

ORIGINAL REPORT

CAREGIVING, PARTICIPATION, AND QUALITY OF LIFE OF CLOSEST NEXT OF KIN OF PERSONS LIVING WITH SPINAL CORD INJURY IN NORWAY

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Objectives: To investigate how next of kin of persons with spinal cord injury (SCI) experience various life areas in terms of caregiving, participation, and quality of life, and the impact of personal characteristics of next of kin and SCI characteristics.

Design: Survey of next of kin linked to data on persons with SCI in the Norwegian SCI Registry.

Participants: A total of 73 next of kin identified by persons with SCI.

Methods: Outcome measures were caregiving (4 measures), participation (1 measure), and quality of life (2 measures).

Results: Participants (73% partners, 73% female, mean age 56.4 years) gave various support to the person with SCI and considered it important to care and were happy to do so. Three-quarters of participants reported good mental health and life satisfaction, while one-quarter reported high levels of caregiver strain, especially related to emotional adjustments. Higher levels of caregiver strain were reported by participants of working age (< 67 years), and by those with middle level education.

Conclusion: The majority of next of kin of persons living with SCI in Norway are doing well in most life areas. Caregiver strain may be reduced by strengthening the ability of next of kin to cope with emotional challenges.

Key words: spinal cord injury; caregiver; caregiver burden; participation; quality of life; Norway.

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Spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people

LAY ABSTRACT

A spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people surrounding them, such as family members. Caregiving for a loved one with SCI involves both physical and emotional investment. A survey was carried out of the caregivers of 73 persons living with SCI in Norway to assess their life situation. The study found that the majority of caregivers of persons living with SCI in Norway are doing well in most life areas. Three out of 4 caregivers reported good mental health and life satisfaction. All participants considered it important to care and most were happy to do so. Nevertheless, one-quarter reported high levels of strain, especially related to emotional adjustments. Most at risk for caregiver strain were participants of working age and those with secondary education. Caregiver strain may be reduced by strengthening the ability of the caregiver to cope with emotional challenges.

surrounding them. Many next of kin (close relatives, spouses, etc.) provide extensive support to persons with SCI (1, 2). This support is often necessary for persons with SCI to continue living at home and to maintain their well-being (3). Previous studies have reported that between 25% and 50% of partners of persons with SCI experience high levels of caregiver burden (4, 5).

The level of caregiver burden can be influenced by caregiver characteristics, such as age, sex, level of education, occupation status, and the type of relationship between caregiver and care recipient (2, 4, 6). In addition, the personal and injury characteristics of the person with SCI receiving support impacts the support provided and the perceived caregiver burden (2). However, the majority of previous studies of next of kin are based on samples that are not representative of the population of next of kin of persons with SCI and on self-reported data on injury characteristics provided by the caregiver (2). Therefore, studies using clinical register data, which

may be available from SCI quality registers, are needed to improve the trustworthiness of the data.

The demands placed on the next of kin of persons with SCI can affect various life areas. Next of kin can experience strained relationships, less control over life, increased stress, and financial difficulties (7–9). There are only a few studies on objective burden of support (1, 4, 10), caregiver participation (11), and positive caregiver experiences (12). These studies show that next of kin provide support in many different types of activities, and that the next of kin of persons with a more severe disability more often provide practical everyday support.

However, currently, most studies in this field are limited to measuring the impact of SCI on 1 or 2 life areas of next of kin, and the broader picture is thus lacking. The results of such a study with a broader approach can be used to identify groups of next of kin who are at risk.

Although Norway has a relatively good health and social system for persons with SCI (13) and the National Norwegian SCI registry (NorSCIR) provides a good overview of the SCI population (www.norscir.no), to date, no information about the next of kin of persons with SCI in Norway exists. This study utilized NorSCIR to recruit a representative sample with good-quality clinical data on SCI characteristics in order to study the life situation of closest next of kin of persons living with SCI in Norway.

This study aimed to describe the next of kin of persons with SCI in Norway and to identify how the personal characteristics of next of kin and the injury characteristics of the related person with SCI, influence different life areas of next of kin; caregiving (objective and subjective burden of care, and positive experiences), participation, and quality of life (QoL) (life satisfaction, and mental health).

METHODS

Study design

The study includes survey data from next of kin linked to data on persons with SCI in NorSCIR. It is part of a research project concerning participation and QoL among persons registered in NorSCIR between 2011 and 2017 and their next of kin.

Participants

During 2019, all persons in NorSCIR were invited to participate in the “Survey among persons with SCI”. Of the 651 invited persons with SCI, 339 participated (52%). All participants were asked to provide contact information for their designated next of kin so that the next of kin could be invited to participate in the “Next

of kin survey”. Next of kin was defined in the questionnaire as “A person who provides unpaid support, or the one who is closest to you. Usually it is a partner or other close relative, such as parent, child or sibling”.

Procedures

A digital invitation was sent to all 92 designated next of kin. Those not registered with a digital mailbox or not answering the digital questionnaire were invited by post. Up to 2 reminders were sent to non-responders. To create awareness among those who were invited, general information about the study was published on the Facebook page and in the magazine of members of the Norwegian SCI consumer organization “LARS”.

Ethical approval for the study was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (2018/294/REK midt).

Measures

Sociodemographic characteristics of next of kin. This information included sex, age, level of education (categorized as primary, middle and higher (college/university) level of education), personal income, vocational status (categorized as currently working or student, retirement pension, social welfare recipient, or other (homemaker, jobseeker)) status and type of relation to the person with SCI. Age was categorized into 3 groups (<55, 55–67 and >67 years), as the retirement age in Norway is 67 years. Personal income was categorized into 2 groups (below and above 500,000 Norwegian kroner per year (approximately 49,500 EUR)).

Spinal cord injury characteristics. Injury characteristics were obtained from NorSCIR, which contains data registered by clinicians using the definitions from the International SCI Core Data Set version 1.1 (14). Study variables included dates of discharge from rehabilitation care, cause of injury and neurological status at discharge from rehabilitation hospital. Causes were categorized as traumatic or non-traumatic. The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) was used to document neurological level of injury and the severity of SCI, as described by the American Spinal Injury Association (ASIA) Impairment Scale (AIS) (15). These characteristics were coded in 4 categories: Tetraplegia (C1–C8) AIS A, B or C; Tetraplegia (C1–C8) AIS D; Paraplegia (T1–S5) AIS A, B or C; Paraplegia (T1–S5) AIS D. None was registered with AIS E.

Outcome measures

Outcome measures were: caregiving (objective burden, subjective burden, and positive caregiver experience), participation, and quality of life, as described below.

Objective burden of care. The objective burden of care for next of kin was measured by a measure of types and frequency of support (1, 4). The measure includes 3 categories of support: activities of daily living (ADL) support (13 items), other practical support (9 items) and emotional support (2 items). Response categories are: never (1), sometimes (2), often (3) and always (4). The total score is the mean of the item scores (range 1–4). Translation of the questionnaire from Dutch to Norwegian was performed according to the guidelines from the World Health Organization (WHO) for the process of translation and adaptation of instruments (16).

Subjective burden of care. It has been recommended to measure subjective burden of care using 2 instruments that complement each other (17); 1 instrument that measures different dimensions of burden, and 1 instrument that measures the caregiver's overall assessment of burden.

The Caregiver Strain Index (CSI) (18) evaluates strain related to care provision, by asking the responder to think of the person he/she is giving care to and to indicate if the following 13 dimensions apply to him/her (yes, no, not applicable), such as sleep disturbances, inconvenience, physical strain, and emotional adjustment. The total CSI score is calculated by summing up the “yes” responses, ranging from 0 to 13. Positive responses to 7 or more items on the index indicate a greater level of strain (4, 18). The CSI has been validated (18, 19) and the available Norwegian version was used (20).

The self-rated burden (SRB) (21) is a single question; “How demanding is it for you to provide care at the moment?”. It is scored on an 11-point scale, from 0 “not demanding at all” to 10 “much too demanding”. SRB is feasible and considered to be at least as valid as other measures of burden (21). It was translated into Norwegian for this study.

Positive caregiver experiences. To describe the positive experiences of caregiving, the current study used the 5 positive items that were added to the CSI in the Caregiver Strain Index Expanded (22). Positive experiences related to care provision are assessed by asking the responder to think of the person he/she is giving care to and to indicate if the subsequent 5 dimensions apply to him/her (yes, no, not applicable): such as I am happy to care, and I handle the care fine.

Participation. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) Frequency subscale was used to measure the frequency of, and time spent on participation in different activities (23). The USER-Participation showed good validity (23), can also be used in people without physical disabilities, such as next of kin, and the 3 scales can

be used separately (24). The English version of the USER-Participation was translated into Norwegian using the same guidelines (16). The frequency scale consists of 2 parts. Part A comprises 4 items on the number of hours spent per week on vocational activities, with answering options ranging from not at all (scored 0), to 36 h or more (scored 5). Part B comprises 7 items on leisure and social activities frequency in the last 4 weeks, with answering options ranging from never (scored 0) up to 19 times or more (scored 5). The sum score based on all applicable items is converted to a 0–100 scale, with higher scores indicating higher levels of participation.

Quality of life. QoL was measured, using 2 constructs, as described in the literature (25–27); life satisfaction and mental health. Life satisfaction was measured with a selection of 5 items from the World Health Organization Quality of life assessment-BREF (WHOQOL-BREF) assessment covering satisfaction with overall QoL, health, daily activities, relationships, and living conditions (World Health Organization Quality of life assessment; WHOQOL-5) (28). Response options range from very poor/very dissatisfied (scored 1) to very good/very satisfied (scored 5) for each item, yielding a total score between 5 (very poor/dissatisfied) and 25 (very good/satisfied).

Mental health was measured with the Mental Health subscale of the Medical Outcomes Study Short Form Health Survey (MHI-5) (29). The MHI-5 consists of 5 items on emotional status concerning nervousness, sadness, peacefulness, depressed mood, and happiness. Respondents rated the frequency of each item during the previous 4 weeks on a 5-point scale. The score is converted to a total score between 0 (lowest mental health) and 100 (highest mental health).

Statistical analysis

Descriptive statistics were used to assess the personal characteristics of the participating next of kin, and injury characteristics of their relation with SCI. Characteristics of participants in the “Survey among persons with SCI” who did or did not have next of kin participating in the current study were compared to assess the representativeness of the next of kin sample.

In separate analyses, with objective burden, participation and each dimension of subjective burden (CSI and SRB) and QoL (WHO QoL5 and MHI-5) as dependent variables, the associations with characteristics of next of kin and the injury characteristics of their relation with SCI as independent variables were assessed. Multivariable linear regression analyses, adjusted for sex and age as a continuous variable, were carried out. Stata® version 16.0 (StataCorp, College Station, TX, USA) was used for all statistical analyses.

RESULTS

Of the 339 persons with SCI who participated in the “Survey among persons with SCI”, 92 persons (27%) provided contact information of their designated next of kin who were invited to participate in this study. Of the 92 persons invited to participate in the “Next of kin survey”, 73 participated (79%) (Fig. 1).

Of the related persons with SCI, 59% had a traumatic SCI, 34% had tetraplegia AIS D and the mean time since discharge from primary rehabilitation was 4.2 years (standard deviation (SD) 1.8, range 1–8 years), at the time of the study (Table I). No significant differences in the characteristics of the persons with SCI were observed between those with vs without related to next of kin participating in this study (Table I).

Descriptive characteristics of the next of kin are shown in Table II. Mean age at the time of the survey was 56 years (median 59 years, range 20–79 years), 73% were female, and 55% had a high level of education (college/university). The majority were a spouse or partner of the person with SCI (73%), and 72% lived together (Table II).

Caregiving – objective burden of care

The mean support score for all respondents was 1.6 (SD 0.5) on a 1–4 scale (Table III). Next of kin of persons with tetraplegia AIS A–C reported providing

more support than next of kin of persons with less severe disability.

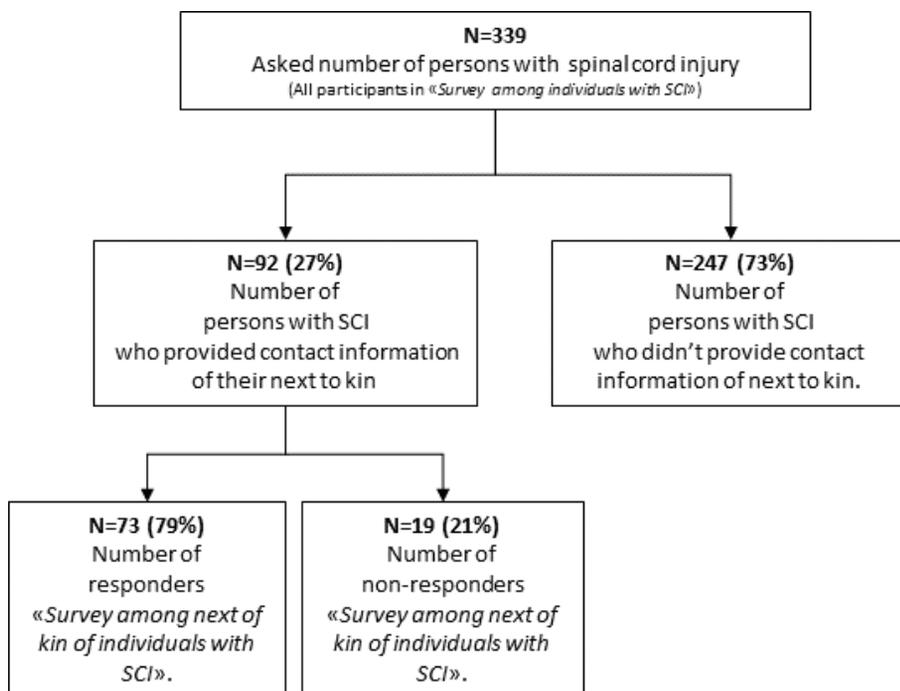
The types and frequencies of support given by next of kin are described in Table IV. Regarding support for ADL, most support was given in preparing meals (44%). This was followed by providing outdoor transportation and various “helping hands” throughout the day. Generally, less support was reported regarding “other practical support”, where most support was given when visiting a doctor (16%). Emotional support in terms of comforting and learning to live with SCI was given often or always by more than one-quarter of next of kin.

Caregiving – subjective burden of care

The mean overall SRB score was 3.2, and the mean total CSI score was 3.7 (Table III). CSI item scores are shown in Table V. The most frequently endorsed item was “emotional adjustments” (55%), followed by “Some behaviour is upsetting” (51%). Approximately one-quarter (19 persons) of the next of kin reported a high level of caregiver strain (CSI score ≥ 7 points).

Caregiving – positive caregiver experiences

Nearly all of the next of kin responded that they found it important to care and were happy to do so, and perceived that their care was appreciated (97%) (Table VI). Most (64%) reported having enough time



Abbreviation: SCI, Spinal Cord Injury.

Fig. 1. Flow chart of participants in the survey of next of kin of individuals with spinal cord injury (SCI).

Table I. Descriptive characteristics of persons with spinal cord injury (SCI) related to next of kin responders ("Participating"), and those who were asked to provide contact information on next of kin

Characteristics of persons with SCI	Participating* (N = 73)	Asked persons with SCI** (N = 266)	p-value ^a for comparison of responders with asked persons with SCI
Age, years, Mean (SD)	59 (17.2)	57 (15.9)	0.5734
Sex, N (%)			0.118
Male	47 (64)	196 (74)	
Female	26 (36)	70 (26)	
Impairment groups (Neurological level and AIS), N (%)			0.292
Tetraplegia, AIS A–C	10 (14)	24 (9)	
Tetraplegia, AIS D–E	25 (34)	77 (29)	
Paraplegia, AIS A–C	18 (25)	58 (22)	
Paraplegia, AIS D–E	20 (27)	103 (39)	
Unknown or not applicable	0 (0)	4 (2)	
Time since discharge, years, Mean (SD)	4.2 (1.8)	4.5 (1.9)	0.3467
Cause of injury, N (%)			0.847
Traumatic	43 (59)	160 (60)	
Non-traumatic	30 (41)	106 (40)	

*Persons with SCI related to next of kin participating in the current study.

**Persons with SCI who were asked to provide contact information for next of kin.

^ap-value from t-test for continuous and χ^2 test for categorical, with Fisher's exact test for impairment groups.

SCI: spinal cord injury; SD: standard deviation; AIS: American Spinal Injury Association Impairment Scale.

for themselves, but this proportion was considerably lower (30%) among next of kin caring for a person with the most severe impairment (tetraplegia AIS A–C).

Participation

The mean USER-Participation Frequency score was 39.3 (Table III). The mean vocational sub-score was 30.0 (SD 11.9), and the mean leisure and social activity sub-score 48.7 (SD 13.5) (detailed scores in Table SI).

Quality of life

For life satisfaction, the mean WHO QoL-5 score was 19.9 (Table III, detailed scores in Table SII). Four in 5

(78%) rated their QoL good or very good. For mental health, the mean MHI-5 score was 78.0 (Table III, detailed scores in Table SIII).

Regression analyses

Table III shows the results of the regression analyses. Only a few of the characteristics showed significant associations with the various life areas. Next of kin in the retirement age group (>67 years) reported higher life satisfaction (WHOQoL-5) and less caregiver strain (CSI) compared with those in the other age groups. Those having a middle level of education provided more support and had higher levels of caregiver strain (CSI) compared with those with a primary and a higher level of education. Female next of kin tended to report higher levels of overall burden (SRB) than males. The frequency of participation increased with higher levels of education and higher income. Next of kin who were social welfare recipients showed lower participation scores compared with those working.

Being the next of kin of a person in impairment group tetraplegia AIS A–C (most severe disability) was associated with reporting higher objective burden of care. Otherwise, no consistent patterns were found between SCI injury characteristics and the life areas reported by next of kin.

DISCUSSION

In this survey of 73 next of kin, investigating how they experience various life areas, 3 out of 4 next of kin reported good mental health and life satisfaction. All participants considered it important to care, and almost all were happy to do so. Nevertheless, one-quarter of next of kin experienced high levels of subjective

Table II. Descriptive characteristics of the next of kin of persons with spinal cord injury (N = 73)

Characteristics	
Age, years, Mean (SD)	56.4 (14.7)
Age groups, years, N (%)	
<55	28 (38)
55–67	29 (40)
>67	16 (22)
Sex, N (%)	
Male	20 (27)
Female	53 (73)
Level of education, N (%)	
Primary	8 (11)
Middle	25 (34)
Higher	40 (55)
Vocational status, N (%)	
Currently working or student	46 (63)
Retirement pension	20 (27)
Social welfare recipient	7 (10)
Personal income (Norwegian kroner per year), N (%)	
Below 500,000	36 (51)
500,000 and above	34 (49)
Relation to person with SCI, N (%)	
Partner	53 (73)
Family or other	20 (27)
Living together with person with SCI, N (%)	
Yes	53 (73)
No	20 (27)

SCI: spinal cord injury; SD: standard deviation.

Table III. Multivariable regression analyses adjusted for sex and age^a: objective burden, subjective burden, participation and quality of life according to characteristics of next of kin and injury characteristics of the related person with spinal cord injury (N = 73^b)

Characteristics	Objective burden			Subjective burden			Participation			Quality of life		
	Support Score (Range 1–4)	Caregiver Strain Index (CSI) (Range 0–13)	Caregiver burden (SRB) (Range 0–10)	USER-P frequency (Range 0–100)	Life satisfaction (WHO QoL-5) (Range 5–25)	Mental health (MHI-5) (Range 0–100)	Mean (95% CI)	p-value	Mean (95% CI)	p-value	Mean (95% CI)	p-value
Mean score (SD)	1.6 (0.5)	3.7 (3.4)	3.2 (2.8)	39.3 (9.0)	19.9 (2.9)	78.0 (13.8)						
Demographic and social variables												
next of kin												
Age-groups, years												
< 55	28 (38)	1.5 (1.3–1.7)	Ref	4.3 (3.0–5.5)	Ref	2.8 (1.8–3.9)	Ref	38.6 (35.3–41.9)	Ref	19.0 (17.9–20.1)	Ref	75.0 (69.9–80.1)
55–67	29 (40)	1.7 (1.6–1.9)	0.102	4.3 (3.1–5.5)	0.991	3.5 (2.5–4.6)	0.352	42.0 (38.7–45.3)	0.153	20.3 (19.2–21.3)	0.106	78.4 (73.4–83.5)
> 67	16 (22)	1.6 (1.3–1.8)	0.878	1.7 (0.1–3.4)	0.017 ^c	3.3 (1.9–4.6)	0.627	35.8 (31.4–40.2)	0.311	21.0 (19.6–22.4)	0.029 ^c	82.5 (75.7–89.3)
Sex												
Male	20 (27)	1.7 (1.4–1.9)	Ref	2.7 (1.2–4.2)	Ref	2.2 (1.0–3.5)	Ref	39.8 (35.7–43.9)	Ref	20.2 (18.9–21.5)	Ref	76.5 (70.4–82.6)
Female	53 (73)	1.6 (1.5–1.7)	0.709	4.1 (3.2–5.0)	0.124	3.6 (2.8–4.3)	0.072	39.2 (36.7–41.7)	0.808	19.8 (19.0–20.6)	0.650	78.6 (74.8–82.3)
Level of education												
Primary	8 (11)	1.3 (0.9–1.6)	Ref	1.7 (0–4.0)	Ref	3.3 (1.3–5.3)	Ref	33.5 (27.2–39.8)	Ref	19.2 (17.2–21.3)	Ref	81.8 (72.0–91.6)
Middle	25 (34)	1.8 (1.6–2.0)	0.005 ^c	4.6 (3.3–5.9)	0.034 ^c	3.6 (2.5–4.8)	0.773	37.2 (33.7–40.7)	0.303	19.2 (18.0–20.4)	0.954	77.3 (71.8–82.8)
Higher	40 (55)	1.6 (1.4–1.7)	0.122	3.6 (2.5–4.7)	0.147	2.9 (2.0–3.8)	0.687	41.8 (39.0–44.6)	0.019 ^c	20.5 (19.6–21.4)	0.264	77.7 (73.3–82.1)
Vocational status												
Currently working or student	46 (63)	1.6 (1.4–1.8)	Ref	3.9 (2.8–5.0)	Ref	3.0 (2.1–3.8)	Ref	41.3 (38.6–44.0)	Ref	19.9 (18.9–20.9)	Ref	77.5 (73.1–81.9)
Retirement pension	20 (27)	1.5 (1.3–1.8)	0.651	3.1 (1.2–4.9)	0.504	3.2 (1.8–4.7)	0.762	38.7 (34.1–43.3)	0.370	20.4 (18.8–22.0)	0.629	79.7 (72.2–87.2)
Social welfare recipient	7 (10)	2.0 (1.6–2.4)	0.064	4.7 (2.1–7.3)	0.575	4.6 (2.5–6.7)	0.162	28.1 (21.6–34.5)	< 0.001 ^c	18.8 (16.5–21.0)	0.361	76.7 (66.1–87.2)
Personal income (Norwegian kroner per year)												
Below 500,000	36 (51)	1.7 (1.5–1.8)	Ref	3.5 (2.3–4.7)	Ref	3.3 (2.4–4.2)	Ref	37.8 (35.1–40.6)	Ref	19.4 (18.4–20.3)	Ref	79.6 (74.9–84.2)
500,000 and above	34 (49)	1.6 (1.4–1.8)	0.551	4.0 (2.8–5.2)	0.566	3.1 (2.1–4.0)	0.733	42.2 (39.3–45.0)	0.034 ^c	20.5 (19.4–21.5)	0.123	77.1 (72.3–81.9)
Relation to patient												
Partner	53 (73)	1.7 (1.5–1.8)	Ref	4.1 (3.2–5.0)	Ref	3.4 (2.6–4.2)	Ref	38.2 (35.7–40.7)	Ref	19.8 (19.0–20.6)	Ref	77.9 (74.1–81.7)
Family or other	20 (27)	1.5 (1.2–1.7)	0.106	2.8 (1.2–4.3)	0.153	2.6 (1.4–3.9)	0.300	42.3 (38.2–46.4)	0.101	20.2 (18.9–21.6)	0.593	78.3 (72.0–84.5)
Injury characteristics of the related person with SCI												
Time since discharge												
4 years or less	36 (49)	1.6 (1.5–1.8)	Ref	3.5 (2.4–4.7)	Ref	3.1 (2.2–4.0)	Ref	39.0 (35.9–42.0)	Ref	19.7 (18.8–20.7)	Ref	79.2 (74.7–83.8)
More than 4 years	37 (51)	1.6 (1.5–1.8)	0.999	3.9 (2.8–5.0)	0.620	3.3 (2.4–4.2)	0.744	39.7 (36.7–42.7)	0.731	20.1 (19.1–21.1)	0.594	76.8 (72.3–81.3)
Impairment groups (level and AIS)												
Tetraplegia A,B,C	10 (14)	2.1 (1.8–2.4)	Ref	4.7 (2.6–6.8)	Ref	3.5 (1.8–5.3)	Ref	43.2 (37.4–49.0)	Ref	20.9 (19.0–22.7)	Ref	73.2 (64.6–81.9)
Tetraplegia D	25 (34)	1.4 (1.2–1.6)	< 0.001 ^c	2.5 (1.1–3.8)	0.072	2.3 (1.2–3.4)	0.216	38.5 (34.8–42.2)	0.180	20.5 (19.3–21.7)	0.712	77.0 (71.5–82.5)
Paraplegia A,B,C	18 (25)	1.7 (1.5–1.9)	0.012 ^c	3.5 (2.0–5.1)	0.362	3.7 (2.4–5.0)	0.877	39.2 (34.9–43.6)	0.276	19.0 (17.6–20.4)	0.104	78.9 (72.5–85.4)
Paraplegia D	20 (27)	1.6 (1.4–1.8)	0.003 ^c	5.0 (3.5–6.4)	0.842	3.7 (2.5–4.9)	0.888	38.5 (34.4–42.6)	0.192	19.6 (18.4–20.9)	0.274	80.8 (74.7–86.9)

USER-P freq: Frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; WHOQoL-5: World Health Organization Quality of life assessment; MHI-5: Mental Health subscale of the Medical Outcomes Survey Short Form Health Survey; SCI: spinal cord injury; AIS: American Spinal Injury Association Impairment Scale; Ref: reference.

^aAll variables except sex and age were adjusted for sex, age.

^bN vary from 69 to 73 for each variable due to missing data, or preferring not to answer.

^cp-value < 0.05 from linear regression.

Table IV. Objective burden of care: Types of support “often” or “always” given by next of kin to persons with spinal cord injury according to the injury group of related persons with spinal cord injury (N = 73). More than 1 type of support could be given

Type of support	Injury group of related persons with SCI				
	All	Tetraplegia AIS A–C (N = 10)	Tetraplegia AIS D (N = 25)	Paraplegia AIS A–C (N = 18)	Paraplegia AIS D (N = 20)
ADL support, N (%)					
Preparing meals	32 (44)	8 (80)	6 (24)	9 (50)	9 (45)
Outdoor transportation	17 (23)	2 (20)	6 (24)	4 (22)	5 (25)
Various helping hands	15 (21)	7 (70)	3 (12)	4 (22)	1 (5)
Dressing	10 (14)	4 (40)	3 (12)	1 (6)	2 (10)
Transfer	10 (14)	5 (50)	2 (8)	1 (6)	2 (10)
Washing/showering	9 (12)	2 (20)	0 (0)	3 (17)	4 (20)
Grooming	6 (8)	3 (30)	1 (4)	1 (6)	1 (5)
Communication	5 (7)	2 (20)	1 (4)	2 (11)	0 (0)
Eating/drinking	5 (7)	2 (20)	0 (0)	3 (17)	0 (0)
Bladder	4 (5)	2 (20)	1 (4)	1 (6)	0 (0)
Bowels	4 (5)	2 (20)	0 (0)	1 (6)	1 (5)
Toileting	4 (5)	2 (20)	0 (0)	1 (6)	1 (5)
Moving around indoors	3 (4)	1 (10)	1 (4)	1 (6)	0 (0)
Other practical support, N (%)					
Visiting doctor	12 (16)	3 (30)	2 (8)	3 (17)	4 (20)
Arranging for care or support	11 (15)	2 (20)	4 (16)	3 (17)	2 (10)
Supplying medication	10 (14)	6 (60)	3 (12)	1 (6)	0 (0)
Supplying ADL materials	8 (11)	2 (20)	3 (12)	2 (11)	1 (5)
Arranging for adaptations	7 (10)	2 (20)	2 (8)	1 (6)	2 (10)
Arranging for adaptive devices	7 (10)	2 (20)	2 (8)	1 (6)	2 (10)
Administrate medication	6 (8)	3 (30)	1 (4)	2 (11)	0 (0)
Putting on splints or orthoses	4 (5)	0 (0)	1 (4)	1 (6)	2 (10)
Performing exercises	2 (3)	0 (0)	0 (0)	1 (6)	1 (5)
Emotional support, N (%)					
Comforting, enlivening	27 (37)	5 (50)	5 (20)	5 (28)	12 (60)
Learning to live with the SCI	20 (27)	4 (40)	4 (16)	5 (28)	7 (35)

SCI: spinal cord injury; ADL: activities of daily living; AIS: American Spinal Injury Association Impairment Scale.

burden, as measured by CSI, especially related to emotional adjustments.

Only a few of the studied characteristics showed significant associations with different life areas, such as that those of working age and having a middle level of education had higher levels of caregiver strain, and that female next of kin tended to express higher levels of overall burden than males. The only SCI injury characteristic associated with a life area of next of kin was that next of kin of a person in the impairment group tetraplegia AIS A–C (most severe disability) reported a higher objective burden of care.

Life areas most influenced

A literature review regarding the impact of SCI on the QoL of family members showed that depression, anxiety, and reduced satisfaction with life were commonly reported (9). This is in contrast with the findings of the current study, in which 4 in 5 (78%) next of kin rated their QoL good or very good, and their mean mental health score was similar to this score among the general population in Norway (MHI-5 score of 79.5) (30). Furthermore, many reported positive caregiving experiences. Although few studies have investigated whether caregiving represents meaning and purpose

Table V. Proportion of next of kin answering “Yes” on the items of the Caregiver Strain Index according to the impairment group of related persons with spinal cord injury (N = 73)

Caregiver Strain Index item, N (%)	Injury group of related persons with SCI				
	All	Tetraplegia AIS A–C (N = 10)	Tetraplegia AIS D (N = 25)	Paraplegia AIS A–C (N = 18)	Paraplegia AIS D (N = 20)
Emotional adjustments	40 (55)	6 (60)	11 (44)	10 (56)	13 (65)
Behaviour upsetting	37 (51)	5 (50)	10 (40)	7 (39)	15 (75)
Changes in personal plans	30 (41)	5 (50)	5 (20)	9 (50)	11 (55)
Confining	24 (33)	7 (70)	5 (20)	5 (28)	7 (35)
Physical strain	23 (32)	4 (40)	5 (20)	6 (33)	8 (40)
Sleep disturbed	23 (32)	4 (40)	3 (12)	6 (33)	10 (50)
Family adjustments	21 (29)	7 (70)	2 (8)	5 (28)	7 (35)
Recipient’s change upsetting	20 (27)	1 (10)	8 (32)	4 (22)	7 (35)
Other demands on time	16 (22)	3 (30)	3 (12)	3 (17)	7 (35)
Work adjustments	13 (18)	2 (20)	1 (4)	2 (22)	6 (30)
Feeling completely overwhelmed	12 (16)	3 (30)	5 (20)	2 (11)	2 (10)
Inconvenient	7 (10)	2 (20)	1 (4)	1 (6)	3 (15)
Financial strain	6 (8)	0 (0)	1 (4)	1 (6)	4 (20)

SCI: spinal cord injury; AIS: American Spinal Injury Association Impairment Scale.

Table VI. Number and percentage of next of kin answering "Yes" on the positive subscale of the Caregiver Strain Index Expanded

Item	Caregivers answering "Yes", N (%)				
	All (N = 73)	Tetraplegia AIS A–C (N = 10)	Tetraplegia AIS D (N = 25)	Paraplegia AIS A–C (N = 18)	Paraplegia AIS D (N = 20)
Taking care is important	73 (100)	10 (100)	25 (100)	18 (100)	20 (100)
Recipient appreciates my care	71 (97)	10 (100)	25 (100)	16 (89)	20 (100)
I am happy to care	69 (95)	9 (90)	24 (96)	16 (89)	20 (100)
I handle the care fine	63 (86)	8 (80)	20 (80)	15 (83)	20 (100)
I have enough time for myself	47 (64)	3 (30)	19 (76)	11 (61)	14(70)

AIS: American Spinal Injury Association Impairment Scale.

(31), it has been shown that partners of persons with SCI who indicated positive effects of caregiving report better mental health (32). More research on the positive aspects of caregiving in future research is therefore warranted to increase awareness and to clarify how this contributes to the QoL of caregivers.

ADL and other practical support were given more often by next of kin of persons with serious disability, while fewer differences were seen between the groups with regard to emotional support. Similar findings were reported in 2 Dutch studies (1, 4). Although next of kin in the current study provided less support to persons with a less severe injury, compared with a previous study including only those who use wheelchairs (4), the proportions that provided support with outdoor transportation were similar (approximately 1 in 4). One reason is that outdoor transportation may be more challenging for disabled people in Norway, due to the demographics of Norway, with long distances, and long winters with much snow.

This study showed that emotional support was one of the types of support provided most, and emotional adjustments were the most frequently perceived strain, but that the severity of the SCI did not seem to influence either. Similar results have been found in other caregiver studies, e.g. advanced cancer (20), but this has not been reported in other SCI studies. This finding could be explained by an association between mental health of the patient and mental health of the next of kin (4), as they have a close relationship and are likely to influence each other.

Impact of next of kin characteristics

Next of kin of working age and with a middle level of education experienced more subjective burden compared with those who were retired or with higher or lower education. This is the opposite of the findings of a study by Post et al., in which the researchers concluded that the increasing age of partners was a significant predictor of caregiver burden (1). A possible explanation is that elderly persons with SCI in Norway receive paid support more often than those in the Netherlands, thus reducing the burden on next of kin. Alternatively, the use of different measures could

have caused this difference. A literature review on the common determinants of caregiver burden in Western countries showed that the age of the caregiver was not a consistent predictor of caregiver burden (33).

One-quarter of the current participants experienced high levels of burden, lower than the 43% in a study among Dutch persons with SCI using a wheelchair (4), but similar to the results from another Dutch SCI study (5). The current finding, that female carers tended to report higher levels of overall burden, was also found in a literature review (33) and other SCI caregiver studies (1). This sex difference in caregiving burden could be related to women experiencing more secondary stressors (relational and financial problems, problems combining different tasks) (34).

Impact of SCI characteristics

Objective burden was the only life area of the next of kin that was influenced by the severity of the injury. Being the next of kin of a person with most severe disability (tetraplegia AIS A–C) was associated with reporting higher objective burden of care compared with next of kin of a person with less severe disability (paraplegia A–D or tetraplegia D). This finding is in line with findings from another study, which found that partners of individuals with tetraplegia provided support more often (4). However, they did not distinguish between the level of completeness (AIS A, B, C or D) within the tetraplegia group (4). Notably, next of kin of persons with paraplegia D tended to report almost similar results for subjective burden of care compared with next of kin of persons with tetraplegia AIS A–C. This finding was unexpected because other studies have indicated a strong association between the severity of disability, level of neurological injury, and the subjective burden of care (1, 35, 36). An explanation could be that individuals with less severe disability experience similar "hidden disabilities", such as incontinence and pain, as their more severely disabled counterparts (37).

Other factors influencing life areas

Life areas of next of kin could be influenced by other factors, such as secondary conditions, coping

behaviour, mood or occupational status of the person with SCI. Findings in the study of Conti et al. from Italy indicated that a reduction in secondary SCI conditions, such as chronic pain and urinary tract infections, was related to less caregiver burden (38). Khazaeipour et al. found in a study from Iran that caregivers' burden was lower when the related person with SCI had a job (36). Thus, more research is needed to gain a more comprehensive understanding of how the life of those who are next of kin to a person with SCI is experienced and of which factors influence this.

Study strengths and limitations

This is the first study of next of kin of patients with SCI in Norway. The main strength is the comprehensive approach, covering several life areas and the linkage between patient data from a national medical SCI quality registry and survey data. In contrast to the majority of other SCI caregiver studies that are based on self-reported injury data provided by the caregiver (2), the current study collected injury data from a national medical SCI quality registry, hence these data are provided by clinicians. The current study combined the variables of the neurological level of injury and severity of the SCI into the recommended impairment categories (39). We have not found any SCI studies using this classification in relationship with caregiver burden. The involvement of a user representative as a member of our research team, who used personal experience to provide input to all steps, from the study design to reporting the results, has ensured an additional perspective on the findings and contributes toward providing people with SCI and their next of kin a voice in the research process.

This study has some limitations. Only 27% of the persons with SCI provided contact information for their next of kin and, consequently, the sample size was small. It might be that persons with SCI with a poor relationship with their next of kin were less interested in providing contact information. The non-responder analysis, however, showed that the persons with SCI whose next of kin participated were reasonable representative of persons with SCI in the register. However, the generalizability of the findings is hampered by the low response rate.

CONCLUSION

A significant majority of next of kin of persons with SCI experience that it is important to provide care, and they are happy to do so. Strengthening the experience of positive aspects of caregiving may enhance better mental health of next of kin. Nevertheless, one-quarter of next of kin in the current study experienced high

levels of caregiver strain, especially regarding the need for emotional adjustments. Most at risk of caregiver strain are those of working age (< 67 years), and those with middle level of education. In order to reduce the subjective burden of care, it seems necessary to increase the ability of next of kin to cope with the emotional challenges related to their caregiver role. Interventions, such as caregiver counselling, could be useful to achieve this. Injury characteristics had only a minor impact on the various aspects of the lives of next of kin caregivers. Although more research is needed, the findings of this study indicate that there are aspects of the life of the closest next of kin of a person with SCI that should be considered during SCI patient rehabilitation, in order to support the everyday life of caregivers.

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Conflicts of interest

The authors have no conflicts of interest to declare. AH is the leader of NorSCIR, but had no role in granting access to or delivery of the NorSCIR data.

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