

Information seeking behavior and perceived health literacy of family caregivers of persons living with a chronic condition. The case of spinal cord injury in Switzerland.

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Abstract

Objective: To examine the information seeking behavior and health literacy of caregivers of individuals living with spinal cord injury in Switzerland and their impact on the caregiving experience.

Methods: Nationwide survey of family caregivers of people with spinal cord injury (N = 717). Caregivers aged 18+ who assisted with activities of daily living were included. Self-reported information seeking behavior, including topics, preferred sources, and health literacy were assessed and analyzed.

Results: Health professionals were the most trusted source of information. Among information-seekers, higher health literacy levels were shown to be associated with lower subjective caregiver burden and, in turn, with higher caregivers' satisfaction with own health.

Conclusion: Caregivers use information on different topics and coming from different sources. In order for information to improve the caregiving experience, however, caregivers need health literacy skills to make sense of it.

Practice implications: Building health literacy is a promising approach to support caregivers in their activities, reduce their subjective burden, and even to improve their health. Interventions should consider involving health professionals, as the most trusted source of information, and address both health-related and more practical issues.

1. Introduction

An informal caregiver is an “unpaid individual (a spouse, significant other, family member, friend, or neighbor) involved in assisting others who are unable to perform certain activities on their own” [1]. By assisting and supporting their relatives or friends, caregivers allow them to live in a familiar comfortable setting and at the same time maximize their independence from the healthcare services despite their health condition [2,3]. Moreover, informal caregiving is associated with reduced healthcare costs and service use [4–8].

Caregiving is a multifaceted activity which requires knowledge and skills [9,10], especially in case of complex chronic conditions, that is conditions involving multiple morbidities and self-management requirements [11,12]. However, many family members often do not have a specific preparation to support their loved ones in activities of daily living as well as in nursing tasks such as medication management or wound care [13], in particular in case of unexpected traumatic events [14]. To face the multiple demands of their role, caregivers need, among other, information [15]. They need especially information about the health conditions of the care receiver, their symptoms and existing treatments, about available services, insurances and financial support [16,17]. Considering that caregivers may play a significant role in a wide range of self-management support activities, they do not only need to be able to access information, but also to understand, appraise, and apply health information in order to participate in decision-making, organize and coordinate care, and communicate with healthcare professionals (HPs) [18]. This set of skills is often referred to as health literacy [19].

Research among patients and in the general population has shown that individuals with higher health literacy are more active information seekers and can better apply health information to their lives [20]. In contrast, individuals with inadequate health literacy perceive barriers to health information seeking compared to those with adequate health literacy [21,22] and are less likely to use the Internet for health-related information [22–25].

Moreover, research conducted among caregivers has shown that those with adequate health literacy are more likely to get information from multiple sources [22,25]. In line with what has been presented in a study in the general population [26], most caregivers reported to have a high level of trust in the information obtained from health professionals compared to other sources [25].

Based on previous studies, we might expect health literacy to be associated not only with information seeking but also with important outcomes for family caregivers. Indeed, health literacy was shown to be indirectly associated with caregiver burden [27,28]. In turn, higher caregiver burden was found to predict worse health status [29–32], lower health-related quality of life [33], and poorer health outcomes [34–36]. However, as noted by Yuen and colleagues in their systematic scoping review, further research is needed to examine relationships between caregiver health literacy, information needs and caregiver outcomes [28].

The present study has the overall objective to examine information seeking and health literacy of caregivers of individuals with spinal cord injury (SCI) and how these impact their caregiving experience. SCI is a complex chronic health condition characterized by a loss or change in the motor or sensation functions [37,38]. The complexity of the condition and its lifelong implications as well as the often extensive and intensive caregivers' investment [39] make SCI a valuable case study to better understand the interplay of health literacy and caregivers' subjective burden.

This study aimed first at determining the prevalence of information seeking among caregivers of people living with SCI in Switzerland and at identifying possible characteristics of the caregivers or the care receivers which could explain this phenomenon. The second aim was to get an in-depth insight into how caregivers of people living with SCI in Switzerland search for information related to their caregiving activities. In particular we focused on the topics searched, the source used, and the degree of trust in different sources. Last, the

present study had the objective to explore the association between health literacy and the caregivers' experience in terms of perceived burden and satisfaction with one's own health.

2. Methods

2.1. Study design

Cross-sectional data from the nationwide community survey on primary family caregivers of persons with SCI collected in 2016 were used. This questionnaire represents the first part of the mixed-methods project "Informal Health Care by Family Members of Persons with Spinal Cord Injury in Switzerland" conducted by the Swiss Paraplegic Research in Nottwil [40].

The Ethic Committee of Northeast and Central Switzerland claimed no jurisdiction over this survey because no clinical parameter or health-related data was collected. Written informed consent was obtained from all participants.

1.2. Population and recruitment

Participants were family members of persons with SCI, aged 18 years or older, who assisted with activities of daily living and were fluent in at least one Swiss official language. To identify the caregivers, we used the database of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) [41], which holds a comprehensive registry of people with SCI living in Switzerland. All community-dwelling individuals with SCI were contacted and asked to give the questionnaire to the family member with the highest time investment in care provision. Response rate was 31% [40].

1.3. Measures

Information seeking was assessed by asking respondents whether they had ever searched for information related to their caregiving activities. Individuals who stated to have looked for

information in the past were asked further questions about these searches. Participants had to indicate a maximum of five topics for which they *most often needed information* and a maximum of three *most used sources*. Additionally, they had to indicate *how much they trust* each of ten possible sources of information in the context of caregiving. Response options ranged from 1 “not at all” to 4 “a lot”. To assess their *health literacy* level, caregivers were asked to answer to six statements taken from the Health Informational National Trends Survey (HINTS) [42] about their perceived ability in the different health literacy domains (accessing, understanding, appraising, and applying health related information) with 1 “completely disagree” to 4 “completely agree”. The internal consistency of the scale was good ($\alpha = .852$) and an average score of all the responses was computed ($M = 2.59$, $SD = .726$). Information seeking behavior, sources of information, and trust in information sources were all assessed by self-report measures adapted from the scale about information needs on cancer of the HINTS [42].

Demographic information of the family caregivers included *gender*, *age* at the time of the questionnaire, and *highest educational achievement*. For the SCI person *gender*, *age*, *lesion level* (paraplegia vs. tetraplegia), and *years since onset of SCI* were considered.

Perceived caregiver burden was assessed with twelve items from the EUROFAMCARE & COPE Index [43]. Individuals were asked to answer with "always"/ "often" / "sometimes" / "never" to statements about repercussions of the caregiving role on their daily life. Items of the original EUROFAMCARE & COPE Index referring to financial support (1 item) and social support (from family and friends, 2 items) were excluded as these aspects were extensively covered in other sections of the questionnaire. The 12-item scale presented good internal consistency ($\alpha = .820$) and an average score for each individual was computed ($M = 1.78$, $SD = .454$).

Objective caregiver burden was assessed by a single item asking the respondents to indicate an estimation of how many hours they dedicate on average to caregiving activities during a week (M = 21.49, SD = 24.876).

Satisfaction with one's health was assessed with a single item with response options ranging on a scale from 0 = "completely dissatisfied" to 10 "completely satisfied" (M = 7.4, SD = 2.15).

1.4. Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics Version 21.0. Univariate descriptive statistics (frequencies, means, and standard deviations) were used to describe the sociodemographic characteristics of the study population as well as their information seeking behavior, topics searched, information sources used, and trust in information sources. Logistic regression analysis was used to assess the role played by individual caregiver's and care receiver's characteristics in explaining information seeking behavior, controlling for all covariates. Bivariate correlation analyses were performed to assess the association between health literacy and topics searched, information sources used, and trust in information sources. Linear regression analyses were used to assess the impact of health literacy on perceived caregiver burden and of perceived caregiver burden on satisfaction with one's health, controlling for all covariates. The indirect effect of health literacy on satisfaction with one's health was tested using a percentile bootstrap estimation approach with 10000 samples [44], implemented with Model 4 of the PROCESS macro Version 3.3 [45].

3. Results

3.1. Sample characteristics

Our sample was composed by N = 717 caregivers of people living with SCI in Switzerland. Detailed data about the sample are presented in Table 1. Caregivers were predominantly females. The average age was slightly under 60 years and most caregivers had a upper secondary school diploma or higher. On average caregivers in our sample spent around 20 hours per week in caregiving activities (objective burden). Overall, the perceived burden related to caregiving activities was low.

Care receivers were predominantly males and had an average age slightly under 60 years. Around two thirds of care receivers were paraplegic and have been living with SCI for slightly less than 20 years on average.

| Table 1 Sample characteristics | | |
|---|----------------|------------------|
| | N = 717 | |
| | n (%) | Mean (SD) |
| Caregiver's characteristics | | |
| Gender | | |
| Male | 203 (28.3) | |
| Female | 511 (71.3) | |
| Missing | 3 (0.4) | |
| Age | | 59.1 (13.9) |
| Education | | |
| No mandatory education | 29 (4.0) | |
| Compulsory school | 178 (24.8) | |
| Upper secondary school diploma | 314 (43.8) | |
| University degree or higher | 178 (24.8) | |
| Missing | 18 (2.6) | |
| Objective burden ^a | | 20.8 (21.86) |
| Perceived burden ^b | | 1.8 (0.45) |
| Satisfaction with one's health ^c | | 7.4 (2.15) |
| Care receiver's characteristics | | |
| Gender | | |
| Male | 519 (72.2) | |
| Female | 183 (22.5) | |
| Missing | 15 (5.3) | |
| Age | | 57.4 (16.30) |
| Lesion level | | |
| Paraplegia | 432 (60.3) | |
| Tetraplegia | 225 (31.4) | |
| Missing | 50 (8.4) | |
| Years since injury | | 18.5 (14.35) |

Notes:

^a Number of caregiving hours per week; ^b 1 = “No burden” to 4 = “Highest burden”; ^c 1 = “Completely dissatisfied” to 10 = “Completely satisfied”.

3.2. Information seekers vs Non-seekers

The first aim of this study was to determine the prevalence of information seeking among caregivers of people living with SCI in Switzerland and to identify possible characteristics of the caregivers or the care receivers which could explain this phenomenon. Almost half of the caregivers in our sample reported having actively searched for information regarding their caregiving activities (40.4%, $n = 290$). Results from a logistic regression analysis (see Table 2) showed that, controlling for all other variables, caregivers with higher levels of education (Odds Ratio (OR) = 1.61, 95%CI = 1.27 – 2.04) were more likely to have searched for information. Increasing perceived burden was associated with an increased likelihood of information seeking (OR = 1.91, 95%CI = 1.20 – 3.04). Similarly, every additional hour of caregiving activities (objective caregiving burden) was shown to be associated with an increased likelihood of having searched for information (OR = 1.02, 95%CI = 1.01 – 1.02). Higher caregiver’s satisfaction with one’s health, on the other hand, was associated with a lower likelihood of information seeking (OR = .90, 95%CI = .82 – .99). As regards the characteristics of the care receivers, only time since injury was negatively associated with having searched for information (OR = .98, 95%CI = .97 – .99). All other caregiver characteristics (such as gender and age) as well as care receiver characteristics (gender, age, and lesion level) did not show any association with information seeking behavior.

Table 2 Logistic regression analysis with information seeking as dependent variable, predicted by caregiver’s and care receiver’s characteristics

| Predictor variable | OR | 95% CI | P |
|---------------------|-------------|--------------------|------------------|
| <i>Caregiver</i> | | | |
| Female ^a | .97 | .54 – 1.75 | .919 |
| Age | .99 | .98 – 1.01 | .454 |
| Education | 1.61 | 1.27 – 2.04 | < .001 |
| Perceived burden | 1.91 | 1.20 – 3.04 | .006 |

| | | | |
|--------------------------------|-------------|--------------------|-------------|
| Objective burden | 1.02 | 1.01 – 1.02 | .001 |
| Satisfaction with one's health | .90 | .82 – .99 | .037 |
| <i>Care receiver</i> | | | |
| Female ^a | .94 | .52 – 1.69 | .826 |
| Age | .99 | .98 - 1.01 | .624 |
| Tetraplegia ^b | 1.25 | .83 – 1.87 | .280 |
| Years since injury | .98 | .97 – .99 | .033 |

Notes:

Model R² = .150 (Nagelkerke)

^a Reference category: Male

^b Reference category: Paraplegia

3.3. Searched topics and trusted sources of information

The second aim of this study was to get an in-depth insight into how caregivers of people living with SCI in Switzerland search for information related to their caregiving activities. Table 3 provides a detailed overview of topics searched, information sources used, and trust in the different information sources.

Overall, the most searched topics among caregivers were general health-related issues, home adaptation, financial issues, and equipment and assistive devices. In regards to sources of information, more than half of the respondents reported having searched for information from their general practitioners, while only around a quarter has searched from a SCI specialist. Other commonly used sources of information include online media and other health professionals. A similar picture emerges from the questions about trust in information sources. HPs are the most trusted source among caregivers, followed by family, friends, and colleagues and by online media.

Table 3 Caregivers' information seeking behavior

| | N = 290 |
|--------------------------------------|----------------|
| Topics searched | n (%) |
| General health-related topics | 195 (67.2) |
| Home adaptation | 143 (49.3) |
| Finances, health insurance | 135 (46.6) |
| Equipment and assistive devices | 125 (43.1) |
| Caregiver and care services | 79 (27.2) |
| Fitness, health promotion, nutrition | 74 (25.5) |
| Mental health | 69 (23.8) |

| | |
|-------------------------|-----------|
| Legal issues and rights | 62 (21.4) |
| Cure and treatment | 46 (15.9) |
| Sexuality and fertility | 40 (13.8) |
| Social relations | 39 (13.4) |
| Employment | 26 (9.0) |
| Accommodation | 20 (6.9) |

| Information sources used | n (%) |
|--|--------------|
| General practitioners | 159 (54.8) |
| Online media (websites, blogs, social media) | 96 (33.1) |
| Family, friends, and colleagues | 78 (26.9) |
| Other healthcare professionals | 74 (25.5) |
| SCI specialists | 67 (23.1) |
| ParaHelp (local home care counselling service) | 63 (21.7) |
| Social services | 40 (13.8) |
| Other people living with SCI | 38 (13.1) |
| Print media (newspapers, magazines) | 37 (12.8) |
| Books | 28 (9.7) |
| Associations of people living with SCI | 21 (7.2) |
| TV and radio | 16 (5.5) |
| Support groups and chat groups (offline) | 8 (2.8) |
| Research institutes | 7 (2.4) |

| Trust in information sources^a | Mean (SD) |
|---|------------------|
| Healthcare professionals | 3.19 (.713) |
| Family, friends, and colleagues | 2.50 (.896) |
| Online media (websites, blogs, social media) | 2.35 (.812) |
| TV | 2.09 (.815) |
| Print media (newspapers, magazines) | 2.05 (.788) |
| Non-profit organizations | 2.07 (.908) |
| Governmental health institutions | 2.01 (.985) |
| Radio | 1.77 (.801) |
| Support groups and chat groups (offline) | 1.62 (.815) |
| Religious organizations | 1.41 (.768) |

Notes:

^a 1 = "Not at all"; 4 = "A lot".

3.4. The impact of health literacy on information seeking and on caregiver's outcomes

Bivariate correlation analyses were used to assess the relationship between health literacy and information seeking (topics searched, sources used, and trust in the different sources).

The analyses did not reveal any relevant patterns. As regards topics, lower health literacy was only significantly associated with more searches for information about mental issues (p

= .025). No significant association was found between health literacy and information sources used, yet higher health literacy was shown to be associated with higher trust in HPs ($p < .001$).

The third specific aim of this study was to explore the association between health literacy and caregiver experience in terms of perceived caregiver burden, and the caregiver's satisfaction with one's health. Results of a regression analysis controlling for all relevant covariates indicated that lower health literacy was associated with higher caregiver burden, unstandardized regression coefficient $B = -.210$, $SE = .039$, $p < .001$, and that higher caregiver burden was associated with lower satisfaction with one's health, $B = -1.604$, $SE = .354$, $p < .001$. These results suggest a mediation effect. Health literacy was not significantly associated with satisfaction with one's health when controlling for perceived burden, $B = .275$, $SE = .210$, $p = .192$, consistent with full mediation. Approximately 21% of the variance in satisfaction with one's health was accounted for by the predictors ($R^2 = .212$). The indirect effect of health literacy was tested using a percentile bootstrap estimation approach with 10000 samples. The analysis indicated that the indirect coefficient was significant, $B = .340$, $SE = .115$, 95%CI = .1614, .6188. An increase in health literacy was therefore associated with higher satisfaction with one's health as mediated by perceived burden.

4. Discussion and conclusion

4.1. Discussion

The overall objective of the present study was to get new insights into the information seeking behavior of caregivers of people living with SCI in Switzerland and into the relationship between information seeking, health literacy, and caregiver experience in terms of perceived burden and satisfaction with one's health.

Almost one in two caregivers in our sample reported to have searched for information in relation to their caregiving activities, confirming results from studies in other fields, which

generally agree that caregivers have needs and that, among these, information needs are common and very important [16,46]. Also, it confirms findings from other studies in the field of SCI which have found that family members rated information among the most important assets when assisting someone with SCI [47]. This interpretation is supported by the findings that caregivers with higher perceived burden search more for information and that caregivers with a high satisfaction with one's health are less likely to search for information. In contrast with current evidence on health information seeking in the general population [48–50], our analyses showed that information seeking among caregivers seems to be equally prevalent across socio-demographic groups. With one important exception: educational level was shown to be positively correlated with information seeking, with caregivers with higher educational level being more likely to have searched for information. Although we were not able to draw a detailed profile of those who are more likely to search for information, this finding alone has some important implications. First, it might suggest that those with lower education experience barriers in searching for information or they do not perceive the value of information and are therefore more likely to lack useful information for their caregiving activities. This interpretation is corroborated by the findings about the role of health literacy which will be discussed in the following paragraph. Second, this result urges policy makers and health educators to put into place dedicated strategies to make relevant information accessible and to raise awareness about its potential value also to those with limited education.

Besides, our analysis also allowed us to get a clearer picture of the specific topics they have searched and of the sources they relied on the most. In line with what was shown in previous studies in other fields, caregivers mostly searched information in relation to the health condition [9,46]. Nearly half of the caregivers in our sample, however also reported having looked for information about home adaptations, about finances and insurances as well as about assistive devices. This variety of topics searched could be explained by the broadness

and complexity of the caregiver's role. Especially when dealing with a person suffering from a complex chronic health condition like SCI, caregiving tasks span from symptoms management to administrative issues, and require caregivers to develop an extensive array of knowledge and skills [17,51]. The fact that information on cure for SCI was only searched by a minority of the interviewees might indicate that they focus more on the day-to-day management of the condition rather than on potential long-term solutions. These findings suggest that caregivers need information on practical matters. Besides information on the management of the health condition, rehabilitation centers and other institutions should also ensure the provision of non-medical information that could greatly contribute to easing caregiving.

As regards sources of information, our respondents reported looking for reliable information mostly from health professionals, followed by online media. This preference is shared with caregivers in other medical fields [52,53] as well as with the general population [26]. Our findings highlighted that HPs are also the most trusted source of information, independently from the age of the caregivers. These are important and reassuring results, in an era of general distrust in institutions, including medical authorities [54,55], and it seems to be a countertrend. However, as explained by Blendon and colleagues, a lack of confidence in the system does often not affect the trust in individual health professionals [56]. Despite HPs being the preferred and most trusted source of information, the Internet is often the most common source used because of its ease of access [26]. The fact that caregivers would regularly turn to general practitioners instead of to SCI specialists for information might also be explained with difficulties in accessing specialized services [57].

Last but not least, we were able to prove a link between health literacy and satisfaction with one's health, mediated by perceived caregiver burden. This finding reflects the results of previous studies of both caregivers of adults and of children, which found an association between low caregiver health literacy and increased caregiver burden [27]. Most importantly,

in addition to the finding that caregivers having a higher burden were more likely to have searched for information, it also suggests a complex interplay between information seeking, health literacy and caregiver experience in terms of perceived burden and satisfaction with one's health. We did not find any other information seeking patterns regarding topics or sources in relation to health literacy level, suggesting that the pathways linking health literacy and outcomes among caregivers are not related to the choice of topics and sources. Yet, we found that people with higher health literacy have more trust in health professionals. We might hypothesize here that this increased trust is also associated with higher reliance on health professionals, which could explain a reduced burden and improved satisfaction with own health. In order to test this hypothesis, however, further in-depth qualitative and quantitative studies are needed.

This study presents some limitations. First, the response rate of 31% is relatively low. This could be explained by the fact that the questionnaires were forwarded to the family caregivers by the persons with SCI. Family members responsible for usual household tasks might not have been considered as caregivers [40]. However, the characteristics of the care recipients in our study (gender, age, lesion level, and time since injury) are similar to those of the participants to the 2012 SwiSCI Community Survey [58], which is our reference population as there is no comprehensive registry of people with SCI living in Switzerland. We are therefore confident that our sample represents well the population of interest and that our results are generalizable. Second, data was gathered using self-reported questionnaires focusing on the lived experience of caregivers, which could lead to some response bias. Furthermore, participants reported about search for information performed during their whole caregivers' career, which was sometimes very long. This could have led to recall biases. Moreover, health literacy was measured only for those having searched for information. Having data for all participants would allow to better understand the complex interaction between information seeking behavior and subjective burden. We also did not

use an established measure of health literacy, such as the TOFHLA [59] or the REALM [60]. This limits the comparability of our findings with those of other studies. Nevertheless, self-reported measures are commonly used in health literacy research [61]. Finally, the study has a cross-sectional design and therefore individual changes over time are not reflected. Longitudinal studies are needed to tackle this limitation and to study changes in information seeking behavior over time as well as in its relation to subjective and objective caregiver burden.

4.2. Conclusion

In the so called information society, several claims are done about the value of information and, specifically in healthcare, of health-related information. This study confirms the important findings that information about health topics, financial aspects, home adaptation and assistive devices are an asset to assist informal caregivers of individuals with SCI. The study, however, also highlights some important challenges as it concludes that not all caregivers in need of assistance actually search for information that could help. For instance, caregivers with high levels of education and health literacy seem to have a stronger relationship with health professionals, which benefits the whole process as shown by a lower perceived burden and higher satisfaction with their own health. On the other hand, caregivers with low levels of education, who are those who are likely to be more in need of support, were shown to search less and to have less trust in health professionals. Because of the potential positive implications of information on the perceived burden of caregiving, this study confirms that health literacy is and should be a major target for interventions to empower caregivers.

4.3. Practice implications

Informal caregivers are a pillar of the health system and they should be involved in the planning of the care and be included in the caring team [2]. The findings of this study point to the need for educational programs and tools directed to caregivers. Their health literacy skills as well as available resources and competing demands should be assessed to ensure that they are able to provide care in the long term [9,62].

Dedicated educational interventions for caregivers are needed to provide them with the necessary health literacy skills to deal with their caregiving activities. Despite the few health literacy interventions studies for caregivers, encouraging results from Cianfrocca and colleagues show that attending a multidisciplinary training course seems to decrease the caregiver burden and increase health information seeking [63]. In view of the generalized high trust in the health professionals, they shall be involved in an intervention targeting the caregivers' information needs. The involvement of health professionals was also mentioned among the components of effective health literacy interventions in a seminal systematic review on health literacy and health outcomes [64].

Furthermore, considering that, in reason of their role, caregivers are often little mobile, the participation in courses at specific times and places might not be feasible. In similar contexts, telehealth has shown potential for responding to the well-known need for emotional support through peer-to-peer interaction as well as to the need for education and information [65–67]. Besides information on spinal cord injury and related conditions, the platform should also offer information on practical and administrative issues such as financial support and insurances. Possibly, information will address questions and issues in relation to the different phases of the life of a person with SCI, as Wackerbarth and Johnson [68] suggested that the course of the disease determines the type of information needs. Besides, the platform should include the possibility to interact with health professionals (for instance to a “doctor online”), as they are the most trusted source of information. In Switzerland, an online platform initiated by the Swiss Paraplegic Group is a

first attempt to offer information and counseling to persons with SCI and their caregivers [69].

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