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An exploration of information seeking behavior among persons living with spinal cord injury in Switzerland

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Abstract

Study design Observational study using data from the second community survey of the Swiss Spinal Cord Injury Cohort Study (Survey 2017).

Objectives To examine information seeking of individuals with spinal cord injury (SCI) in Switzerland and its association with personal characteristics, quality of life, satisfaction with health, and healthcare services utilization.

Setting Community.

Methods Descriptive statistics were used to describe information needs, information sources, and health literacy of the participants. Linear, logistic, and Poisson regression analyses were used to assess the association of information-related variables with personal characteristics, quality of life, satisfaction with health, and healthcare services utilization.

Results One quarter of the 1294 study participants (24.6%) reported having information needs. Most frequently mentioned were needs for medical information about SCI, complications and comorbidities (30.5%), and information on living with SCI (28.6%). The most often used sources of information were healthcare professionals (72.3%), the Internet (43.2%), and other people living with SCI (40.8%). Almost half of the participants (41.4%) were only somewhat or not at all confident in their ability to find information. Having information needs was associated with suboptimal outcomes.

Conclusions This study confirms the importance of information for individuals living with SCI. By providing evidence on topics to be addressed and modalities of information delivery, our findings can help institutions in developing information to support individuals living with SCI in their daily activities. Information should cover all aspects of living with SCI, be relevant to and understandable for people of all backgrounds, and be made available online and offline.

Introduction

Health information can improve understanding of health conditions, prevention and treatments, and contribute to the empowerment of patients and their families [1–3]. In the age of shared decision-making, health information also supports individuals in deciding in an informed way, supporting their autonomy [4]. Besides, it contributes to improving adherence to treatments and self-management

[5], and even to reduce unnecessary healthcare utilization and costs [6, 7]. Considering its potential benefits and the consequent need for institutions to provide useful information to citizens, it is important to better understand, for instance, what kind of information people search for, how personal characteristics impact this search, and what are possible consequences of not having the necessary skills to access information.

Health information seeking has been studied extensively in the general population and in specific sub-populations of individuals, both healthy (e.g., [8]) and affected by chronic conditions (e.g., diabetes [9] and cancer [10]). This paper focuses on information needs and practices of individuals with spinal cord injury (SCI). Although health information holds a potential to support people with SCI in the self-management of their condition [11], studies examining information seeking behavior and health literacy (i.e., the ability to access, understand, evaluate, and apply information [12]) among people with SCI are scarce. These suggest that

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individuals with SCI particularly trust information from SCI experts and healthcare professionals, but they often search online (see e.g., [13]). Aging, research, financial aid, and education are frequently identified as topics on which they need information [14, 15]. To date, the link between information seeking and outcomes or healthcare services utilization among persons with SCI has not been studied.

In an effort to define what kind of information (e.g., on what topics, from which sources) best suits the needs and preferences of individuals with SCI and to develop targeted interventions to support them in using this information, this study has the overall objective to examine information seeking behavior among people living with SCI in Switzerland. More specifically, it aims at (1) describing information needs, sources of information used, and health literacy, (2) investigating their association with socio-demographics and lesion characteristics, and (3) exploring the association of information seeking with quality of life, satisfaction with health, and healthcare services utilization.

Methods

Study design

A cross-sectional study, based on data from the second community survey of the Swiss Spinal Cord Injury Cohort Study (Survey 2017), was conducted. Rationale and design of the entire SwiSCI study as well as of Survey 2017 specifically are described elsewhere [16, 17].

Study population

All community-dwelling persons aged 16 years and older with traumatic or non-traumatic SCI living in Switzerland were eligible to take part to the survey. Eligibility and exclusion criteria, sampling, and recruitment strategy are detailed elsewhere [17]. Out of 3,959 eligible persons, 1,294 participated in both questionnaires of Survey 2017 (response rate 32.7%) and were included in this analysis.

Measures

Data were collected through the two Survey 2017 questionnaires [18]. The questions used for this manuscript, with response options and documentation of sources, are available in Appendix 1.

Socio-demographic characteristics included *gender*, *age*, *years of education*, and *socioeconomic position*. Socioeconomic position was assessed using a pictorial representation that uses a symbolic ladder, developed to capture the perception of social status based on usual socioeconomic status indicators. SCI-related data included *lesion level* (paraplegia vs. tetraplegia) and *time since injury*.

Information on *perceived information needs* was collected by asking participants whether there are any issues of their SCI on which they would need more information. Those who responded affirmatively were asked to describe their needs in an open-ended answer. *Sources of information used* were identified by asking the participants to select from a list all sources of information about SCI they have used, without a specification of a timeframe (i.e., at any time since their injury). Participants could also select the option "Other" and specify its nature. *Health literacy* was operationalized using the item "How confident are you that you can get the information you need to be able to minimize the occurrence of SCI related complications".

Quality of life was assessed using the item "How would you rate your quality of life?", while *satisfaction with health* was assessed using the item "How satisfied are you with your health?". *Healthcare services utilization* was assessed asking participants to select from a list of 14 health professionals providing outpatients services all health professionals they had visited in the last 12 months, and to indicate the number of visits for each of them. Two sum scores were computed, one for the *total number of visits* and one for the *total number of different services* used.

Data analysis

Quantitative data were analyzed using IBM SPSS Statistics 21.0. Descriptive statistics were used to describe the composition of the sample in terms of socio-demographics, lesion characteristics, information seeking behaviors, quality of life, satisfaction with health, and use of healthcare services. Frequency counts and percentages (binary and categorical variables) as well as means and standard deviations (continuous variables) were computed. To assess the association between personal characteristics and information seeking behaviors, linear (*health literacy*) and logistic (*information needs* and *sources of information*) regression models were run with the information seeking variables as outcomes and all personal characteristics as predictors. To explore the association between information seeking behavior and quality of life, satisfaction with health, and use of healthcare services, linear (*quality of life*, *satisfaction with health*) and Poisson (*number of visits* and *number of services*) regression models were run. Personal characteristics were added to all regression models as covariates. Data normality of all variables was confirmed using skewness and kurtosis of the distribution [19], except for *number of visits*. Additional linear regression analyses were run with its log transformation to account for possible effects of outliers. Listwise deletion was used for missing data, resulting in the exclusion of up to 211 cases.

Qualitative thematic analysis was used to analyze the open-ended question assessing perceived information needs. The coding into themes was the result of an inductive process. One researcher first read all answers and reorganized them to group all those clearly referring to the same topic (e.g., all answers mentioning bladder management, all answers mentioning a cure). The second step consisted of developing categories by attributing a descriptive label to every topic (e.g., "assistive device" for the topic "mattress", "health maintenance" for "nutrition", "prevention" for "prevention of pressure injuries"). The third step consisted of grouping these categories into themes. For instance, the categories Bladder and bowel management, Health maintenance, Prevention, and Mental health were gathered under the theme "Health self-management". We kept a certain granularity in the themes (e.g., not incorporating "health self-management of SCI" into "living with SCI") in order not to lose the richness of the qualitative findings. A second researcher was involved all along the process for discussing doubts, supporting in the formulation and revision of the themes, and reviewing the final findings for consistency. A binary variable was created for each identified theme. A value of 1 on each variable was assigned when a participant mentioned a need belonging to that specific theme.

Results

Sample characteristics

A total of 1294 people participated in the survey. Participants were predominantly males (70.9%), had a mean age of 56 years, reported a mean of 14 years of education, and perceived their relative socio-economic status as average. As regards SCI characteristics, 70.4% had paraplegia and 29.6% tetraplegia, and the mean time since injury was 19 years. A more detailed description of the sample can be found in Table 1.

Information needs

Around one out of four participants reported a need for information (24.6%). Logistic regression analyses (see Table 2) showed that older participants (Odds Ratio (OR) 0.98) and those perceiving to be in a better socioeconomic position (OR 0.90) were significantly less likely to report information needs. On the other hand, those with more years of education were significantly more likely to report an information need (OR 1.07). No significant associations were found between having an information need and gender or SCI characteristics.

The qualitative analysis revealed information needs on a broad range of topics (see Appendix 2 for an overview).

Participants predominantly indicated to need medical information about SCI and its complications, and information about living with SCI. Some participants also reported needing information on treatments and research. Less than one in ten participants reported a need for information on self-management and only a few were interested in information about a cure for SCI. The results of a series of logistic regression analyses showed that both personal and SCI characteristics were linked to information needs (see Table 2). For instance, to name the most striking, compared to people with tetraplegia, people with paraplegia were almost five times as likely to report a need for information about self-management (OR 4.86) and more than twice as likely to report a need for information on treatments (OR 2.36) but only one fourth as likely to report a need for information on a cure (OR 0.26).

Sources of information

Healthcare professionals were the most frequently cited source of information, with almost three out of four participants (72.3%) reporting to rely on them for SCI-related information. Many participants also reported relying on online media (43.2%) and on other people with SCI (40.8%). Only a minority reported using traditional media (18.9%) or an organization for people with SCI (13.3%). A series of logistic regression analyses was performed to assess the role played by personal and SCI characteristics in the use of the different sources of information (see Table 3). Male participants were significantly less likely to use traditional media (OR 0.70). Older age was significantly associated with lower reliance on other people with SCI (OR 0.97) and on online media (OR 0.99) and with greater reliance on traditional media (OR 1.02). Participants with more years of education were significantly more likely to report using healthcare professionals (OR 1.08) and online media (OR 1.07) as well as traditional ones (OR 1.089). Lastly, longer time since injury was significantly associated with an increased likelihood to rely on other people with SCI (OR 1.01) and on an organization for people with SCI (OR = 1.01). No significant association between subjective socio-economic position or lesion level and sources was observed.

Health literacy

Slightly less than two thirds of the participants perceived themselves as very or completely confident in their ability to get necessary information to effectively manage SCI complications (58.6%). Most of the others perceived themselves as somewhat confident (29.3%) and only a minority as little or not at all confident (12.2%). A linear regression analysis (see Table 3) showed that higher health literacy was associated with more years of education (B 0.021, $p < 0.05$), higher

Table 1 Sample characteristics.

Variable	N	Response	n (%)	Mean (SD)
Personal characteristics				
Gender	1294	Male	918 (70.9)	
Age	1294			56.4 (14.4)
Years of education	1238			14.3 (3.5)
Socio-economic status (scale 1–10)	1233			5.6 (1.9)
SCI characteristics				
Lesion level	1268	Paraplegia	893 (70.4)	
		Tetraplegia	375 (29.6)	
Time since injury (years)	1215			18.8 (13.1)
Information				
Information needs	1294	Yes	318 (24.6)	
Information topics	318	Medical information about SCI	97 (30.5)	
		Living with SCI	91 (28.6)	
		Treatments	67 (21.1)	
		Research	41 (12.9)	
		Self-management of SCI	28 (8.8)	
		Cure	14 (4.4)	
Information sources	1294	Other people with SCI	528 (40.8)	
		Organization for people with SCI	172 (13.3)	
		Healthcare professionals	935 (72.3)	
		Online media	559 (43.2)	
		Print media	244 (18.9)	
		Other	29 (2.2)	
Health literacy (ability to get the information needed to minimize the occurrence of SCI-related complications)	1251	Not at all confident	31 (2.5)	
		Little confident	121 (9.7)	
		Somewhat confident	366 (29.3)	
		Very confident	554 (44.3)	
		Completely confident	179 (14.3)	
Quality of life, satisfaction with health, and healthcare services utilization				
Quality of life	1261	Very bad	18 (1.4)	
		Bad	65 (5.2)	
		Moderate	333 (26.4)	
		Good	634 (50.3)	
		Very good	211 (16.7)	
Satisfaction with health	1264	Very unsatisfied	46 (3.6)	
		Unsatisfied	202 (16.0)	
		Neither unsatisfied nor satisfied	301 (23.8)	
		Satisfied	604 (47.8)	
		Very satisfied	11 (8.8)	
Number of visits to healthcare professionals	1294			51.4 (63.1)
Number of different services used	1294			4.8 (2.3)

Table 2 Individual correlates of information needs.

| | Information needs | | | | | | |
| | Overall (N = 1119) | Living with SCI (N = 271[a]) | Self-management (N = 271[a]) | Medical information (N = 271[a]) | Treatments (N = 271[a]) | Cure (N = 271[a]) | Research (N = 271[a]) |
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Male (ref. Female)	0.78 (0.58–1.06)	0.66 (0.36–1.19)	0.45 (0.19–1.09)	0.80 (0.46–1.40)	1.29 (0.66–2.51)	4.08 (0.50–33.12)	3.13* (1.23–7.96)
Age	0.98** (0.97–0.99)	0.99 (0.97–1.02)	0.99 (0.96–1.02)	1.01 (0.99–1.03)	1.01 (0.99–1.03)	1.01 (0.97–1.06)	0.97* (0.94–0.99)
Education (years)	1.07** (1.03–1.12)	1.08* (1.01–1.19)	1.03 (0.92–1.15)	0.96 (0.89–1.03)	0.99 (0.92–1.08)	1.05 (0.89–1.24)	1.02 (0.92–1.12)
Subj. socio-economic status	0.90* (0.84–0.98)	1.25* (1.07–1.45)	0.97 (0.77–1.23)	1.01 (0.88–1.16)	0.86 (0.73–1.01)	0.80 (0.58–1.09)	1.06 (0.89–1.28)
Paraplegia (ref. Tetraplegia)	0.90 (0.67–1.22)	0.89 (0.49–1.64)	4.86* (1.10–21.42)	0.69 (0.39–1.20)	2.36* (1.11–5.01)	0.26* (0.07–0.93)	0.69 (0.33–1.43)
Time since injury (months)	1.00 (0.99–1.01)	1.01*** (1.01–1.01)	1.00 (0.99–1.01)	1.00 (0.99–1.01)	0.99 (0.99–1.01)	0.99 (0.99–1.01)	1.00 (0.99–1.01)

Estimates are from a series of logistic regression analyses with the different information needs as outcome variable.

OR Odds Ratio, *95% CI* 95% Confidence Interval, OR ≤ 1.0 indicate a higher likelihood of having the information need compared to the reference category or with increasing scores on the predictor variable, OR > 1.0 indicate a higher likelihood of having the information need compared to the reference category or with increasing scores on the predictor variable.

*p < 0.05; **p < 0.01; ***p < 0.001.

[a]Only those who reported an information need are included in these analyses.

subjective socio-economic status (B 0.098, $p < 0.001$), and longer time since injury (B 0.001, $p < 0.021$).

Associations of information seeking with quality of life, satisfaction with health, and healthcare services utilization

Around two thirds of the participants (67%) rated their quality of life as good or very good, one out of four rated it as moderate (26.4%), and only fewer than one in ten (6.6%) as bad or very bad. The majority of the participants also reported to be satisfied or very satisfied with their health (56.6%), around one out of four to be neither satisfied nor dissatisfied (23.8%), and less than one fifth (18.6%) to be dissatisfied or very dissatisfied. The mean number of visits to a healthcare professional reported over the last year was 51.4 and the mean number of different services used was around 5. A more detailed description of healthcare services utilization among our participants can be found elsewhere [20, 21].

Greater quality of life was associated with not having information needs (B −0.108, $p = 0.018$) and with higher health literacy (B 0.141, $p < 0.001$). A greater satisfaction with one's health was associated with not having information needs (B −0.117, $p = 0.033$), with using an organization for people with SCI as a source of information (B 0.146, $p = 0.030$), and with not using healthcare professionals as a source of information (B −0.120, $p = 0.026$). As regards utilization of healthcare services, a Poisson regression analysis showed that the total number of visits was significantly greater among those reporting a need for information (OR 1.24) and among those with higher health literacy (OR 1.03). Higher number of visits was also significantly associated with having relied for information on other individuals with SCI (OR 1.15), on an organization for people with SCI (OR 1.23), on healthcare providers (OR 1.15), as well as on traditional media (OR 1.15). Having used the internet was significantly associated with lower number of visits (OR 0.91). Substituting number of visits with its log transformation and with number of services used led to similar results, with the exception of use of media (both online and traditional) and health literacy, where no significant associations were found (see Table 4 for details).

Discussion and conclusion

The most important finding of this study is the association of information seeking behavior with quality of life, satisfaction with health, and healthcare services utilization among people with SCI. This link to date has not been studied in SCI, but was already proven in other conditions (see, e.g., [22]). Information needs were shown to be associated with both a lower quality of life and a lower

Table 3 Individual correlates of use of information sources and health literacy.

	Use of information sources					Health literacy (N = 1091)
	Other individuals with SCI (N = 1119) OR (95% CI)	Organization for people with SCI (N = 1119) OR (95% CI)	Healthcare professionals (N = 1119) OR (95% CI)	Online media (N = 1119) OR (95% CI)	Traditional media (N = 1119) OR (95% CI)	B (SE) p value
Male (Ref. Female)	1.11 (0.84–1.46)	0.82 (0.564–1.201)	0.97 (0.72–1.31)	1.07 (0.82–1.40)	0.70* (0.51 to 0.97)	− 0.006 (0.060) 0.927
Age	0.97*** (0.96–0.98)	1.01 (0.993–1.020)	1.01 (0.99–1.02)	0.98*** (0.98–0.99)	1.02** (1.01 to 1.03)	− 0.002 (0.002) 0.381
Education (years)	1.04 (0.99–1.01)	1.02 (0.96–1.07)	1.08** (1.03–1.13)	1.07** (1.03–1.11)	1.09*** (1.04 to 1.14)	0.021 (0.008)* 0.014
Subj. socio-economic status	0.98 (0.92–1.05)	1.10 (0.99–1.21)	1.03 (0.96–1.11)	0.96 (0.90–1.02)	0.99 (0.91 to 1.08)	0.098 (0.015)*** < 0.001
Paraplegia (Ref. Tetraplegia)	1.01 (0.77–1.33)	1.30 (0.87–1.93)	1.12 (0.84–1.50)	0.99 (0.76–1.29)	0.94 (0.68 to 1.30)	0.017 (0.020) 0.390
Time since injury (months)	1.01*** (1.01–1.01)	1.01** (1.01–1.01)	1.00 (0.99–1.01)	1.00 (0.99–1.01)	1.00 (1.00 to 1.01)	0.001 (0.001)* 0.021

Estimates are from a series of logistic regression analyses with the different information sources used as the outcome variable and from a linear regression analysis with health literacy as the outcome variable.

OR Odds Ratio, 95% CI 95% Confidence Interval, B unstandardized correlation coefficient, SE Standard Error, OR < 1.0 indicates a lower likelihood of use the source compared to the reference category or with increasing values of the predictor variable, OR ≥ 1 indicates a higher likelihood of having used the source compared to the reference category or with increasing scores on the predictor variable.

*p < 0.05; **p < 0.01; ***p < 0.001.

satisfaction with health. Greater quality of life was associated with a higher health literacy and a similar trend was also observed for satisfaction with health, although the association did not reach statistical significance. Despite the impossibility to draw causal conclusions, these associations suggest a positive effect of information. Utilization of healthcare services was associated with information needs and choice of sources of information. Our data also indicate an association with health literacy, although this was significant only for number of visits and only when using the non-transformed variable. The interpretation of these results is challenging, as our data do not allow us to distinguish between necessary and unnecessary visits and to interpret a higher or a lower number of visits as either a positive or negative outcome.

A second central result of this study is that most participants reported no information needs. This is encouraging, as it suggests that the information available to individuals living with SCI in Switzerland is adequate to satisfy their needs. At the same time, however, one in four participants mentioned one or more topics they would like more information about. Interestingly, whereas higher perceived socio-economic status was associated with lower information needs, the opposite was true for those with higher education. This could mean that education alone is not enough, thus stressing the importance of designing and providing information to target people of all educational levels. Unmet information needs have been shown in this study, as well as in the international literature [23], to be associated with suboptimal outcomes. This could mean, for instance, that those with poor health lack important information on how to self-manage their condition. It is thus crucial for institutions to respond to these needs and to invest in the provision of comprehensive, timely, and accessible information to support individuals with SCI.

This study can inform education programs for people with SCI, by highlighting the topics on which individuals with SCI need information and the sources they use. Our analyses showed that information needs are varied, but most frequently concern medical information about SCI, complications, and comorbidities and living with SCI. Despite patient education during initial rehabilitation and the availability of information from different sources, some still perceive a lack of information about their condition and its complications. This might be due to the fact that during initial rehabilitation individuals are overwhelmed by the situation and struggle with processing the large amount of information they receive or that several of SCI complications tend to appear later on in life [24]. It is important to note, moreover, that several participants reported having information needs in relation to the various aspects that characterize life with SCI and that information needs were different depending on both personal and SCI characteristics. To ensure the delivery of truly "person-centered

Table 4 Association of information needs, use of sources of information, and health literacy with health outcomes and service utilized.

	Health services utilization				
	Quality of life (N = 1083)	Satisfaction with health (N = 1083)	Number of visits (N = 1083)	Number of visits (log-transformed) (N = 1083)	Number of different services (N = 1083)
	B (SE) p value	B (SE) p value	OR (95% CI)	B (SE) p value	OR (95% CI)
Information needs (Ref. No needs)	−0.11 (0.05)* 0.018	−0.12 (0.06)* 0.033	1.24*** (1.22–1.26)	0.12 (0.04)** 0.004	1.12** (1.05–1.19)
Sources of information					
Other individuals with SCI (Ref. Not used)	−0.01 (0.04) 0.808	0.03 (0.05) 0.537	1.15*** (1.13–1.18)	0.14 (0.04)*** 0.000	1.12*** (1.06–1.18)
Organization for people with SCI (Ref. Not used)	−0.04 (0.06) 0.479	0.15 (0.07)* 0.030	1.23*** (1.20–1.26)	0.11 (0.5)* 0.035	1.14** (1.06–1.23)
Healthcare professionals (Ref. Not used)	−0.02 (0.05) 0.675	−0.12 (0.05)* 0.026	1.15*** (1.13–1.18)	0.12 (0.04)** 0.003	1.10** (1.03–1.18)
Online media (Ref. Not used)	−0.07 (0.04) 0.087	0.02 (0.05) 0.762	0.91*** (0.90–0.93)	0.01 (0.04) 0.823	1.04 (0.98–1.10)
Traditional media (Ref. Not used)	0.02 (0.05) 0.753	−0.02 (0.06) 0.749	1.15*** (1.13–1.17)	0.01 (0.05) 0.780	0.96 (0.90–1.03)
Health literacy	0.14 (0.02)*** < 0.001	0.05 (0.03) 0.086	1.03*** (1.02–1.04)	0.01 (0.03) 0.916	1.01 (0.98–1.05)

Estimates are from linear regression analyses (*quality of life, satisfaction with health,* and *number of visits - log-transformed* as outcome variables) and from Poisson regressions analyses (*number of visits* and *number of different services* as outcome variable).

OR Odds Ratio, *95% CI* 95% Confidence Interval, *B* unstandardized correlation coefficient, *SE* Standard Error, OR < 1.0 indicates a lower use of visits or healthcare services used compared to the reference category or with increasing values of the predictor variable, OR ≥ 1 indicates a higher number of visits or healthcare services used compared to the reference category or with increasing scores on the predictor variable; all models include gender, age, years of education, subjective socio-economic status, lesion level, time since injury, quality of life, and satisfaction with own health as covariates.

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

care", it is therefore crucial that institutions provide information that is relevant to the different groups (e.g., people with paraplegia vs tetraplegia) and that covers both medical topics (e.g., complications, treatments) and topics of living with SCI (health-related, e.g., self-management, pregnancy, sexuality; not health-related, e.g., housing, career, social insurances). Among the mentioned topics, ageing deserves a special mention as people with disabilities are living longer than they did in the past [25].

Additionally, this study provides information on the sources of information most used by individuals with SCI. In line with findings from international research [26], healthcare professionals were by far the most frequently used source, followed by online media and other people with SCI. Also, greater satisfaction with one's health was associated with using an organization for people with SCI as a source. In light of this result, which mirrors findings from international research showing that people search for and value the opinion of "people like me" [26], it is important to invest in communication tools combining these sources. One existing example is the platform Paraplegie Community [27] which offers both expert and peer advice online. One further aspect to consider is that the SCI population is aging and older people in our study were shown to be less likely to use both online media and peers as sources of information. Although this might be a cohort effect that will disappear in a few years when older people too will be acquainted with technology, it is important to ensure, for the time being, that information is also available through traditional channels. The risk is otherwise to create disparities in information access between older individuals with SCI who are confident in using technologies and those who are not [28].

Lastly, this study provides us with a glimpse of the health literacy of people living with SCI in Switzerland. More specifically, more than one third of our participants were only somewhat or not at all confident in their ability to find information for the management of SCI complications. This result is in line with findings from international studies showing that substantial segments of the population, especially those with lower education and socio-economic status have suboptimal health literacy [29]. With limited health literacy being a risk factor for several health outcomes, it is important to ensure that institutions provide information that is accessible to everyone. This includes using simple language, avoiding medical jargon, and using illustrations to explain complex concepts. Using simple and accessible information benefits people of all health literacy levels [30].

Limitations

This study has some limitations. First, its cross-sectional nature does not allow us to draw conclusions on causality.

After this first exploratory endeavor, further longitudinal research is needed to get more robust insights into the complexity of the phenomenon. It would also be important to assess the role of other factors that can be associated with both information seeking behavior and outcomes (e.g., number and severity of complications). Second, we acknowledge that we did not use a validated measure of health literacy and that our operationalization does not capture the complexity of the concept, but is limited to its functional component (i.e., finding information). However, the use of measures focusing on a single component, although not ideal from a conceptual point of view, is common practice in health literacy research (see, for instance, [31]). Third, as already mentioned, we were not able to distinguish between necessary and unnecessary visits to healthcare professionals and this limited our interpretation of the results. To make this distinction, different data collection methods are needed (e.g., a combination of self-reported data with information from medical records). Differences among healthcare services should also be recognized: some need many sessions (e.g., physiotherapy) whereas others need only one or a few visits (e.g., general practitioner). To reduce distortions in the data, we excluded use of home care services from the sum score, as many participants reported high use of these services. Additionally, analyses were repeated using a log-transformed variable for *number of visits* (to account for outliers) as well as a variable counting the *total number of different services*. Although the results from the three analyses did not substantially differ, we acknowledge that some of our findings might reflect differences in the services themselves. Last, we acknowledge that our sample may not be fully representative of Swiss residents with SCI.

Conclusion

Our study was the first to investigate information seeking among people living with SCI in Switzerland and to study the link between information seeking, outcomes, and use of healthcare services in a SCI population. Our findings provide additional evidence for the need for institutions to invest in the development and provision of information to support lifelong individuals living with SCI. That information should be about all aspects of living with SCI, understandable by and relevant to people of all socio-demographic backgrounds, and delivered by different sources.

Data availability

Owing to our commitment to SwiSCI study participants and their privacy, datasets generated during the current study are

Compliance with ethical standards

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