# **ORIGINAL ARTICLE**

# Care needs of persons with long-term spinal cord injury living at home in the Netherlands

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Study design: Cross-sectional survey.

**Objectives:** To describe the care received, care needs and preventability of secondary conditions according to persons with long-term spinal cord injury (SCI) living at home.

**Setting:** The Netherlands.

**Methods:** A questionnaire was sent to all members of the Dutch SCI Patient Organisation. From a list of 26 SCI secondary conditions, participants chose the five conditions they perceived as most important. For each of these conditions, they described the type of care they received, their need for (extra) care and its preventability.

**Results:** Response rate was 45% (n=453) and mean time after injury was 13.3 years. In case of secondary conditions, participants were more likely to visit their general practitioner (58%) than another medical specialist (29%) or rehabilitation specialist (25%). For all most-important secondary conditions, care was received in 47% and care, or extra care, was needed in 41.3%. Treatment was the type of care most often received (29.5%) and needed (17.2%). However, for information and psychosocial care, the care needed (12.2 and 9.9%, respectively) was higher than the care received (7.6 and 5.9%, respectively). Thirty-four percent of all most-important secondary conditions were perceived as preventable, the rate increasing to 52.8% for pressure sores, of which 29.9% were considered to be preventable by the participants themselves.

**Conclusions:** This study showed substantial unmet care needs in persons with long-term SCI living at home and underlines the further improvement of long-term care for this group. Information, psychosocial care and self-efficacy seem to be the areas to be enhanced.

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# Introduction

Spinal cord injury (SCI) causes sensory, motor and autonomic impairments, but often also a variety of secondary conditions. Long-term secondary conditions can occur on different domains, for example, physical (bladder and bowel problems, pain, spasms, pressure sores and sexuality), psychological (anxiety and depression) and social (transport, finance, equipment, housing, care management and employment).<sup>1–4</sup>

Patients report an average of 8–14 secondary conditions per year.<sup>1,5</sup> Many are potentially preventable or reducible.<sup>5–7</sup> They may cause morbidity and rehospitalizations along with increased costs of care and decreased quality of life.<sup>3,7–9</sup> The

prevalence of secondary conditions and rehospitalization rates in persons with SCI does not diminish over time, suggesting that persons with SCI need long-time follow-up and that health education and long-term care can be improved.<sup>1,3,8</sup>

Depending on the health delivery system, a general practitioner (GP) is the first person to be contacted for SCI secondary conditions. However, the GP is usually not familiar with SCI.<sup>1,8,10</sup> When the GP cannot treat the secondary condition himself, the person will be referred to a general medical specialist or a physiatrist. Some persons contact a physiatrist directly or a specialized nurse in a specialized centre. Long-term care varies between specialized rehabilitation centres in The Netherlands.<sup>11</sup> Standard follow-up procedures are generally adhered to in the first 1–2 years after initial SCI, mainly by the physiatrist or nurse practitioner. Thereafter, the follow-up is dependent on the

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occurrence of secondary conditions and/or on the initiative of the person with SCI.

Knowledge of the views of persons with SCI on their secondary conditions is important to improve long-term health care for this group. Patients' views on health care may differ from those of health professionals, managers and policy makers.<sup>12</sup> The validity of the consumer's view on health-care quality has gained acceptance, with health-care providers, health insurance companies and health policy makers increasingly using patient surveys to evaluate and improve the performance of health-care systems.<sup>5,13,14</sup> A few studies have explored SCI patients' care needs and their views on health care.<sup>2,6,14–16</sup> This study, which was part of a larger research project on secondary conditions after SCI,<sup>1</sup> focused on the care needs perceived by persons with long-term SCI.

The research objectives were as follows:

- (1) To determine the care received in case of secondary conditions by persons with SCI living at home and to determine their (extra) care needs.
- (2) To determine whether these secondary conditions were preventable according to persons with SCI themselves.

# Materials and methods

#### Data collection

A postal questionnaire was sent to all members of the Dutch SCI Patient Organisation. Individuals younger than 18 years of age were excluded. A reminder was sent after 4 weeks. The study protocol was approved by the Medical Ethics Committee of the SRL/iRv.

# Questionnaire

The questionnaire included sociodemographic and injury characteristics. Participants were asked for the frequency of SCI-related contacts with professional caregivers during the last 12 months. This included the GP, rehabilitation specialist, other medical specialists, district nurse, home help, nurse in the rehabilitation centre, private care employed by the participant, physiotherapist, occupational therapist, social worker, psychologist and others. In the case of the GP, rehabilitation specialists, they were asked to specify the reason for contact: a SCI secondary condition or routine SCI follow-up.

The questionnaire further included a list of 26 physical, psychological and social SCI secondary conditions.<sup>1</sup> Participants were asked to indicate the conditions that they experienced in the last 12 months. After that, they were asked which of these conditions they perceived as most important, with a maximum of five. For each of these most-important secondary conditions, they were asked to indicate the kind of care they received and what kind of care they needed or needed in addition to the care received. The response options were none, treatment (medication, other medical intervention, physical or occupational therapy), practical care (help with ADL, housekeeping, domestic adaptations or assistive devices), information (availability

of aids, medical information), psychosocial care or others. The participants could select more than one care type per secondary condition. In addition, the participants were asked if and how this condition could have been prevented. The response options were no, by paying attention to my own health or behaviour, by adaptations or allowances, by better information supply, by changing the amount of care, by changing the quality of care (more expertise, more flexible) or others. They could select more than one option.

They were finally asked which kind of extra care or support they needed in general, not linked to a specific secondary condition, with the options being none, consultation by telephone, consultation in the rehabilitation centre, multidisciplinary reevaluation day in the rehabilitation centre, home visiting, possibility of receiving incidental ADL support or housekeeping and others. They also stated who the preferred caregiver would be: nurse, rehabilitation specialist, GP, psychologist, social worker, physiotherapist, occupational therapist or others. Except for the physicians, they could choose between a caregiver working in the rehabilitation centre or in the community. The questionnaire is available on request to the corresponding author.

## Statistical analysis

Analyses were performed using SPSS. Descriptive statistics were used to present sociodemographic and injury characteristics. Two different descriptive statistical analyses were performed to describe the care, care needs and preventability. The first used all selected secondary conditions perceived as most important (n = 1751). In the second, care, care needs and preventability were described separately for the secondary conditions perceived as most important by at least 20% of all participants.

# Results

#### Participants

Of the 997 members of the Dutch SCI Patient Organisation older than 18 years of age, 453 (45.4%) responded to the questionnaire. Eighty-five percent were initially rehabilitated in an SCI specialized rehabilitation centre. Table 1 shows the participants' characteristics.

#### Care received

Within the previous 12 months, 77% of participants had one or more SCI-related contacts with their GP (58% for secondary conditions and 22.5% for follow-up), 57% had contact with their physiatrist (25% for secondary conditions and 38% for follow-up) and 65% with another medical specialist (29% for secondary conditions and 44% for followup). The frequency of contact with different caregivers is shown in Table 2. Contact with physicians was most often restricted to 1–3 times per year. Physiotherapy and home help were generally received 1–6 times a week and nursing mainly daily, if applicable. Fewer participants had been in contact with a nurse from a rehabilitation centre, or with an occupational therapist, psychologist or social worker.

Age (years)		Time nost injury (years)	
Mean (s.d.)	47.7 (13.3)	Mean (s.d.)	13.3 (10.9)
Range	18-82	Range	0.6–62
Male (%)	65.1	5	
Level and type of SCI (%)		Cause of injury (%)	
Complete tetraplegia	19.9	Trauma	72
Incomplete tetraplegia	14.4	Disease/complication of medical treatment	23
Complete paraplegia	46.3	•	
Incomplete paraplegia	19.4	Other	5
Housing situation (%)		Living situation (%)	
Normal, non-adapted house	12	With partner	66
adapted house	82	With parents	8
Independent living centre	6	On one's own	26

#### Table 1 Participant characteristics (N = 453)

Abbreviation: SCI, spinal cord injury.

 Table 2
 Frequency of contact with caregivers in the last 12 months (N=453)

	Not at all	1–3 times a year	4–11 times a year	1–3 times a month	1–6 times a week	Daily
General practitioner	23	31	17	19	4	0
Rehabilitation specialist	43	36	8	6	2	0
Other medical specialist	35	40	11	7	1	0
District nurse	72	2	2	1	8	15
Home help	79	0	0	0	18	2
Nurse rehabilitation centre	90	4	0	1	2	1
Private caregiver	89	0	0	0	6	4
Physiotherapist	40	1	2	4	50	1
Occupational therapist	86	4	1	1	6	0
Social worker	92	2	1	3	2	0
Psychologist	92	1	1	4	2	0
Other	85	3	2	3	4	2

All figures are percentages.

The sum of frequency percentages is not always equal to 100%, because of missing values for this question.

#### Most important secondary conditions

Table 3 presents all 26 secondary conditions and the percentage of participants who mentioned that condition as one of their most important problems. On an average, participants mentioned eight secondary conditions and 3.9 most-important secondary conditions (total 1751). The secondary conditions most often selected as most important were body function impairments such as bladder regulation, bowel regulation, pain, spasms, sexuality and pressure sores (Table 3). The percentages of care received and (extra) care needed for each of these six most-important secondary conditions are shown in Table 4. Treatment was the type of care most often received and needed.

Figures on perceived preventability of these six mostimportant secondary conditions are shown in Table 5. Half of the pressure sores and a quarter of the bladder, bowel and sexuality problems could have been prevented, according to the participants. For pressure sores, 29.9% believed they themselves could have prevented it by paying attention to their own health or behaviour. For bladder and bowel regulation, this percentage was, respectively, 9.2 and 13.1%. In contrast, very few participants mentioned spasms and pain as conditions that could be prevented by themselves. Changing care quality was, however, the most often-mentioned remedy, illustrated by many spontaneous comments varying from the needed development of new medications to lack of expertise and carelessness by, mainly, nonspecialized health professionals of all disciplines.

#### Need for additional care in general

Seventy-two percent of all participants (n = 453) indicated a need for additional care in general: 26.0% expressed the need for a consulting hour in the rehabilitation centre, 25.4% for a reevaluation day in the rehabilitation centre, 24.3% for a consulting hour by telephone, 23.4% for home visiting, 19.0% for incidental ADL support, 18.5% for incidental housekeeping and 8.6% for other interventions. They preferred specialized rehabilitation care above community care with respect to medical care (37.3% against 13.3), nursing (19.4 against 8.2%), physical therapy (12.6 against 7.5%), occupational therapy (7.3 against 3.1%) and social worker (7.1 against 4.2%). In 14.6% of all participants, another caregiver was preferred, mainly peers, home help or care manager/coach.

Table 3 Prevalence of all selected secondary conditions that were perceived as most important problems in the last 12 months (N=453)

Rank	Secondary condition	Percentage
1	Bladder regulation (for example, incontinence, urinary tract infections)	51.7
2	Bowel regulation (for example, incontinence, diarrhoea, constipation)	41.7
3	Pain	41.3
4	Spasms	33.1
5	Sexuality	22.5
6	Pressure scores	20.8
7	Dependency (having difficulties being dependent on personal help)	18.3
8	Oedema (accumulation of liquid in the legs)	15.9
9	Handicap management (extra time needed for personal care and arranging all kind of things due to SCI)	14.8
10	Increased weight	13.7
11	Facilities, equipment and housing (for example, problems in arranging them or in not having them)	12.6
12	Coping with handicap	10.2
13	Daily living activities (eating, personal care, dressing, transfers, mobility)	10.2
14	Excessive sweating	8.8
15	Functioning in non-adapted environments	8.8
16	Asking for help, being assertive	8.4
17	Contractures (decreased joint mobility due to reduction of muscle length)	7.3
18	Breathing/respirator (for example, shortness of breath, infection of respiratory tract)	7.3
19	Relationships (family, friends, relatives)	6.0
20	Household activities (for example, cooking, cleaning, shopping)	6.0
21	Work	5.7
22	Leisure-time activities (association, club, sport, social activities such as going to the movies and going out for dinner)	5.1
23	Heterotrophic ossification (calcification or the growth of bone around joints below the level of injury)	4.2
24	Low blood pressure	2.4
25	Communication (writing, reading, phoning, environmental control devices)	1.5
26	Thrombosis (blood clots in blood vessel)	1.1

All figures are percentages.

Table 4 Care received and care needed for all most important secondary conditions together and each of the six most important secondary conditions

	All <sup>a</sup>		Bladder		Bowel		Pain		Spasms		Sexuality		Pressure sores	
	R	N	R	N	R	N	R	N	R	N	R	N	R	Ν
Total care	47.0	41.3	62.4	40.6	45.0	38.1	58.3	48.1	52.0	37.4	26.5	47.4	73.4	53.2
Treatment	29.5	17.2	44.0	19.7	29.1	16.4	44.9	28.9	44.0	26.7	9.8	12.7	56.4	28.7
Practical	11.1	8.0	9.0	5.1	10.1	5.8	8.6	5.9	5.3	3.3	1.0	4.9	20.2	12.8
Information	7.6	12.2	11.5	14.5	7.9	13.8	8.0	10.2	4.0	4.0	5.9	16.7	11.7	13.8
Psychosocial	5.9	9.9	3.0	4.7	2.1	6.3	5.3	7.5	4.0	4.7	6.9	13.7	2.1	5.3
Other	4.2	4.6	5.1	2.1	3.7	2.6	4.3	5.9	0.7	1.3	3.9	6.9	3.2	2.1

All figures are percentages and percentages >10% are shown in bold.

<sup>a</sup>All: all selected most important secondary conditions together; R: care received; N: (extra) care needed.

 Table 5
 Perceived preventability for all most important secondary conditions together and for each of the six most often mentioned important secondary conditions separately

	All <sup>a</sup> (n = 453)	<i>Bladder</i> (n = 229) <sup>b</sup>	<i>Bowel</i> (n = 183) <sup>b</sup>	Pain (n = 172) <sup>b</sup>	Spasms (n = 144) <sup>b</sup>	Sexuality (n = 93) <sup>b</sup>	Pressure sores (n = 89) <sup>b</sup>
Total preventability	34.1	26.6	23.5	19.8	12.5	26.9	52.8
Own health or behaviour	9.6	9.2	13.1	0.6	1.4	4.3	29.9
Changes in society	8.9	3.9	2.2	2.3	2.1	2.2	4.5
Better information supply	7.4	7.4	6.0	2.9	2.8	8.6	5.6
Changing care amount	3.5	2.6	2.7	2.9	0.7	1.1	1.1
Changing care quality	11.6	10.5	4.9	9.9	6.3	8.6	14.6
Other	3.6	0.9	2.2	5.2	3.5	5.4	5.6

<sup>a</sup>All selected most important secondary conditions together.

<sup>b</sup>All figures in this column are percentages of all participants who selected that secondary condition as one of the most important problems and filled in the preventability question. Because of missing values, the *n* value is not the same as the *n* value given in the table.

# Discussion

This study showed substantial unmet care needs for persons with long-term SCI living at home. Treatment was most

often mentioned. Relative to the amount of care given, information and psychosocial care were most needed. Of all secondary conditions, 34.1% were perceived to be preventable, not the least by the participants themselves.

They preferred specialized rehabilitation care above community care.

#### Care received

Participants contacted their GP more often than the physiatrist or other medical specialist for secondary conditions. The physiatrist and other medical specialists were contacted mainly for routine follow-up. These outcomes agree with data on persons with SCI in America, Canada and the United Kingdom, who also depended more on their GP (65–90%) than on their rehabilitation specialist (45–65%) for SCI-related problems and who visited their rehabilitation specialist mainly for SCI-specialized testing and follow-up.<sup>10</sup> Participants, however, preferred specialized rehabilitation care. In the Dutch health-care system, people are encouraged to contact first their GP for health problems, but the limited expertise on SCI of the GP was seen by persons with an SCI as the greatest barrier to needs being met.<sup>2,10</sup>

#### All most-important secondary conditions

For all most-important secondary conditions together, 12.2% of participants needed information. An Australian study<sup>2</sup> showed an even greater need for information (19%) and in the United Kingdom,<sup>17</sup> information was one of the two least-frequently met care needs in persons with severe disabilities. Care providers might not be aware of this need for information, as it was shown that provision of information was valued more by patients than by physicians.<sup>18</sup> Other studies have also highlighted the psychosocial care need found in our study. Lifestyle and emotional issues were not addressed by GPs and specialists for over 75% of patients in the United Kingdom, Canada and the United States,<sup>10</sup> and the prevalence of depression in persons with SCI of approximately 20% was higher than that in the average population (10%).<sup>4,8,9,19</sup>

#### *The six most often mentioned important secondary conditions*

The need for care or extra care was highest for pressure sores and pain. Sexuality showed the strongest discrepancy between care received (26.5%) and care needed (47.1%). It seems to be the most undertreated secondary condition. The percentages of participants needing care for pain, spasms, sexuality and pressure sores were lower in an Australian study, being 41, 28, 24 and 17%, respectively.<sup>2</sup>

The most often mentioned type of care needed was treatment. This could mean that participants are more focused on cure than on care. Conversely, the percentages of care need for treatment of these important conditions were far below 100%. This might indicate that participants have accepted their secondary conditions, possibly because earlier treatment was not, or only partly, effective. For information and psychosocial care, the percentage of participants needing care was higher than the percentage of participants receiving care, so that these two types of care needs seem to be relatively more often unmet.

# Preventability

An important finding of this study is the high number of participants stating that a particular secondary condition could have been prevented, not the least by their own behaviour. This study did not specify how they thought they could have prevented it. Pressure sores were most often mentioned as preventable conditions. No studies have been found specifically on the preventability of secondary conditions according to persons with SCI. A few studies link to this subject and showed that education on bowel, bladder and skin care was perceived as most important by individuals with an SCI living in the community<sup>20</sup> and that persons with an SCI felt ill-prepared to live in the community, including finding information on and accessing community services.<sup>13</sup> Rehabilitation aims at preparing persons with SCI to live in the community with a life-long disability, in which education on the prevention and management of secondary conditions has an important part. The outcome of this study suggests that rehabilitation does not reach this goal and educational/self-efficacy programs for persons with longterm SCI might be needed.<sup>6,9,20</sup>

## Limitations

This study has some limitations. All data were reported by persons with SCI themselves. For obvious reasons, participants remained anonymous so that it was impossible to perform a nonresponse analysis based on data from medical records. There are two facts that could have led to an overrepresentation of secondary conditions and care needs. First, the participants were recruited from members of the Dutch SCI Patient Organisation, in which persons with an incomplete SCI are underrepresented. Second, the study had a relatively low response rate of 45%, and persons with secondary conditions might have been more willing to participate in this study. On the other hand, it is also said that members of a patient organization are more familiar with how to get care, which could have led to an underrepresentation of secondary conditions and care needs. Finally, the cross-sectional design of this research limits the exploration of care received and care needed over a longer period of time.

#### Implications for research

Our study underscores the ongoing need to develop better treatments for secondary conditions as spasms, pain, bladder and bowel problems. It is further recommended to explore self-management strategies of persons with SCI and to evaluate whether providing more information and psychosocial care in out-patient rehabilitation leads to fewer and/or less long-lasting secondary conditions.<sup>20</sup>

# Implications for clinical practice

The availability and accessibility of specialized care seems important to persons with long-term SCI. Specialists and therapists are suggested to actively check during outpatient rehabilitation and routine follow-up the need for information and psychosocial care.

# **Conflict of interest**

The authors declare no conflict of interest.

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