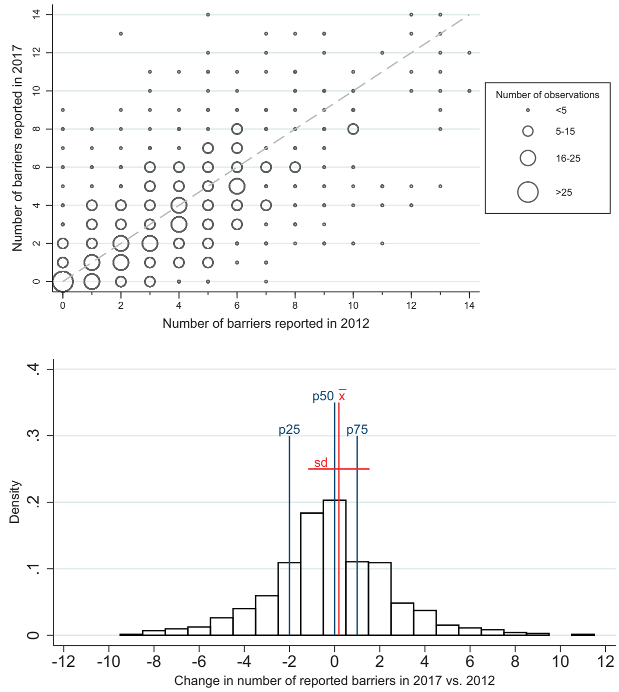

Fig. 1 Number of environmental barriers reported in 2012 vs. 2017 for the longitudinal cohort and distribution of change in the number of barriers experienced. 1.1 Bubble plot of outcome in 2012 and 2017. **1.2** Distribution of change in outcome, 2017 vs. 2012. p25 25th percentile, p50 50th percentile (median), p75 75th percentile; sd standard deviation, $\bar{x}$ mean.

both surveys reported 4.2 barriers (SD = 3.1) on average in 2012 and 4.0 (SD = 3.1) in 2017 (SMC = 0.07 with $p =$ 0.07). In spite of the small difference in sample means across time points for the longitudinal sample, almost 80% of the participants reported fewer or more barriers in 2017 with changes mostly ranging from one to three barriers and observed in both directions (Fig. 1, see EA 3 for histograms of the number of barriers by sub-sample).

Figure 2 (see EA 4 for detailed estimates) shows the percentage of people who reported particular barriers in Survey 2012 compared to Survey 2017 for the full sample (upper panel) and the longitudinal cohort (lower panel). To a large degree, patterns of barriers experienced were similar for the full sample and the longitudinal cohort. Most frequent barriers at both measurement occasions were unfavorable climate and inaccessibility of public infrastructure. Those were followed by inaccessibility of friends' and relatives' homes, lack of or insufficient devices for moving around over short distances and means of transportation for long distances, lack of or insufficient government services, and financial problems. Most barriers were less often reported in Survey 2017. This was particularly obvious for climate, finances, and government services, where changes in the longitudinal cohort also indicated a lesser impact on people's life over time (also see EA 4 and 5). While the full sample of Survey 2017 also clearly reported fewer barriers with regard to accessibility than participants of Survey 2012 this was not obvious for the longitudinal cohort. Proportions of participants who changed their rating ranged from 10.6 (communication devices) to 43.2% (climate) (see EA 5 for details).

Change in predictor variables for longitudinal cohort

Table 2 illustrates change in time-variant independent predictors for participants in both SwiSCI surveys. More participants married or registered a partnership than vice versa. Educational achievement increased by almost 1 year of formal education, on average. People's household income tended to increase as well. The number of reported health problems increased and at least 10% of the participants reported an increase by four or more health problems in 2017. Physical independence declined, on average. The SF-36 MH score showed no marked change in mean. However, the mental health of at least 10% of the participants decreased by 15 points or more between 2012 and 2017, while at least ten percent reported an increase in mental health by 15 points or more within the same time interval.

Effects of time-invariant and time-variant predictors on the number of barriers experienced

Effects of time-invariant and time-variant predictors on the number of barriers are given in Fig. 3 (for detailed estimates see EA 6).

The directions of effects for *between estimation* of parameters for time-invariant and time-variant covariates were largely consistent across models, although varying in size. Better mental health (unadjusted IRR = 0.85, 95% CI 0.83-0.87; adjusted IRR = 0.92, 95% CI 0.9–0.94), greater physical independence (unadjusted IRR = 0.68, 95% CI 0.66-0.71; adjusted IRR = 0.72, 95% CI 0.69–0.75) and higher income (unadjusted IRR = 0.8, 95% CI 0.74-0.86; adjusted IRR = 0.86, 95% CI 0.79-0.93) were consistently associated with a lower number of barriers experienced, while a greater number of reported health problems was associated with more barriers (unadjusted IRR = 1.12, 95% CI 1.11-1.13; adjusted IRR = 1.07, 95% CI 1.05–1.08). A most notable exception was SCI level. Having tetraplegia was associated with a greater number of barriers in the unadjusted model (IRR = 1.05, 95% CI 0.99–1.13) but with less barriers in the adjusted model (IRR = 0.86, 95% CI 0.8–0.93). Moreover, a pronounced effect of having complete SCI on experiencing a greater number of barriers found in the

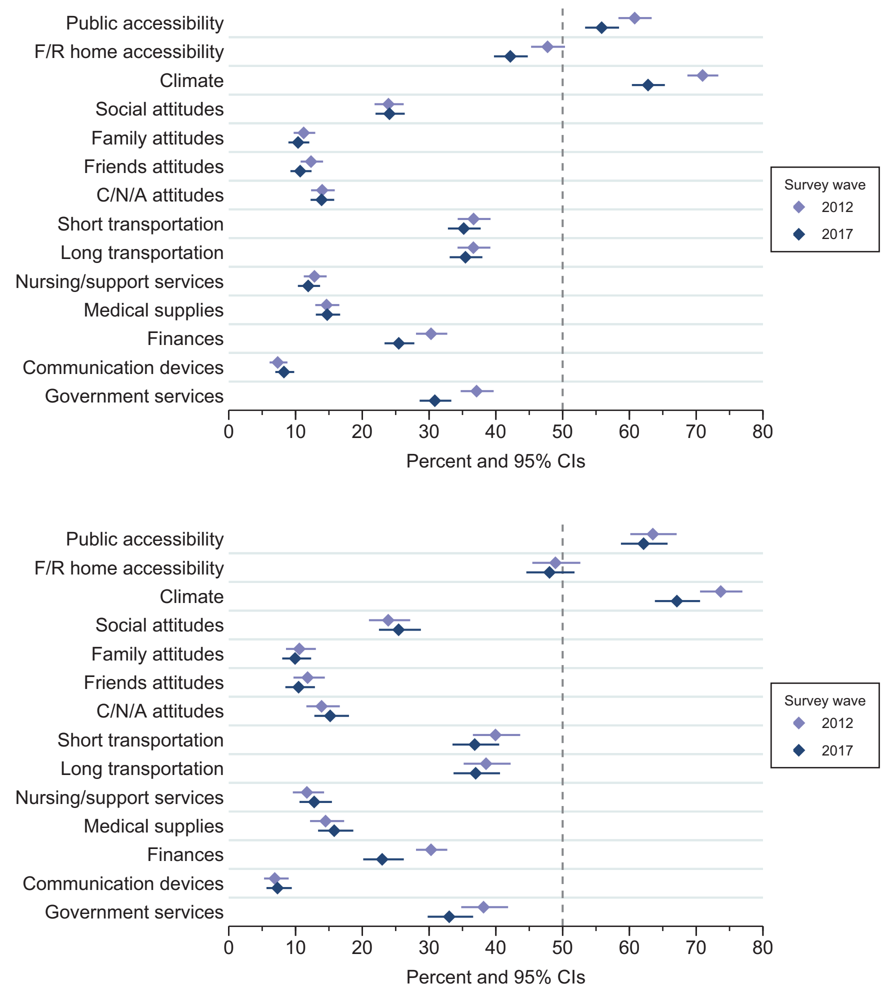

Fig. 2 Percent endorsing barrier as having made their life a little harder or a lot harder in Survey 2012 and Survey 2017 with 95% confidence intervals for (1) the full sample and (2) the longitudinal cohort. 2.1 Full sample. **2.2** Longitudinal cohort. C/N/A = Colleagues/Neighbors/Acquaintances; F/R = Friends/Relatives. Confidence intervals have been calculated with cluster-robust standard errors estimated from log-linear Poisson regression.

unadjusted model (IRR = 1.27, 95% CI 1.19–1.35) was reduced when the effect was adjusted for covariates (IRR = 1.04, 95% CI 0.97–1.12). In contrast older age showed a stronger association with a lower number of barriers experienced in the adjusted model than in the unadjusted model (unadjusted IRR = 0.99, 95% CI 0.98–1.00; adjusted IRR = 0.97, 95% CI 0.95–0.98).

Regarding *within estimation* for time-variant predictors, increase in household income (unadjusted and adjusted IRR = 0.82, 95% CI 0.73–0.92), and improvement in mental health (unadjusted IRR = 0.93, 95% CI 0.9–0.97; adjusted IRR = 0.94, 95% CI 0.9–0.98) and physical independence as measured with the SCIM-SR (unadjusted IRR = 0.88, 95% CI 0.77–0.99; adjusted 0.87, 95% CI 0.75–1.01) were consistently associated with a reduced number of barriers experienced in 2017. Sensitivity analysis showed consistent directions of effects when comparing the model estimated from complete observations with models estimated from MI data. The effect of female gender was however stronger and the effects of lesion level and change in SCIM-SR were somewhat weaker in both MI models (see EA 7 for details).

Discussion

In both surveys, participants on average reported about four barriers that made their life somewhat harder. The average number of barriers reported did not differ greatly across samples and average change between 2012 and 2017 was small for the longitudinal cohort. However, the latter finding does not imply that no change occurred. Almost 80% of the longitudinal cohort changed the number of reported barriers with some reporting more and some fewer barriers. Leading issues were climate, accessibility, transportation, finances, and state services, although participants of Survey 2017 reported these barriers less frequently. However, a decline in problems with accessibility of public and private infrastructure and transportation barriers was not obvious for the longitudinal cohort.

Table 2 Change in time-variant independent variables from 2012–2017 for longitudinal cohort.

	Distribution	Effect size*	$P^{‡}$
Demographics			
Marital status ($n = 752$)			
Not married/registered partnership in 2012 but in 2017, *n* (%)	86 (11.4)	0.02	<0.001
Married/registered partnership in 2012 but not in 2017, *n* (%)	39 (5.2)		
Not married/registered partnership at both measurement occasions	256 (34.0)		
Married/registered partnership at both measurement occasions	371(49.3)		
Average percent change in being married/in registered partnership (95% CI)	6.3 (3.4,9.1)	0.16	<0.001
Education ($n = 724$)			
Average years of formal education 2012 (sd)	14.0 (3.1)		
Average years of formal education 2017 (sd)	14.8 (3.2)		
Average change in years of formal education (95% CI)	0.8 (0.7,0.9)	0.54	<0.001
Range of of change in years of formal education, P10, P90	0, 3		
Income ($n = 586$)			
Not having a household income over CHF 6000 in 2012 but in 2017	84 (14.3)	0.03	<0.001
Having a household income over CHF 6000 in 2012 but not in 2017	39 (6.7)		
Not having a household income over CHF 6000 at both measurement occasions	241 (41.1)		
Having a household income over CHF 6000 at both measurement occasions	222 (37.9)		
Average percent change in having an income over CHF 6000 (95% CI)	7.7 (4.0,11.3)	0.17	<0.001
Health status measures			
Health problems ($n = 741$)			
Average number of health problems in 2012 (sd)	4.3 (2.7)		
Average number of health problems in 2017 (sd)	4.8 (3.0)		
Average change in number of health problems, $n = 741$ (95% CI)	0.5 (0.4,0.7)	0.22	<0.001
Range of change in number of health problems, P10, P90	−2, 4		
Mental Health ($n = 704$)			
Average SF-36 MH score in 2012 (sd)	70.1 (15.8)		
Average SF-36 MH score in 2017 (sd)	70.5 (16.6)		
Average change in SF-36 MH score (95% CI)	0.5 (−0.6, 1.5)	0.03	0.367
Range of change in SF36-MH score, P10, P90	−15, 15		
Physical independence ($n = 732$)			
Average SCIM-SR score in 2012	73.2 (9.6)		
Average SCIM-SR score in 2012	72.4 (9.9)		
Average change in SCIM-SR score	−0.8 (−1.1, −0.6)	−0.21	<0.001
Range of change in SCIM-SR score, P10, P90	−3.1, 5.3		

CI Confidence Interval, *CHF* Swiss Francs; *P1*0 10th percentile, *P90* 90th percentile, *SCIM-SR* Spinal Cord Independence Measure-Self Report (Rasch-transformed and rescaled from 0-100), *sd* standard deviation, *SF-36 MH* Medical Outcomes Short Form-36 Mental Health subscale.

*Effect size is discordant proportion ratio sum (contingency tables) or standardized mean change between 2012 and 2017 (mean comparison). ‡*P* values are from exact McNemar symmetry tests (chi-squared, contingency tables) or paired two-tailed *t*-tests (mean comparison).

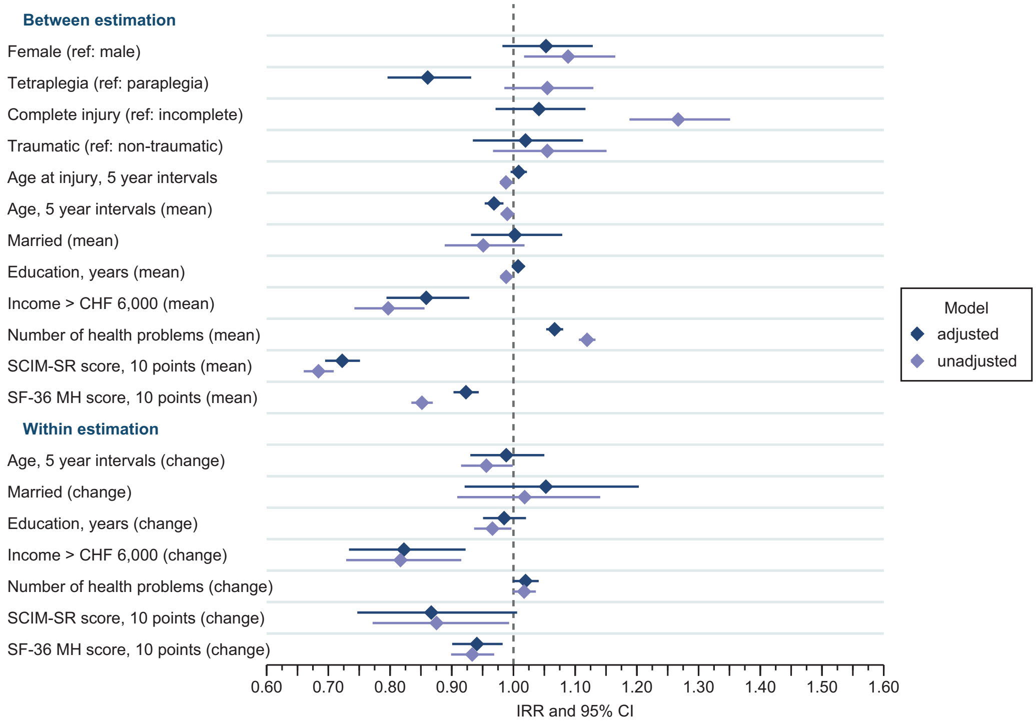

Fig. 3 Incidence rate ratios and 95% confidence intervals for between-within estimation from adjusted and unadjusted random-effects Poisson regression of the number of barriers experienced on sociodemographic and health-related predictors (*n* = 1704, observations = 2210, adjusted model). CHF Swiss Francs, CI Confidence Interval, IRR Incidence Rate Ratio, SCIM-SR Spinal Cord Independence Measure Self-Report, SF-36 MH Medical Outcomes Short Form-36 Mental Health subscale.

We also found that participants in the longitudinal cohort improved in socio-economic status with gains in education and income. However, it remains unclear if improvements in income were related to individual factors such as advancement in employment careers or macro-economic influences. As regards health status, we found a slight decline in physical independence and a growing number of reported health problems as well as a considerable variation in mental health. Declines in health and improvements in income are likely counteracting factors which may be responsible for the small average change in environmental barriers experienced over time found in this study.

We found in RE Poisson regression that improvements in income were related to a decrease, while a reduction in health was related to an increase in reported barriers. With the above-mentioned model, we estimated between-subject effects of time-invariant predictors and time-variant predictors as well as within-subject effects of time-variant predictors.

Regarding *between estimation*, we found health status measures being among the strongest predictors in both the adjusted and unadjusted models, with those reporting fewer health problems, better mental health, and greater physical independence experiencing fewer barriers. This is consistent with previous findings from Switzerland [9] and the USA [31]. We moreover found a social gradient in so far as higher household income was associated with fewer barriers. Older age was associated with fewer barriers in the adjusted model only. One explanation is that the between-estimator for age basically represents a longer experience of living with SCI when age at injury and health-related variables are statistically controlled for. In the adjusted model higher (average) age may reflect adaptation to living with SCI, both actively, e.g., developing better strategies to deal with barriers, and passively, e.g., reduced perception of barriers because of habituation effects. Moreover, a longer experience with SCI may also entail withdrawal from social life and avoidance of situations where barriers have previously been encountered, and this reduction in participation may also lead to a reduction in opportunities where barriers can be experienced. Whiteneck and Dijkers have named this phenomenon the "paradox of barriers" [32]. In the unadjusted model, the effects of biological age and time living with SCI are confounded (age at injury and average age at time of the survey are highly correlated with $r = 0.70$) so that possibly opposite effects of chronological age and time lived with SCI could cancel each other out. While having tetraplegia was related to a greater number of barriers in unadjusted models, the opposite was the case when the model was adjusted for covariates. This is a finding that we have previously reported [9, 18] and explained with the different reference groups to which people living with tetraplegia and paraplegia may compare themselves when appraising their experience of environmental barriers, i.e., people with tetraplegia may compare themselves with people with paraplegia, while those with paraplegia may compare themselves with those without SCI. This effect may reveal itself under the condition that differences in physical independence and other health status indicators are held constant statistically. A similar explanation is conceivable for our finding that the effect of a complete lesion was largely reduced when the model was adjusted for covariates including physical independence. Our findings with regard to within-subject change of time-variant predictors are novel and need to be scrutinized by future research.

Within-subject effects were mostly weaker than between-subject effects. This may be related to the fact that we could only draw on two measurement occasions representing a 5-year interval for within-subject estimation. The smaller subsample for the estimation of longitudinal effects furthermore leads to increased uncertainty about those effects. Within-subject effects were pointing in the same direction as between-subject effects. Increases in household income, mental health, and physical independence over the 5-year observation period were all linked to a reduction in barriers experienced. This implies that continuously providing people living with SCI with the means to promote their health and physical independence as well as with opportunities for increasing their household income can also help them better cope with their environment.

While the data presented here cannot provide detailed guidance on the specific design of policy or clinical interventions, we could show the following: Not only are people with lower income and worse health disadvantaged as compared to others with more privileged status (an issue of social structure), but improvements in health and income can possibly reduce this disadvantage (an issue of social change). Consequently, investment in life-long rehabilitation and economic support policies may reduce the experience of barriers for people with SCI. It must be noted in this context that it is likely not the income that is directly related to fewer encounters with barriers, but the resources and flexibility higher income provides may be instrumental in overcoming barriers (e.g., availability of an adapted car) or in buffering their impact on daily life (e.g., reduced dependence on government services). Providing people with resources and options to cope with their environment could thus be an alternative policy approach.

This study has several limitations. First, although sociodemographic and SCI characteristics of the sample analyzed were largely comparable to population-based samples of other high-income countries such as the USA and Canada [15], environmental factors including geological features, policies, services, and transportation differ considerably. Generalizability of our findings to other countries including those with high income is thus limited. Second, we did not account for unit non-response in primary or sensitivity analyses (see EA 2.4). However, detailed analyses of the SwiSCI response showed only marginal non-response bias [13, 15]. Furthermore, effects of income, mental health, functional independence, and intra-individual change in those factors, on the quantity of barriers experienced appear to be robust. Third, as income was not adjusted for inflation, the effect of income may have been under- or overestimated. However, this likely played a minor role if any, since the variable was dichotomized for analysis. Fourth, current data are from only two measurement occasions which precludes non-linear modeling of the effects of change in independent variables such as age. Fifth, having only two measurement points within an interval of 5 years makes it impossible to employ time-lagged models. Conclusions regarding causality cannot be drawn at this point. Sixth, the relatively small sample size of the longitudinal cohort made it impossible to meaningfully model interactions between subject-level time-invariant predictors and time-variant covariates at the level of measurement occasions. Seventh, the current paper is of limited scope, and while we investigated predictors of change in the total number of barriers experienced, we did not analyze predictors of change for particular barriers such as accessibility of public infrastructure or social attitudes. The current report is only a first paper in a series of planned studies that will look into individual barriers and their interrelations in more detail.

Conclusion

Inaccessibility of public and private infrastructure and lack of appropriate means for moving around over short and long distances remained major barriers in the Swiss SCI population over a 5-year period. Improving accessibility of buildings and public spaces as well as availability of transportation adapted to the needs of persons with disability should be priorities of Swiss disability policy. People with reduced physical health and those with lower income are vulnerable groups. Policies targeting income as well as the resources and flexibility higher income provides, and life-long rehabilitation targeting health maintenance may be suitable means to reduce the experience of environmental barriers.

Data availability

Owing to our commitment to SwiSCI study participants and their privacy, datasets generated during the current study are not made publicly available but can be provided by the

SwiSCI Study Center based on reasonable request (contact@swisci.ch).

Acknowledgements We thank the SwiSCI Steering Committee with its members Xavier Jordan, Fabienne Reynard (Clinique Romande de Réadaptation, Sion); Michael Baumberger, Hans Peter Gmünder (Swiss Paraplegic Center, Nottwil); Armin Curt, Martin Schubert (University Clinic Balgrist, Zürich); Margret Hund-Georgiadis, Kerstin Hug (REHAB Basel, Basel); Laurent Prince (Swiss Paraplegic Association, Nottwil); Heidi Hanselmann (Swiss Paraplegic Foundation, Nottwil); Daniel Joggi (Representative of persons with SCI); Nadja Münzel (Parahelp, Nottwil); Mirjam Brach, Gerold Stucki (Swiss Paraplegic Research, Nottwil); Armin Gemperli (SwiSCI Coordination Group at Swiss Paraplegic Research, Nottwil).

Funding SwiSCI is hosted and funded by Swiss Paraplegic Research.

Author contributions JDR designed the study, wrote the first draft, and performed the data analysis. CSF provided Rasch-transformed SCIM-SR scores, and revised the manuscript critically for content. MWMP designed the study and revised the manuscript critically for content. All authors have read and approved the submitted version of the manuscript.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval Ethical approval for Survey 2012 was granted by Kantonale Ethikkommission Luzern (internal application 11042, approved 28.06.2011, Commission Cantonale Valaisanne d'Ethique Médicale Sion (internal application CCVEM042/11, approved 06.12.2011), and Ethikkommission Basel (internal application 306/11, approved 06.09.2011). Ethical approval for Survey 2017 was granted by the Ethikkommission Nordwest-und Zentralschweiz (EKNZ, Project-ID = 11042 PB_2016-02608, approved Dec 2016). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

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