



## LIVING SITUATION OF FAMILY CAREGIVERS OF PERSONS WITH SPINAL CORD INJURY

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**Objective:** To describe the living situation of family caregivers of persons with spinal cord injury.

**Design:** Cross-sectional questionnaire.

**Subjects:** Primary family caregivers of persons with chronic spinal cord injury in Switzerland.

**Methods:** Cross-sectional study of family caregivers of persons with spinal cord injury. For comparison, the study population was matched to family caregivers of persons dealing with long-term health conditions in the general population, using a propensity score based algorithm.

**Results:** A total of 717 family caregivers participated in the survey (35% response rate). Participants were mostly female (72%), mean age 57 years, and had spent approximately 13 years caring for their relative. A mean of 21 h/week was spent providing care and assistance. The vast majority of family caregivers reported coping well with their situation. However, support from public services was deemed inadequate. Compared with family caregivers in the general population, family caregivers of persons with spinal cord injury performed more caring tasks and reported a slightly lower quality of life.

**Conclusion:** Family caregivers of persons with spinal cord injury are self-reliant to cope with their situation, but report discontent with public support services. The healthcare system could provide alternative support measures, such as direct financial compensation.

**Key words:** community medicine; family caregiver; home care service; home nursing; independent living; informal sector; nursing; spinal cord injury.

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Family members provide essential assistance to persons with spinal cord injury (SCI), which is often unplanned due to sudden life-changing event (1). Family caregiving allows the person with SCI to remain in a familiar setting and to maintain their personal and community contacts (2). However, such a commitment can be detrimental to the caregiver in terms of reduced social participation, family life, leisure activities and

### LAY ABSTRACT

Family members are often the most important providers of care and assistance for persons with a spinal cord injury. Although they are a large population group, little is known about how family members cope with their duties as lay caregivers, or about their joys and sorrows. To find out about their living situation, a large, nationwide questionnaire survey was conducted in Switzerland. The results show that family caregivers are mostly females (72%), and have spent a mean of approximately 13 years caring for their family member, for a mean of 21 h/week. Although family caregivers are very busy, they handle their caregiving duties and report coping well with the situation. They rarely use public respite services (i.e. short-term services organized to relieve family caregivers), in which they show little trust. In conclusion, given this situation, it is not advised to offer further respite provision, but rather to provide financial compensation to the caregivers for their efforts. This would demonstrate recognition for their work and stimulate the individual initiative of the caregivers.

personal care (3). Compromises in working life, such as reducing their work hours, terminating employment, and restricting career choices, suggests that a large proportion of family caregivers for persons with SCI assume no other roles (4).

Worldwide, the need for informal care is likely to increase, due to increasing life expectancy and the number of persons dealing with chronic conditions, further aggravated by cost-cutting in the public sector budget (5, 6). Moreover, shrinking and increasingly geographically scattered family structures challenge the management of family assistance (7). In Switzerland, family members carry the legal obligation to care for close relatives; thus, family caregivers are not compensated, as no such option exists, despite the high expenditure in social security (26% of the gross domestic product (GDP)) and healthcare (12.2% of the GDP) in 2016 (8), which makes Switzerland the country with the second-highest healthcare budget in the world (9).

Informal care is difficult to investigate, as it takes place in the concealed home environment. In contrast to clinical studies on patients, there are no institutional records (such as visits to physicians), financial tracking

data (from health or social insurance), or any other routine information on family caregivers. As a result, comprehensive epidemiological studies on informal care are rare and focus mainly on frail elderly people (10) and, infrequently, on long-term conditions, such as SCI (11, 12). In addition, most studies have been restricted to spouses, with little attention paid to other family members, such as caregiving parents or siblings (13). The vast majority of informal care studies have been on psychological outcomes; areas such as social participation, caring tasks, information needs, service utilization, interpersonal relationships and employment have been little-studied (13).

The objective of this study was to illustrate the situation of family caregivers of persons with SCI, in order to identify areas that require support. This was the first national study on family caregivers in SCI. The specific aims of this study were: (i) to present the survey design; (ii) to characterize the main family caregiver in relation to their role, caring tasks, living situation and burden of care; and (iii) to provide insights in terms of personal factors, caring activities and outcomes, when comparing family caregivers of persons with SCI with caregivers in the general population. The study aimed to better inform planning and decision-making on how to relieve and empower family caregivers of persons with long-term health conditions, such as SCI.

## METHODS

### *Study setting and design*

A cross-sectional questionnaire survey was conducted in family caregivers of persons with SCI in Switzerland. The questionnaires were sent by post in August 2016. There was the option to use an online version, or to obtain assistance from the study personnel based on an interview by phone or face-to-face. The latter was granted on request. Two written reminders were sent to non-responders.

### *Ethics approval and consent to participate*

The ethics committee of Northeast and Central Switzerland, claimed no jurisdiction because no health-related data were collected. All participants signed a written consent form to participate in the survey.

### *Participants*

Family caregivers of persons registered with SCI in the Swiss Spinal Cord Injury Cohort Study (SwiSCI) (14) were invited to participate in the study. The invitation was sent first to all persons with SCI not living in a residential home, irrespective of whether they had participated in previous SwiSCI surveys or if they had ever claimed to have no family caregiver ( $n=4,502$ ). The invitation letter asked the persons with SCI to forward the attached questionnaire to their primary family

caregiver; otherwise, to return a statement indicating that they did not have a family caregiver. The inclusion criteria for family caregivers was age 18 years or above and knowledge of one of the Swiss official languages (German, French and Italian).

The comparison between family caregivers of persons with SCI and caregivers of persons with long-term health conditions in the general population was enabled by matching the survey to the Swiss Health Survey 2012 (15). The Swiss Health Survey, part of the survey programme of the federal census, is a nationwide survey conducted every 5 years by the Federal Government. In the 2012 survey, 41,008 adult residents were randomly drawn from the central census registry, of which 21,597 persons (54%) participated. The survey collected information on health status and health-related behaviour. Participants were further asked whether they assumed caring roles for family members, which was affirmed by 2,928 persons.

### *Variables and measurements*

A questionnaire was developed by a team consisting of nursing experts, clinical SCI specialists, social counsellors, health scientists, representatives of homecare and patient organizations, and persons with SCI. The questionnaire was developed in German and translated into French and Italian. It addressed 128 items on demographics, living and family situation (civil status, household size, etc.), leisure and social life (frequency of performing different activities, adopted from the Swiss Household Panel (16)), working life and financial conditions (current employment, satisfaction with employment, etc.), investment in caregiving and assistance (number of hours invested in specific caring tasks), service utilization (number of times of using specific respite services in the last 12 months; use of professional home care), information needs (most used information sources; trust in information from specific sources, etc.) and interpersonal relationship to the care recipient (satisfaction with personal relationship, adapted from the Swiss Household Panel (16), intimacy with persons, adapted from the Swiss Health Survey (15)). An additional 10 questions were included on the living situation and functioning of the person with SCI (age, sex, employment, lesion characteristics). The negative impact and positive value of informal care was assessed using the Carers of Older People in Europe (COPE) index (17), while the financial burden of care was evaluated using instruments from EUROFAMCARE (18). Satisfaction with financial situation was rated on a scale from 0 to 10, with 10 indicating the highest satisfaction. Information needs were measured via instruments provided by Matter et al. (19), Burkell et al. (20) and by modified items of the cancer-related Health Information National Trends Survey (HINTS) 4 (21). Quality of life was investigated using Organization quality of life instrument WHO-QoL (22). Questions on satisfaction with personal relationships and social environment (rated on a scale from 0 to 10, with 10 indicating the highest satisfaction) were adapted from an instrument used in the Swiss Household Panel, and the subjective social status was determined using the McArthur scale in comparative view to other persons in Switzerland (23).

The questionnaire was pilot-tested with a retired, older man caring for his life partner, and a young woman working part-time and caring for her father-in-law. A think-aloud approach was employed to diagnose and remove potential problems with the questions (24).

### Statistical analysis

Descriptive statistics were presented using mean or median for continuous variables and relative frequency for categorical variables. The distribution of continuous variables was further illustrated by providing the lower and upper quartiles ( $Q_1$ ,  $Q_4$ ). As no hypotheses were foreseen for this descriptive study, no statistical inference was envisioned, thus no  $p$ -values were provided. All variables were presented as is, with no categorization of continuous variables. All available data were included in a complete case analysis. Statistical analyses were conducted using Stata version 14 for Windows (College Station, TX, USA).

To match the caregivers in the SCI survey with caregivers in the general population, propensity score matching was employed, which, in the first stage, estimated the propensity of the combined records to belong to the SCI caregiver survey, conditioned on the caregivers' characteristics: age, sex, marital status, households with children, nationality, language region and household income. In the second stage, the observations between the 2 surveys were matched using the estimated propensity score, with observations of similar propensity scores matched as more likely. A one-to-many match with replacement was conducted with a single participant from the survey on caregivers of persons with SCI to potentially many participants from the Swiss Health Survey. The multiple matches were weighted according to similarity using an Epanechnikov kernel with bandwidth 0.1.

The matched samples were compared for the following outcomes: quality of life, personal relations, caregiver tasks and working status. For the comparison weighted difference between the samples in proportions, for categorical outcomes, and in weighted means for continuous outcomes were computed as well as standardized differences. Following Cohen (25), the effect sizes of 0.2, 0.5 and 0.8 in absolute values were considered as small, medium and large, respectively (25).

## RESULTS

An invitation to participate was sent to 4,502 persons with SCI, of whom 864 were subsequently identified as not eligible or duplicates and 326 could not be contacted. Of the remaining 3,312 persons, approximately one-third reported having no family caregiver ( $n=1,259$ ). Finally, 717 out of 2,053 (35%) eligible family caregivers returned the questionnaire (Fig. 1).

### Descriptive analysis

Most caregivers were females (72%) and were spouses of the person they were caring for (77%), as shown in Table I. The mean age of both caregivers and persons with SCI was 57 years (Table II). Caregiving was undertaken for a mean of 13 years, in 85% of situations without interruptions, and with 25% of participants being the family caregiver for more than 20 years.

The non-retired participants worked mostly in part-time employment (35%), and to a lesser extent, in full-time employment (13.5%). Of these 251 persons,

one-third worked 40% or less, one-third between 40% and 60%, and the rest more than 60% of a full-time equivalent week. Among the caregivers with remunerative employment, 60% reported having the flexibility to combine working with caring tasks, mostly via individual arrangements with their employer, such as flexible working hours, compensating with overtime, etc. Nevertheless, 27% reported that they would like to work fewer hours, and 13% that they would like to work more hours. Since taking up the role as caregiver, 15% had left their job; the others had reduced their work quota by a mean of 30%.

The study participants rated satisfaction with their financial situation with a mean of 7 (median 7,  $Q_1=5$  h,  $Q_4=9$  h) on a scale of 0–10. One-quarter of participants gave a rating of 9 or 10, and 5% between 0 and 2. Half of the participants reported having extra financial expenses as a result of their role as caregivers. The mean amount reported was 635 Swiss Francs (CHF)/month for 275 participants and 50,000 CHF as a one-off payment for 79 participants.

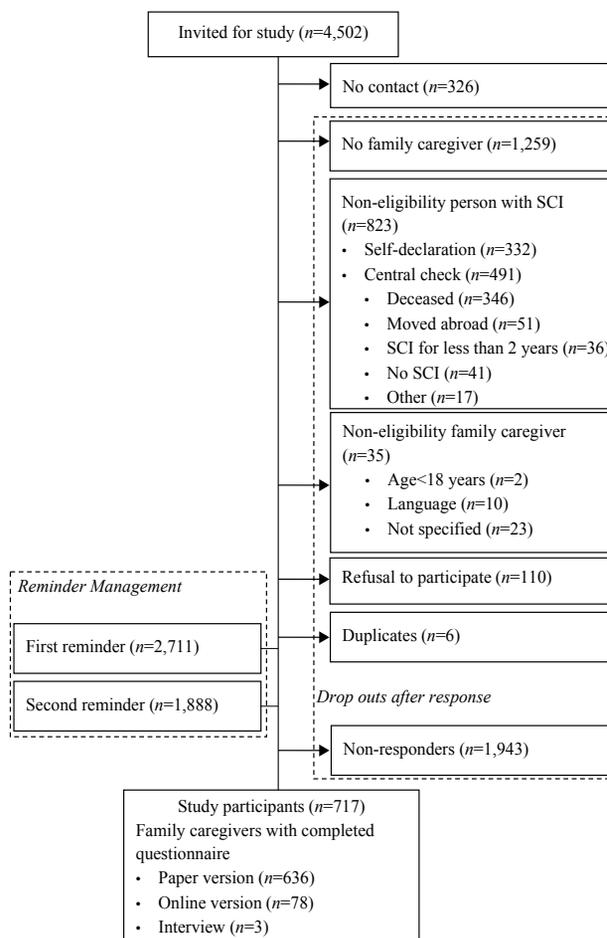


Fig. 1. Study flow-chart. SCI: spinal cord injury

**Table I.** Socio-demographic characteristics of family caregivers

Variable	Frequency Total (n=717)
Female, n (%)	511 (71.6)
Age, years, mean (SD)	57.2 (13.94)
Swiss nationality, n (%)	642 (89.5)
In partnership, n (%)	561 (79.6)
Households with children, n (%)	91 (12.7)
Cohabit with person with spinal cord injury, n (%)	596 (83.69)
Years as caregiver, mean (SD)	13.0 (11.50)
Caregiving h/week, mean (SD)	21.5 (24.88)
Relationship with person with spinal cord injury, n (%)	
Spouse/life partner	539 (76.9)
Child	39 (5.6)
Sibling	21 (3.0)
Mother/father	94 (13.0)
Other relatives	8 (1.1)
Language region, n (%)	
German	527 (73.5)
French	154 (21.5)
Italian	31 (4.3)
Highest education, n (%)	
No mandatory education	29 (4.1)
Elementary school	178 (25.5)
High-school or vocational training	314 (44.9)
University, technical college, professional certificate	178 (25.5)
Household income/month, CHF, n (%)	
< 1,500	3 (0.5)
1,500–3,000	49 (7.5)
3,000–4,500	104 (15.9)
5,400–6,000	141 (21.6)
6,000–7,500	117 (17.9)
7,500–9,000	95 (14.5)
>9,000	145 (22.2)
Financial satisfaction, mean (SD) <sup>a</sup>	6.88 (2.44)
Occupational situation, n (%) <sup>b</sup>	
Remunerative employment full-time	97 (13.5)
Remunerative employment part-time	251 (35.0)
In education	11 (1.5)
Co-worker in family business	30 (4.2)
Protected job	8 (1.1)
Homemaker	81 (11.3)
Retired person of older age <sup>c</sup>	253 (35.3)
Retired person with disability <sup>c</sup>	42 (5.9)
Unemployed	28 (3.9)
Other	18 (2.5)

<sup>a</sup>Financial satisfaction was measured from a 0 (not at all satisfied) to 10 (very satisfied) scale. <sup>b</sup>Options under the category "occupational situation" are not exclusive. CHF: Swiss Francs. <sup>c</sup>Retirement under the social insurance scheme in Switzerland is for all people above the age of 64 years (women) or 65 years (men). SD: standard deviation.

The total investment in care was estimated at a mean of 21 h/week ( $Q_1 = 5$  h,  $Q_4 = 30$  h, median 12 h) and was reduced when the person with SCI was able to walk (mean 15 h, median 10 h). After housekeeping, shopping and paperwork, most caregivers (59%) assisted the person with SCI in transfer or transport activities, in personal care (50%), and in tasks that required more specific skills (30%) (e.g. bladder/bowel management and respiratory care). The most time-consuming tasks were household chores (mean 12 h,  $Q_1 = 4$  h,  $Q_4 = 15$  h), personal care (mean 9 h,  $Q_1 = 2$  h,  $Q_4 = 11$  h), support in eating and drinking (mean 9 h,  $Q_1 = 3$  h,  $Q_4 = 14$  h), and transfer or transport activities (mean 8 h,  $Q_1 = 2$  h,  $Q_4 = 8$  h). For bowel/bladder management and respira-

**Table II.** Socio-demographic characteristics of persons with spinal cord injury

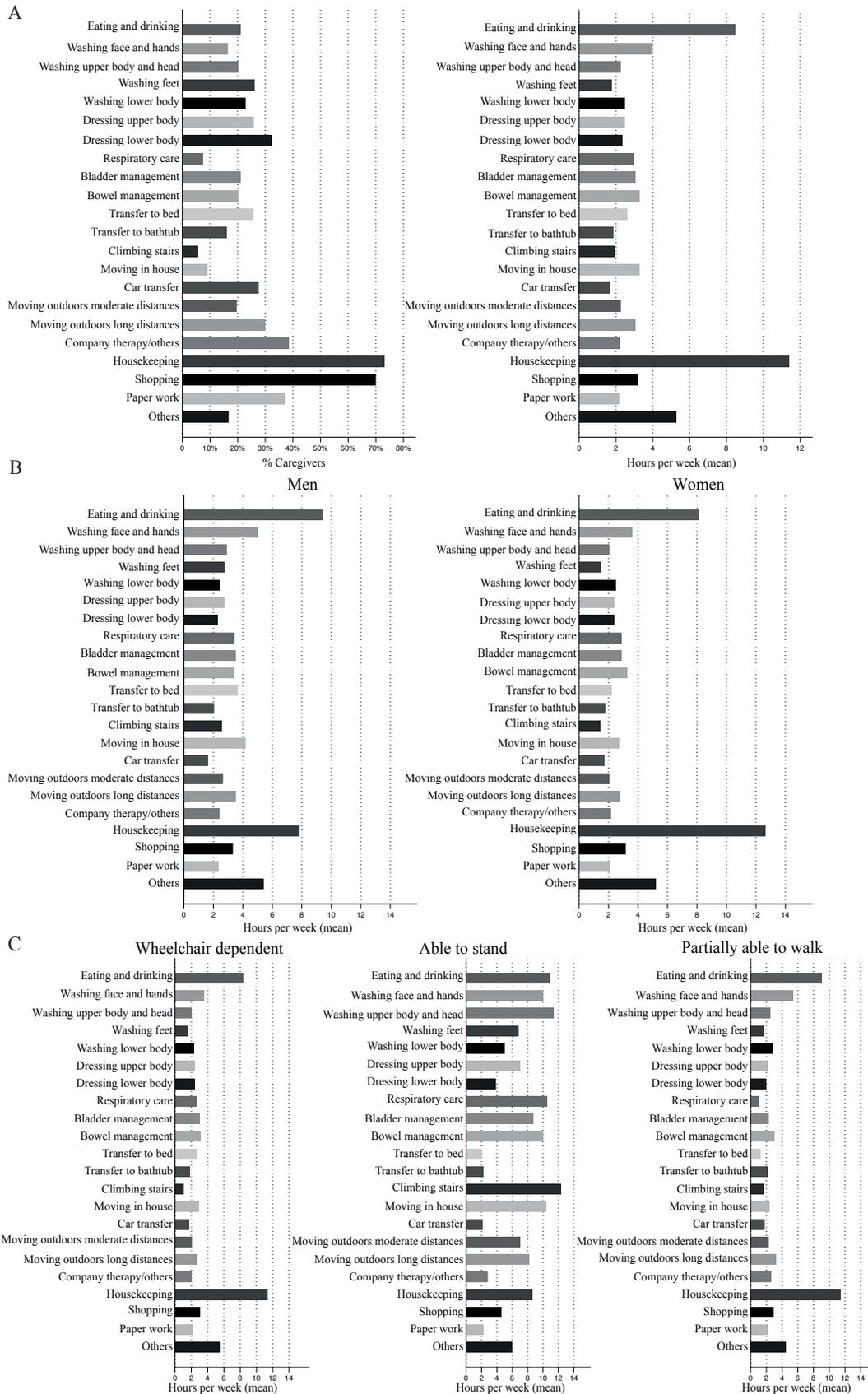
Variable	Frequency Total (n=717)
Male, n (%)	519 (73.9)
Age, years, mean (SD)	56.5 (16.30)
Years since spinal cord injury, mean (SD)	17.5 (14.34)
Cause of spinal cord injury, n (%)	
Accident	509 (73.6)
Illness	125 (18.1)
Other	58 (8.4)
Type of spinal cord injury, n (%)	
Paraplegia	432 (65.8)
Tetraplegia	225 (34.2)
Capacity, n (%)	
Wheelchair-dependent	484 (71.6)
Able to stand	23 (3.4)
Partially able to walk	169 (25.0)
Occupational situation, n (%)	
Remunerative employment	223 (31.1)
Vocational education	6 (0.8)
In education	20 (2.8)
Unpaid work (re-education, apprenticeship, etc.)	5 (0.7)
Unemployed	27 (3.8)
Homemaker	44 (6.1)
Retired person of older age <sup>a</sup>	251 (35.0)
Retired person with disability pension <sup>a</sup>	377 (52.6)
Other	67 (9.3)

<sup>a</sup>Retirement under the social insurance scheme in Switzerland is for all people above the age of 64 years (women) or 65 years (men). SD: standard deviation. Options under the category "occupational situation" are not exclusive.

tory care, a mean of 6 h ( $Q_1 = 1$  h,  $Q_4 = 8$  h) were spent per week (Fig. 2).

There were no marked sex differences, either in the nature of the tasks or in the time spent in the respective task. The only exception was housekeeping, which was more likely to be performed by women (76% vs 67%), who also invested more time on it (13 h/week by women vs 8 h by men). Similarly, the capacity level of the person with SCI did not determine the frequency of the tasks performed by the caregiver. Nevertheless, the time spent on people able to stand was significantly higher than the time spent on wheelchair-dependent people, and on people who were partially able to walk. Care and support tasks were complemented by other family members in 35% of cases, and by a friend or neighbour in 14% of cases. Additional support from a professional homecare organization was provided in 33% of cases, at a mean of 10 h/week ( $Q_1 = 4$  h,  $Q_4 = 14$  h).

Most caregivers reported information needs in relation to caring tasks in the area of health (34%), followed by home adaptation (26%), and financial support (22%). The most common source of information was the general practitioner (GP) (mentioned by 29% among the 3 most-used sources of information), while support groups played the least role. In between, caregivers reported trusting information from family, friends, media and the internet. Forty-four percent of participants reported



**Fig. 2.** Support provided by the main family caregiver (h/week/task). (A) Total study population. (B) By sex. (C) By capacity of the person with spinal cord injury (SCI). The mean number of hours includes only those persons who reported performing the tasks.

**Table III.** Impact of caregiving on mental and physical well-being

Impact of caregiving	Total n (100%)	Always n (%)	Mostly n (%)	Sometimes n (%)	Never n (%)
Negative on physical health	685	9 (1.3)	61 (8.9)	299 (43.6)	316 (46.1)
Negative on emotional wellbeing	689	15 (2.2)	53 (7.7)	422 (61.2)	199 (28.9)
Too demanding	690	11 (1.6)	43 (6.2)	403 (58.4)	233 (33.8)
Stuck in caregiver role	690	32 (4.6)	57 (8.3)	314 (45.5)	287 (41.6)
Problems within family	683	3 (0.4)	18 (2.6)	155 (22.7)	507 (74.2)
Negative on relationship to friends	686	13 (1.9)	41 (6.0)	203 (29.6)	429 (62.5)
Is a worthwhile task	672	322 (47.9)	204 (30.4)	86 (12.8)	60 (8.9)
Copes well with the caregiver's role	686	242 (35.3)	390 (56.9)	44 (6.4)	10 (1.5)
Good relationship with the supported person	693	465 (67.1)	198 (28.6)	21 (3.0)	9 (1.3)
Experiences appreciation as a caregiver	685	336 (49.1)	209 (30.5)	106 (15.5)	34 (5.0)
Sufficiently supported by health- and social services	629	89 (14.1)	227 (36.1)	161 (25.6)	152 (24.2)
Overall, adequately supported as caregiver	652	113 (17.3)	283 (43.4)	159 (24.4)	97 (14.9)

having no trust in the information provided by federal institutions, and only 7% reported great trust. Twenty percent of those seeking information were not confident that they would find relevant advice.

Respite services that allow family caregivers to take a break from their caregiving duties were hardly used. In the 12 months previous to the survey, day or night

care or companionship services were used by less than 9% of family caregivers. Similarly, publicly funded professional assistance was used by 13%. Less than 1% engaged in educational courses or support groups related to their caregiving role. As reasons for the non-utilization, 52% reported no need, enough support from family and friends (17%), costs (8%), non-availability

**Table IV.** Comparison between all caregivers (Swiss Health Survey) and caregivers of persons with spinal cord injury

	Original sample		Matched sample (kernel matching)			Standardized difference
	SHS n=2,928	SCI n=717	SHS n=1,793	SCI n=506	Difference	
Socio-demographic characteristics						
Age, years, mean (SD)	49.1	57.2	56.9	56.9	0.09	0.01
Male, %	41.2	28.4	29.9	28.5	0.01	0.03
Lives in partnership, %	63.1	79.6	80.5	77.7	0.03	0.07
Lives in household with children, %	29.4	12.7	13.2	12.6	0.01	0.02
Swiss nationality, %	91.0	89.5	91.9	92.1	0.00	-0.01
Language region, %						
German	64.9	73.5	74.5	76.9	-0.02	-0.06
French	26.5	21.5	21.9	19.6	0.02	0.06
Italian	8.6	4.3	3.5	3.6	0.00	0.00
Household income/month, CHF, %						
< 3,000	1.5	8.0	6.1	7.7	-0.02	-0.06
3,000-4,500	4.5	15.9	16.5	15.0	0.01	0.04
4,500-6,000	6.0	21.6	21.3	20.4	0.01	0.02
6,000-7,500	9.6	17.9	17.1	17.6	-0.01	-0.01
7,500-9,000	19.3	14.5	14.6	15.4	-0.01	-0.02
>9,000	59.0	22.2	24.4	23.9	0.01	0.01
Quality of life, %						
Very good	44.6	22.6	39.4	25.9	0.13	0.29
Good	48.0	56.1	49.9	55.7	-0.06	-0.12
Neither good nor bad	6.3	19.4	10.1	17.0	-0.07	-0.20
Bad/very bad	1.1	1.9	0.6	1.4	-0.01	-0.07
Personal relations, %						
Missing relation	20.9	22.2	23.2	22.3	0.01	0.02
Having someone to count on?	96.6	88.1	95.7	89.3	0.06	0.24
Caregiver tasks, %						
Physical and medical care	17.6	71.5	25.8	72.5	-0.47	-1.06
Housekeeping	58.4	81.6	63.2	84.2	-0.21	-0.49
Other tasks	79.3	98.5	75.8	98.2	-0.22	-0.71
Working status, %						
Full-time employment	36.2	13.5	20.5	15.0	0.05	0.14
Part-time employment	28.2	35.0	26.6	36.4	-0.10	-0.21
Unemployed	1.9	3.9	2.0	4.0	-0.02	-0.11
In education	4.5	1.5	2.6	1.4	0.01	0.09
Homemaker	18.9	11.3	22.2	11.3	0.11	0.30
Retired person of older age	2.9	35.3	5.6	34.6	-0.29	-0.78
Retired person with disability	0.8	5.9	1.5	5.7	-0.04	-0.22

SHS: Swiss Health Survey 2012; SCI: caregivers of persons with spinal cord injury; SD: standard deviation. Propensity score matching was applied with many-to-one matching and kernel-based weights attributed to SHS participants in order to align their total influence in comparison. Hence, the 1,793 records in the SHS weight up to the same population as in the SCI population. Difference denotes the difference in proportion. CHF: Swiss Francs.

(3%), scheduling issues (2%), bad past experiences (2%), or mistrust (1%). Similarly, the placement of the person with SCI in an institutional setting was not considered an option, due to the strong wish of the cared-for person to remain at home (62%). More professional homecare support, however, was desired by 24% of caregivers, of which, 44% reported costs as a barrier, 15% had bad experiences, and 22% reported scheduling issues. Unavailability of the service was reported as a barrier in 13% of the cases.

Caregiving responsibilities had a negative impact on mental or physical wellbeing in only a few participants. Only 8% of caregivers reported a predominantly negative impact on their mental health and 9% on their physical wellbeing. In 29% (mental wellbeing) and 46% (physical wellbeing) of cases, caregiving had no impact (Table III). A minority reported that their caring duties were too arduous and that it led to problems in the family or had a negative impact on family and friends. In most cases (78%), caregiving was considered a worthwhile duty. Ninety-two percent of family caregivers reported mostly coping well with their situation. In general, family caregivers shared a good relationship with the person they cared for and experienced appreciation for their work. Nevertheless, 15% (“never”) and 24% (“mostly not”) felt that they were not backed as a caregiver. In particular, the support by state-run health and social services was reported as “not” or “mostly not” being present by 50% of participants.

Satisfaction with personal relationships in family and society showed a median value of 8 ( $Q_1=5.4$ ,  $Q_4=9$ ). Only 3% of the caregivers rated their satisfaction as 3 or lower, while 35% rated it as 10. Subjective social status, as perceived in relation to other persons in Switzerland, was given a median rating of 6. Eleven percent of participants gave a rating of 3 or below and 18% of 8 or higher.

#### *Comparison with caregivers in the normative population*

In comparison with the normative Swiss caregiver population, caregivers of persons with SCI were older (57 vs 49 years, respectively) and more likely female (72% vs 59%) (Table IV). Caregivers in the normative population were more likely to live in households with children and had a higher household income.

From the normative population, 1,793 caregivers were matched to 503 caregivers of persons with SCI. The matching performed well, with good overlap in propensity scores between the groups (Fig. S1<sup>1</sup>) and standardized differences between 0.01 and 0.06 in

the matched socio-demographic characteristics. By comparing matched samples (Table IV), caregivers of persons with SCI reported a lower quality of life (18% vs 11%, respectively) and a smaller likelihood to have a person to count on (96% vs 89%, respectively). Also, caregivers of persons with SCI performed significantly more caring tasks that included physical and medical care, housekeeping chores and other tasks. Full-time employment thought was lower in caregivers of persons with SCI compared with the general population (15% vs 21%), they were also more likely to be employed part-time (36% vs 27%). Finally, caregivers of persons with SCI were more likely to be retired because of old age or disability and less likely to be homemakers.

## DISCUSSION

### *Sex differences in family caregivers*

Worldwide, family caregivers are mostly female (26). The rate of 72% females in this study compared with 59% females in the Swiss general caregiving population relates to the study population of persons with SCI, of whom 72% are males (27), with spouses being the typical family caregiver. Unlike the Swiss Health Survey, the current study focused on the main caregiver, which might bias the sex comparison, since males were also involved in caring for family members with disabilities, but, to a lesser extent, as the main caregiver (28). The low participation in professional life is not a reflection of the sex differences, as these differences between SCI and the normative population persisted after matching for sex.

### *Employment and financial situation*

The majority of study participants with remunerative employment reported having the flexibility to combine work with their caring duties. Satisfaction with their financial situation was high, despite various caregivers having to deal with substantial expenses due to their role. Also, an adequate social standing was perceived, with a mean rating of 6 (on a scale from 1=lowest to 10=highest), with 18% providing a rating of 8 or higher. These ratings were comparable to the normative population (29). Yet, the study population reported a lower quality of life and a lower participation in professional life. It questionable how public support services could adequately address these issues without much intervention in the cherished private situation.

### *Care provision*

The investment in care was found to be rather low in this study, compared with other caregiver studies in

<sup>1</sup><https://doi.org/10.2340/16501977-2762>

SCI (30–34). Generally, care provision varies between 2.3 to 12 h/day and depends on the injury level, injury severity and needs of the cared-for person (35). Study participants in related studies frequently reported having nobody else to provide assistance (32, 33). In contrast, the current study showed that 79% of the participants were not the sole caregiver, with one-third of participants being supported by professional homecare organizations. Compared with a Dutch study, participants in the current study conducted more tasks at a lower intensity (36); similarly, no sex differences regarding nursing tasks, with the exception of housekeeping, were identified.

### *Public support*

There was little trust in public institutions. Unfavourable ratings on the trust and support of public agencies suggest that other ways to support and provide relief to family caregivers, such as direct payments that empower families to organize their best individual solution, may be preferable; a solution that has been tested and has proven effective in many different settings (37). Still, measures to effectively prevent fraud or negative incentives to aiming for gainful employment should be introduced, such as monitoring or certification programmes.

### *Strengths and limitations*

A strength of this study is its sample size and comprehensiveness of investigation: it was conducted nationally, based on the best current source of information on persons with SCI living in the community in Switzerland. It reached 717 primary family caregivers who completed a questionnaire of 128 items covering all dimensions of family care and provided in 3 national languages. In a literature review on the quality of life of primary family caregivers of persons with SCI, the sample size in each of the 21 studies was substantially lower than in the current study (maximum 173; 18 studies had sample size <100) (4). Also, the Swiss Health Survey, used for comparison with the normative population, is a nationally representative random sample with 21,587 participants. Still, with a response rate of 35% it is questionable whether the representativity of the target population in the current study was met. It might well be that persons who were heavily involved in care did not find the time to answer the extensive questionnaire. A survey of family caregivers during end-of-life cancer care in England reached a sample size of 1,504, but had a response rate of only 28.5% even without written consent from the participants (38). In a US study of 1,635 family members of people diagnosed with cancer, a response

rate of 62% was achieved with a significant financial incentive to participate (39).

This study addressed the situation of the family member who was primarily responsible for the care and support of the person with SCI, as judged by the person with SCI. The study population thus represents the pinnacle of caregivers in terms of investment in care, with other persons also involved to a lesser extent. As a consequence, the results cannot be interpreted from the perspective of the cared-for person and how much care they need, as the caring responsibilities were potentially shared amongst many persons. This further affects the comparison between family caregivers in SCI with caregivers in the normative population. The former focusing on the main caregiver per dependent person, while the latter includes all persons who see themselves as caregivers. This may partly explain the higher burden found in family caregivers of persons with SCI compared with family caregivers in the normative population.

Although all Swiss Cantons with all 3 official Swiss languages were represented, the study missed the population who were not capable of completing a questionnaire in German, French or Italian. In 2016, 24% of the adult Swiss population did not have as main language one of the three official languages (40). It is unknown how many of these were able to answer a questionnaire in one of the official languages. In cultures with strong family ties and a language barrier, and thus with impeded connections with local service organizations, the role of family caregivers is assumed to be even more central.

Eighty-four percent of family caregivers lived in the same household with the person with SCI, and the majority were spouses. It must be assumed that some participants completed the questionnaire together with the person with SCI, as both were at some point involved in the survey logistics and might share a common interest in the survey. This joint completion might have affected the caregiver's judgement on items about interpersonal relationships or quality of life, compared with solo completion of the questionnaire.

### *Conclusion*

In conclusion, family caregivers are a highly used resource in supporting and caring for persons with SCI. They manage more care duties than the normative family caregiver and share fewer opportunities to participate full-time in professional life. Still, the majority feel well adapted to their situation and self-reliant to cope with their situation. In general, caring for family members appears to be regarded worthwhile; however, there is discontent with public support and recognition.

Relief and respite services were hardly used, and the participants managed the situation largely on their own. Mistrust of federal institutions as a source of information was prevalent. In this situation, more public service offerings may not be productive to relieve family caregivers. Instead, financial compensation of family caregivers could be envisioned as a tool to bring them recognition. Direct payments would empower families themselves to create an environment that best suits their individual situation.

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Availability of data and materials. The data that support the findings of this study are available from the corresponding author. Data from the Swiss Health Survey can be provided, on request, from the Federal Office of Statistics ([www.bfs.admin.ch/bfsstatic/dam/assets/1661847/master](http://www.bfs.admin.ch/bfsstatic/dam/assets/1661847/master)). Restrictions apply to the availability of the data from the Swiss Health Survey as used in this study, which were used under license for the current study, and cannot be shared by the study authors.

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### REFERENCES

- Boschen KA, Tonack M, Gargaro J. The impact of being a support provider to a person living in the community with a spinal cord injury. *Rehabil Psychol* 2005; 50: 397–407.
- Genet N, Boerma WG, Kringos DS, Bouman A, Francke AL, Fagerström C, et al. Home care in Europe: a systematic literature review. *BMC Health Serv Res* 2011; 11: 207.
- Schulz R, Eden J, Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, Engineering National Academies of Sciences. *Family caregiving roles and impacts*. Washington DC: National Academies Press (US); 2016.
- Lynch J, Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. *Spinal Cord* 2017; 55: 964–978.
- World Health Organization. *World report on ageing and health*. Geneva: World Health Organization; 2015.
- Lipszyc B, Sail E, Xavier A, European Commission, Directorate-General for Economic and Financial Affairs. *Long-term care: need, use and expenditure in the EU-27*. Economic papers 496. 2012. [Accessed Oct 2020]. Available from: [https://ec.europa.eu/economy\\_finance/publications/economic\\_paper/2012/pdf/ecp469\\_en.pdf](https://ec.europa.eu/economy_finance/publications/economic_paper/2012/pdf/ecp469_en.pdf).
- Genet N, European Observatory on Health Systems and Policies. *Home care across Europe: current structure and future challenges*. Copenhagen: World Health Organization; 2012.
- Swiss Federal Statistical Office. *Total social security accounts 2016*. [Accessed Oct 2020]. Available from: <https://www.bfs.admin.ch/bfs/en/home/statistics/catalogues-databases/press-releases.assetdetail.5389010.html>.
- OECD Health Policy Overview. *Health policy in Switzerland*. Available from: <https://www.oecd.org/els/health-systems/Health-Policy-in-Switzerland-July-2017.pdf>.
- Kotsadam A. Does informal eldercare impede women's employment? The case of European welfare states. *Fem Econ* 2010; 17: 121–144.
- Boschen K, Gargaro J. Experiential outcomes of the SCI support provider role. *Top Spinal Cord Inj Rehabil* 2009; 14: 69–87.
- Foster M, Amsters D, Carlson G. Spinal cord injury and family caregivers: a description of care and perception of service need. *Aust J Prim Health* 2005; 11: 91–101.
- World Health Organization, International Spinal Cord Society. *International Perspectives on Spinal Cord Injury*. Geneva: World Health Organization; 2013.
- Post MWM, Brinkhof MWG, von Elm E, Boldt C, Brach M, Fekete C, et al. Design of the Swiss spinal cord injury cohort study. *Am J Phys Med Rehabil* 2011; 90: S5–S16.
- Swiss Federal Office of Statistics. *Swiss health survey 2012*. 2013. [Accessed Oct 2020]. Available from: <https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/erhebungen/sgb.html>.
- FORS. *Swiss household panel*. FORS. 2017. [Accessed Oct 2020]. Available from: <http://forscenter.ch/projects/swiss-household-panel/>.
- McKee KJ, Philp I, Lamura G, Prouskas C, Oberg B, Krevers B, et al. The COPE index—a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging Ment Health* 2003; 7: 39–52.
- EUROFAMCARE. *Support and relief for family carers of older people*. A European comparative study. Description of workpackage. [Accessed Oct 2020]. Available from: [https://www.uke.de/extern/eurofamcare/wp\\_09.php](https://www.uke.de/extern/eurofamcare/wp_09.php).
- Matter B, Feinberg M, Schomer K, Harniss M, Brown P, Johnson K. Information needs of people with spinal cord injuries. *J Spinal Cord Med* 2009; 32: 545–554.
- Burkell JA, Wolfe DL, Potter PJ, Jutai JW. Information needs and information sources of individuals living with spinal cord injury. *Health Inf Libr J* 2006; 23: 257–265.
- Westat. *Health information national trends survey 4 (HINTS 4)*. Cycle 4 Methodology Report, National Cancer Institute. Bethesda, MD 20892-9760. 2015. [Accessed Oct 2020]. Available from: [https://hints.cancer.gov/docs/HINTS\\_4\\_Cycle\\_4\\_Methodology\\_Report.pdf](https://hints.cancer.gov/docs/HINTS_4_Cycle_4_Methodology_Report.pdf).
- World Health Organization. *Division of Mental Health and Prevention of Substance Abuse*. WHOQOL measuring quality of life. Geneva: World Health Organization; 1997.
- Adler NE, Stewart J. *The MacArthur scale of subjective social status*. 2007. [Accessed Oct 2020]. Available from: <https://macses.ucsf.edu/research/psychosocial/subjective.php>.
- Brancato G, Macchia S, Murgia M, Signore M, Simeoni G, Blanke K, et al. *Handbook of recommended practices for questionnaire development and testing in the European statistical system*. European Commission Grant Agreement 2004103000002, 2006.
- Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd edn. Hillsdale, NJ: L. Erlbaum Associates; 1988.
- World Health Organization, United Nations Population Fund. *Women, ageing and health: a framework for action: focus on gender*. Geneva: World Health Organization; 2007.
- Brinkhof MWG, Fekete C, Chamberlain JD, Post MWM, Gemperli A, SwiSCI Study Group. *Swiss national community survey on functioning after spinal cord injury: protocol*.

- characteristics of participants and determinants of non-response. *J Rehabil Med* 2016; 48: 120–130.
28. Sharkey P. *Essentials of community care*. London: Macmillan International Higher Education; 2006.
  29. Bodenmann P, Favrat B, Wolff H, Guessous I, Panese F, Herzig L, et al. Screening primary-care patients forgoing health care for economic reasons. *PLOS One* 2014; 9: e94006.
  30. Gajraj-Singh P. Psychological impact and the burden of caregiving for persons with spinal cord injury (SCI) living in the community in Fiji. *Spinal Cord*; 49: 928–934.
  31. Nogueira PC, Rabeh SAN, Caliri MHL, Dantas RAS. Health-related quality of life among caregivers of individuals with spinal cord injury. *J Neurosci Nurs J* 2016; 48: 28–34.
  32. Blanes L, Carmagnani MIS, Ferreira LM. Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord* 2007; 45: 399–403.
  33. Robinson-Whelen S, Rintala DH. Informal care providers for veterans with SCI: who are they and how are they doing? *J Rehabil Res Dev* 2003; 40: 511–516.
  34. Charlifue SB, Botticello A, Kolakowsky-Hayner SA, Richards JS, Tulsy DS. Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits. *Spinal Cord* 2016; 54: 732–736.
  35. Smith EM, Boucher N, Miller WC. Caregiving services in spinal cord injury: a systematic review of the literature. *Spinal Cord* 2016; 54: 562–569.
  36. Post MWM, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord* 2005; 43: 311–319.
  37. Polivka L. *Paying Family members to provide care: policy considerations for States*. Washington DC: Family Caregiver Alliance; 2001.
  38. Grande G, Rowland C, Berg B van den, Hanratty B. Psychological morbidity and general health among family caregivers during end-of-life cancer care: a retrospective census survey. *Palliat Med* 2018; 32: 1605–1614.
  39. Kim Y, Shaffer KM, Carver CS, Cannady RS. Quality of life of family caregivers 8 years after a relative's cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers. *Psychooncology* 2016; 25: 266–274.
  40. Swiss Federal Office of Statistics. Spoken languages in Switzerland. [Accessed Oct 2020]. Available from: <https://www.bfs.admin.ch/bfs/en/home/statistics/population/languages-religions/languages.html>.