

Original Article

Burden of support for partners of persons with spinal cord injuries

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Study design: Cross-sectional survey.

Objectives: (1) To describe the support given to persons with spinal cord injuries (SCI) by their partners, (2) to describe the perceived burden of support by partners and (3) to examine predictors of perceived burden of support.

Setting: The Netherlands.

Methods: All members of the Dutch patients organisation DON ($N=1004$) and their caregivers, if applicable, were invited. Physical disability of the person with SCI was measured using the Barthel Index (BI). A number of secondary conditions, other practical problems and psychosocial problems were recorded. Partner support was described using a list of ADL support, other practical support and emotional support. Burden of support was measured by a six-item measure (Cronbach's alpha 0.92), Nonparametric descriptive statistics and correlations were used. Linear regression was used to identify predictors of caregiver burden.

Results: Responses were obtained from 461 persons with SCI. Of 265 couples, patient as well as partner data were available. Mean age of the partners was 49.4 years (SD 12.2) and 69.8% were women. Mean BI of the persons with SCI was 12.3 (SD 4.7) on a 0–20 scale and 60.4% were seriously disabled ($BI < 15$). Most partners provided various kinds of support. ADL support and other practical support were given much more often by partners of persons with serious disability, but less difference was seen regarding emotional support. Professional (paid) support was obtained by 45.3% of all couples. Perceived burden of support was high in 24.8% of partners of persons with serious disabilities against 3.9% of partners of persons with minor disabilities. Significant predictors of caregiver burden were (in order of importance) the amount of ADL support given, psychological problems of the patient, partner age, partner gender, BI score and time after injury (total explained variance 47%).

Conclusion: A substantial proportion of partners of persons with SCI suffer from serious burden of support. Prevention of caregiver burnout should be part of the lifelong care for persons with SCI.

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Keywords: caregivers; spouse; spinal cord injuries; long-term care

Introduction

Many persons with spinal cord injuries (SCI) face challenges regarding their physical, psychological and social functioning and a substantial proportion of persons with SCI need support in these areas for the rest of their lives.^{1,2} The spouse is the key support person for many persons with SCI and a good marriage is a primary source of physical as well as emotional support.^{3–6} It is probably for this reason that being married is a powerful predictor of adjustment and

quality of life of persons with SCI.^{6–9} A study by Elliott *et al*⁵ showed that poor problem-solving abilities of the caregiver were associated with the occurrence of pressure sores and adjustment problems of the persons with SCI in the early phase of the injury.

However, being a partner and caregiver of someone with SCI is not unproblematic.¹⁰ Family caregivers operate as an integral component of the health care delivery system and are responsible for a wide range of services that, in the past, were provided formally by traditional health care providers and that usually have to be given for an indefinite period.^{1,5} Moreover, family caregivers may also have to deal with possible negative psychological consequences of SCI like depression and

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aggressive behaviour by the person with SCI.¹¹ Caregiver stress can proliferate when the caregiver has difficulty meeting ongoing demands (eg role overload, or loss of self in the caregiving role), which in turn may create new problems for the caregiver.¹² Boschen *et al* explored caregiver burden using in-depth analysis of focus group discussions attended by caregivers (partners and others). Their study reveals the challenges that caregivers are confronted with like, for example, realigning self, dealing with new personal and social relationships and accommodating severe economic constraints. Caregivers have to adapt to the new circumstances, modify preinjury lifestyle and move forward one step at a time.¹³ Several studies have shown negative effects of giving support on the quality of life of the caregivers of persons with SCI.^{11,14–19} Weitzenkamp *et al* studied stress and depression in 124 spouses of persons with SCI that had been injured more than 23 years ago. Spouses who were caregivers reported higher levels of stress, burnout, fatigue, resentment and depression compared to spouses who were not caregivers.¹⁵ Several studies showed self-reported levels of psychological distress in partners of persons with SCI to be comparable or even higher than in the persons with SCI themselves.^{15,18,19}

Most studies that have explored caregiver burden experienced by partners of persons with SCI, however, suffer from several limitations. Firstly, most studies have concentrated on caregiver outcomes like psychological functioning, health and life satisfaction. The amounts and types of support given by caregivers and the relationships between support given and burden of support as perceived by caregivers have rarely been investigated. For this reason, it is not easy to interpret the sometimes conflicting results regarding the impact of severity of the injury, secondary conditions and the impact of duration of the injury. Unalan *et al*,¹⁶ for example, found no correlation between the seriousness of the SCI and complications and caregivers' quality of life, whereas Schulz *et al*²⁰ reported that the amounts of assistance provided for the persons with SCI were strongly correlated with depression of caregivers. Further, most studies used small sample sizes^{14,16,18} or used mixed samples of partners, other family members, nonfamily members or professional caregivers.^{5,10,13,14,16} As a result, the burden of support as perceived by partners of persons with SCI still needs clarification.

The goal of this partner study was: (1) To describe the support given to persons with SCI by their partners, (2) to describe the perceived burden of support by partners and (3) to examine predictors of perceived burden of support for partners of persons with SCI.

Methods

Subjects

This study was part of a larger research project concerning health problems and care needs of persons with SCI living independently in The Netherlands.²¹ All

members of the Dutch patients organisation DON ($N=1004$) were sent a package that included a questionnaire for the person with SCI, a questionnaire for his or her primary caregiver and a prepaid return envelope. Both the person with SCI and his or her caregiver (if applicable) were asked to fill in 'their' questionnaire independently of each other and to send them back to our research institute. A digital version of the questionnaire was available for persons with SCI having difficulty with writing. One reminder was sent and the study was promoted in the journal of the patients organisation.

Instruments

Type of injury, self-care ability, secondary conditions and other problems were part of the questionnaire for persons with SCI. Support given and perceived burden of support were part of the questionnaire for the caregivers.

Type of injury was based on information given by the patients about the level of injury, and about motor and sensory completeness of injury.

Self-care ability was measured using the self-report version of the Barthel Index (BI).²² The BI contains 10 questions about self-care (eg dressing, grooming, toileting), continence for urine and bowels, and mobility (moving around indoors, negotiating stairs). This Dutch self-report version showed good internal consistency and criterion validity in an SCI population.²³ Cronbach's alpha of the BI in this study was also good (0.85). BI scores ranging from 0 to 4 indicate very severe disability, between 5 and 9 severe disability, from 10 to 14 moderate disability, from 15 to 19 minor disability and the maximum score of 20 indicates independence in the basic activities of daily living.²²

The other measures were self-developed, based on clinical experience and the results of previous research.^{4,24,25} Drafts were discussed with physiatrists and nurses from different rehabilitation centres and with representatives of the patient's organisation.

Number of secondary conditions consisted of a list of 14 secondary conditions and the person with SCI could indicate whether or not he or she had suffered from that condition during the previous 12 months. This list included items like bladder problems, spasms, pain, obesity, excessive sweating, thrombosis, and respiratory problems. The score is the sum of applicable secondary conditions and ranges between 0 and 14.

Number of activities problems included seven possible problems in daily life activities like having to function in a poorly adapted environment, housekeeping, work and having problems spending one's time in a satisfactory way. The total score of this measure ranges from 0 to 7.

Number of psychological problems included five possible problems: unpleasant feelings of being dependent on help from others, difficulty with asking for help, difficulty in accepting the SCI, relational problems and sexual problems. The total score of this measure ranges from 0 to 5.

Caregiver support was measured by a self-developed questionnaire for the partner including three categories of support: *ADL support* (14 items, Cronbach's alpha=0.91), *other practical support* (nine items; alpha=0.84) and *emotional support* (two items; alpha=0.87). All support items are displayed in Table 1. On all items, the caregiver rated the frequency of giving that type of support on a 4-point scale (never, sometimes, often, always). The total score of each scale is the mean of the item scores and is also between 1 and 4.

Burden of support as perceived by partners was measured using a self-developed questionnaire consist-

ing of six items with possible answers: no burden (1), minor burden (2), moderate burden (3), serious burden (4). The items are displayed in Table 3. The total score is the mean of the item scores and ranges also from 1 up to 4. Cronbach's alpha of this measure was excellent (0.92). To identify the group of partners experiencing serious burden, a cutoff point of 3 on the burden scale was used. This cutoff point was chosen because a mean score of 3 reflects the answering category 'moderate burden' and all partners with a mean score above 3 rated at least one of the aspects of care in this questionnaire as a 'serious burden' (item score = 4).

Professional support was divided in nursing care (eg bowel management, bathing), housekeeping, providing information (eg management of secondary conditions, or the provision of aids), and providing psychosocial support. Caregivers were asked to indicate the types of support they received at least once a week during the previous year. Additionally, we asked caregivers if they felt a need for support or more support, using the same types of care. No distinction was made between self-paid support and reimbursed support.

Table 1 Types of support most often given by partners of persons with SCI

	Percentage of partners giving this type of support 'often' or 'always'		
	BI < 15 (N = 157)	BI ≥ 15 (N = 103)	All (N = 260)
<i>ADL support</i>			
Preparing meals	66.9	28.2	52.1
Outdoor transportation	51.6	26.2	41.9
Various helping hands	48.4	12.6	34.7
Dressing	48.4	1.9	30.2
Moving around outdoors	41.4	12.6	29.8
Transfers	42	2.9	26.4
Washing/showering	41.4	1	25.7
Bowels	37.6	1.9	23.4
Bladder	34.4	0	21.3
Toileting	32.5	1.9	20.4
Eating/drinking	17.8	1	11.3
Grooming	18.5	0	11.3
Communication	8.3	0	4.9
Moving around indoors	7	1	4.1
<i>Other practical support</i>			
Visiting doctor	62.4	31.1	50.2
Supplying ADL materials	43.9	18.4	34.3
Supplying medication	42	17.5	32.8
Arranging for care or support	42	6.8	27.3
Arranging for adaptations	28	17.5	23.8
Arranging for adaptive devices	26.8	13.6	21.9
Giving medication	24.8	0	15.1
Putting on splints or orthoses	14.6	1	9.4
Performing exercises	12.1	4.9	9.1
<i>Emotional support</i>			
Comforting, enlivening	45.2	35	41.5
Learning to live with the SCI	45.9	35	41.1

Analyses

Descriptive statistics were used to describe support and perceived burden of support. Since all measures were of ordinal level, mainly non-parametric techniques were used: χ^2 and Mann-Whitney's *U* for differences between groups, Kendall's Tau for associations between dichotomous variables and between dichotomous and ordinal variables and Spearman correlations for associations between ordinal variables. Stepwise linear regression analysis was used to analyse the combined influence of partner characteristics, partner support and professional support on perceived caregiver burden. The default criteria for entry ($P < 0.05$) and exclusion ($P > 0.10$) of variables in the analysis were applied. Scores of continuous variables were log-transformed, if necessary, to obtain a sufficiently normal distribution. Age, and gender of patients and caregivers were highly correlated with each other and therefore we used only the demographic characteristics of the partners. All analyses were performed using SPSS 11.5.

Results

A total of 1004 packages with both questionnaires were sent and 461 persons with SCI and 365 caregivers responded. A nonresponse analysis was not possible due to lack of information about person and injury characteristics of the total group of DON members. The group of caregivers included 265 caregivers who were partners and for whom both partner and patient data were available. Based on answers of the persons with SCI, 299 had a partner, so that a 88% response of this group (265/299) was obtained. Only the data of these 265 couples will be used in this article.

Demographic and injury characteristics

Mean age of the persons with SCI was 50.4 years (SD 12.3) and most (69.2%) were male. Mean age of the partners was 49.4 years (SD 12.2) and 68.9% were women. All but eight couples were heterosexual and 97.0% lived in ordinary, adapted or nonadapted houses in the community. Time after injury varied between 0.6 and 62.6 years and mean time after injury was 13.2 years (SD 11.4).

A minority of all persons with SCI (32.0%) had an injury at cervical level. A total of 55.9% had a motor complete injury (ASIA Impairment Scale A or B). Mean score on the BI was 12.3 (SD 4.7). A total of 18 persons (6.9%) had very severe disabilities, 50 persons (19.2%) had severe disabilities, 89 persons (34.2%) had moderate disabilities, 96 persons (36.9%) had minor disabilities and only seven persons (2.7%) of all patients had no limitations in basic ADL and mobility. Nearly all (98.3%) persons with SCI had suffered from one or more secondary conditions in the 12 months before the study. Most reported problems concerned bladder regulation (71.5%), bowel regulation (61.7%), spasms (56.4%) and pain (55.1%). The mean number of different secondary conditions was 4.6. Activity problems occurred less often but were still mentioned by 69.2% of all persons with SCI. The mean number of activity problems was 1.9. The mean number of psychosocial problems was 1.4 and 62.8% did report one or more psychosocial problems. More information about occurrence, predictors and consequences of these problems is given elsewhere.²¹

Support

In Table 1 the types of support given by partners are described. Regarding ADL support, preparing meals, providing outdoor transportation and various 'helping hands' throughout the day were 'often or always' given by more than one-third of all partners. Support with basic self-care activities such as dressing and transfers was given often or always by nearly one-quarter of all partners. The types of support that were least often given were with eating/drinking, grooming and communication. With regard to other practical support, partners often supported when visiting a doctor and with the supply of ADL materials and medication. Partners were least often involved in exercise. Emotional support, finally, was given often or always by more than 40% of all partners. Figures in Table 1 also show that partners of persons with moderate or severe disabilities (BI < 15) provide much more ADL and other practical support than partners of persons with minor disabilities (BI ≥ 15). In this last group, the main types of support were emotional support, preparing meals, outdoor transportation and accompanying on visits to doctors.

About half of all couples (54.7%) did not receive any professional support at all (Table 2). Weekly or daily nursing was obtained by 21.3%, housekeeping by 29.7%, information by 8.7%, psychosocial help by 8.4%, and other types of help by 6.1%. Not surpris-

Table 2 Types of professional support received and wanted by partners of persons with SCI

	<i>Percentage of partners receiving support or wanting more support</i>		
	<i>BI < 15</i> (N = 157)	<i>BI ≥ 15</i> (N = 103)	<i>All</i> (N = 260)
<i>Professional support received</i>			
Nursing	31.8	5.9	21.7
Housekeeping	31.8	26.7	29.8
Information	12.1	3	8.5
Psychosocial	9.6	6.9	8.5
Other	8.3	2	5.8
No professional help at all	47.1	66.3	54.7
<i>Need for (more) professional support</i>			
Nursing	13.5	2	8.9
Housekeeping	17.3	18.6	17.8
Information	11.5	6.9	9.7
Psychosocial	18.6	18.6	18.6
Other	4.5	3.9	4.3
No need at all	61.5	66.5	63.6
<i>Specific types of support wanted</i>			
Telephone consultation hour	13.4	16.5	14.6
Home visit	20.4	10.7	16.5
Consultation hour in RC	13.4	13.6	13.5
Partner support group	19.5	15.5	18.1
Ad-hoc nursing	22.9	7.8	16.9
Ad-hoc housekeeping	23.9	20.4	22.3
Other	13.4	11.7	12.7

ingly, partners of persons with serious disabilities received nursing support more often than partners of persons with minor disabilities. The amount of paid housekeeping however did not differ much between both groups. There were no gender differences regarding nursing support, information or psychosocial support, but couples of whom the caregiver was male received support more often (41.5%) than couples of whom the caregiver was female did (24.4%; $P < 0.01$). Many partners (37.4%) expressed a need for one or more types of support or extra support. Except for nursing support, the types of support needed did not differ much between partners of persons with serious disabilities and partners of persons with minor disabilities.

Burden of support

The burden of support perceived by partners of persons with SCI is shown in Table 3. All aspects were rated as moderately or seriously burdensome by about one-thirds of partners.

Again a clear difference existed between partners of persons with more or with less serious disabilities: 50.3% of partners with BI < 15 rated their overall burden of support as moderate or serious, against

Table 3 Proportion of partners of persons with SCI reporting ‘moderate’ or ‘serious’ burden of support

Items of the caregiver burden scale	BI < 15 (N = 157)		BI ≥ 15 (N = 103)		All (N = 260)	
	Moderate	Serious	Moderate	Serious	Moderate	Serious
Over-all evaluation of burden of support	39.5	10.8	17.5	1.9	30.8	7.3
Total time required for support	33.8	10.8	12.6	2.9	25.4	7.7
Physical strain induced by support	35.7	12.7	16.5	2.9	28.1	8.8
Need to give support on fixed schedules	26.1	22.3	7.8	2.9	18.8	14.6
Need to give support frequently every day	20.4	18.5	6.8	2.9	15	12.3
Impact on own activities and social life	29	25.2	12.4	4.1	22.6	17.1

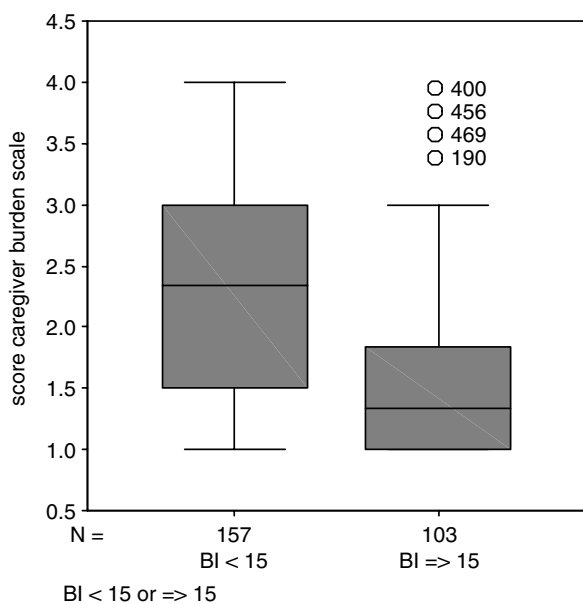


Figure 1 Score distribution of the caregiver burden scale

19.4% of partners of persons with $BI \geq 15$ ($P < 0.01$). The distribution of the total score for perceived burden of support for each group of partners is displayed in Figure 1. In this figure also a clear difference in perceived burden of care is shown between partners of persons with minor disabilities and partners of persons with moderate or severe disabilities. The mean score on the burden scale of the partners of patients with $BI \geq 15$ is 2.3, against 1.6 in the other group of partners ($P < 0.01$). Of all partners, 16.2% obtained a mean burden score above 3, indicating serious burden. Again, this proportion is substantially higher in the group of partners of persons with $BI < 15$ (24.8%) than in the group of partners of persons with $BI \geq 15$ (3.9%; $P < 0.01$).

In Table 4, the relationships are displayed between the consequences of the injury, the care provided by the partner and by professional caregivers, and caregiver burden as perceived by the partner. Caregiver burden was significantly related to all other variables (bottom row of Table 4), but most strongly to the amount of ADL support given by the partner (0.62), the Barthel Index score (-0.55), and the amount of other practical

support given (0.49). Getting professional support was related to increased burden. Other correlates of burden (not in Table 4) were age of the partner (0.31; $P < 0.01$) and duration of the SCI (-0.14 ; $P < 0.05$). Gender was not significantly related to burden.

Table 4 also shows that the amount of ADL support provided by the partner was strongly related (-0.77) to the BI score, moderately (0.38) related to the number of secondary conditions, and weakly related to the numbers of activities and psychosocial problems of the person with SCI. The amount of other practical support given by the partner was moderately related (-0.53) with the BI score, weakly related to the number of secondary conditions (0.29) and was not significantly related to the number of activities problems and psychosocial problems. The amount of psychosocial support given by partners was moderately related (0.31) to the BI score, and weakly related to the number of secondary conditions (0.15) and of psychosocial problems (0.16) and was not significantly related to the number of activities problems. The three dimensions of partner support were moderately to strongly correlated with each other.

The relationships between getting professional support and the consequences of the injury and partner support were mostly weak. The only moderately strong relationships seen were getting nursing support with BI (-0.34) and with partner ADL support (0.35). The relationships between partner’s support and professional support were all positive, indicating that partners with professional support provided more support by themselves than partners without professional support did.

To study the predictive value of these variables for perceived burden, all of them were entered in a stepwise regression analysis. The final model is displayed in Table 5. The order of the variables in Table 5 is the order of entry in the analysis. The amount of ADL support given by the partner was the strongest determinant of caregiver burden, predicting 35% of the variance of perceived burden. Other significant determinants were the number of psychosocial problems of the patient, age (older partners reporting higher burden) and gender of the partner (women reporting higher burden than men), BI of the patient and duration of the SCI (higher burden in the early phase of the injury). The final model predicted almost half of the

Table 4 Relationships between the consequences of the spinal cord injury, the care given by partners and professionals, and perceived caregiver burden by the partners ($N = 255-265$)

	<i>Barthel Index</i>	<i>Secondary conditions</i>	<i>Activities problems</i>	<i>Psycho-social problems</i>	<i>Partner ADL support</i>	<i>Partner practical support</i>	<i>Partner emotional support</i>	<i>Profess. nursing support</i>	<i>Profess. house-keeping</i>	<i>Profess. information</i>	<i>Profess. psychosocial support</i>
<i>Patient's situation^a</i>											
Barthel Index	X										
Secondary conditions	-0.36**	X									
Activities problems	-0.10	0.37**	X								
psychosocial problems	-0.08	0.34**	0.54**	X							
<i>Partner support^a</i>											
ADL support	-0.77**	0.38**	0.19**	0.15*	X						
Other practical support	-0.53**	0.29**	0.10	0.07	0.68**	X					
Emotional support	-0.31**	0.15*	0.09	0.16**	0.33**	0.36**	X				
<i>Professional support^b</i>											
Nursing	-0.34**	0.06	0.09	0.14*	0.35**	0.19**	0.09	X			
Housekeeping	-0.10*	0.08	0.12*	0.19*	0.17**	0.08	0.02	0.39**	X		
Information	-0.17**	0.02	0.01	0.05	0.18**	0.16**	0.19**	0.25**	0.17**	X	
Psychosocial	-0.06	0.10	0.15**	0.25**	0.07	0.08	0.17**	0.04	0.14*	0.21**	X
Caregiver Burden ^a	-0.55**	0.28**	0.24**	0.25**	0.62**	0.49**	0.30**	0.28**	0.11*	0.18**	0.10*

^aOrdinal variables; Spearman correlations

^bDichotomous variables; Kendall's Tau

* $P < 0.05$

** $P < 0.01$

Table 5 Predictors of burden perceived by partners of persons with SCI ($N = 252$)^a

	<i>Beta</i> ^b	<i>t-value</i> ^b	<i>P-value</i> ^b	<i>Explained variance (%)</i>
Partner ADL support	0.37	5.16	0	35
Patient psychosocial problems	0.17	3.40	0.001	39
Partner age	0.23	4.51	0	43
Partner gender	0.11	2.21	0.028	44
Barthel Index	0.19	2.63	0.009	45
Duration of SCI	-0.13	-2.52	0.012	47

^aVariables not entered in the stepwise regression analysis: patient medical problems, patient activities problems, partner other practical support; partner emotional support; professional nursing, professional housekeeping; professional information and professional psychosocial support

^bFigures of the final regression model

variance of caregiver burden (MR = 0.68; adj. $R^2 = 47\%$). Interestingly, the relationship between gender of the partner and burden was bivariately insignificant. It only became significant after step 2, the inclusion of psychosocial problems of the patient.

Discussion

In this study, the levels of perceived burden of care by partners of persons with SCI and its determinants are examined. Strong features of this study are the focus on partners only instead of using a heterogeneous group of caregivers, the large number of 265 partners included in the study and the detailed information about various types of support given.

Burden

Our results show that, using a cutoff point of >3 on the burden measure, approximately one-quarter (24.8%) of all partners of patients with moderate or serious disabilities perceived high levels of caregiver burden. Perceived burden was highest in partners who provided much ADL support, were older, were female, and whose partner had more severe disabilities, a more recent SCI and more psychosocial problems. Together these variables predicted a substantial amount (47%) of the level of caregiver burden. As stated before, we were not able to find other studies into caregiver burden and its predictors in partners of persons with SCI. Replication of this study would be useful to confirm its results and replication in other countries is necessary to study likely crosscultural differences.

Care

Most persons with SCI in our study group 'often' or 'always' received some kind of support from their partners and 45.3% received some form of professional care at least once a week. Kemp studied assistance of persons with SCI in Australia.¹ In his group, 59.5% of all respondents received some kind of assistance with their everyday living on a daily basis. This proportion ranged from almost 100% of persons with complete

tetraplegia down to 14.4% of persons with no movement or with sensory problems. Paid care was received by 57% of respondents receiving everyday assistance. As in our study, Kemp found that for most persons paid care was received in addition to informal care, which was primarily given by the partner, if available.¹

Relationships between severity of the injury and caregiver burden

We found a strong correlation between level of physical disability and caregiver burden. Other literature in this patient group is not available. Samsa *et al*²⁶ reported a comparably strong correlation of 0.70 between caregiver hours and self-reported disability, but this is at best indirect support for our results because caregiver hours and caregiver burden are different (although related) concepts. As stated before, most other studies have not used caregiver burden measures but used psychological distress and quality of life measures. Schulz *et al*²⁰ reported that the level of assistance provided in daily living activities and hours per day spent assisting the persons with SCI were strongly correlated with depression of caregivers. However, two studies in nonwestern countries, Turkey and South India, did not find significant relationships between severity of the injury or secondary conditions with caregiver's distress or quality of life.^{14,16} Perhaps these differences reflect the influence of cultural, ethnical or social factors upon the way informal caregivers appraise their efforts and the way they express their feelings to others.²⁷

Relationships between caregiver gender and caregiver burden

Our study showed that women reported higher levels of caregiver burden than men, after controlling for the impact of other variables. Other studies also showed higher levels of distress in women caring for a partner with SCI than in men caring for a partner with SCI.⁶ This may be due to a difference in actual levels of support given. Shackelford *et al*²⁸ reported that males with SCI were more likely to have their spouse or parents assist, whereas females with SCI were more

likely to have a paid attendant or other relatives than spouse or parent as a caregiver. In our study this difference was seen for housekeeping support only and not for other types of professional support. The higher level of burden reported by female caregivers in our study might however also be a reflection of the differences in how men and woman perceive and react to life in general, women being less reluctant to report distress than men.⁶

Limitations of this study

Despite the strengths of this study, a few possible limitations apply. Firstly, this study concerned a selected group of persons with SCI who were members of the patient organisation DON. This patient organisation includes relatively few persons with incomplete SCI. Further, our main study into health problems suffered from a relatively low response rate (46%) and may have triggered responses mainly from persons with serious injuries or those who were suffering from secondary conditions. Finally, although the response of the partners was very high (88%), it is possible that partners who were also caregivers responded more often than partners who were not caregivers. However, the level of disability of persons with SCI in this study (mean score BI 12.3; SD 4.7) was only a little bit below the mean BI score of 13.6 (SD 5.4) seen in an earlier Dutch study using a representative sample of persons with SCI 1–6 years after clinical rehabilitation.²³ Therefore, if we had used a representative sample, the results might have shown lower levels of support and perceived caregiver burden, but the differences would probably have been small.

A second limitation is that measures of psychological characteristics of the partners, like coping, locus of control, personality, etc were not included in this study. Other studies showed strong influence of these variables on caregiver distress, depression and perceived health.^{13,18,19} In those studies, however, no measure of perceived burden was included and therefore the relationships between amounts of provided care, capabilities of the partner to cope with the situation, perceived burden of care and quality of life of partners of persons with SCI remains a subject for future research.

Implications for practice

Our study shows that a substantial proportion of partners perceive serious caregiver burden and these partners may be 'at risk' for burnout at some time in the future. This applies particularly to partners of persons with complete tetraplegia who are dependent on assistance for personal care, who require various 'helping hands' throughout the day, and who have the most difficulties with adjustment to their injury.^{21,29} Further, the positive relationship between caregiver age and perceived burden may be seen as a warning for future developments since more and more persons with SCI

will reach old age. Creating the conditions for keeping caregiver burden within acceptable limits is therefore of utmost importance. Monitoring of caregiver burden, whether perceived by a partner or by other family members, should be part of the life-long surveillance for persons with SCI and when a caregiver suffers from a serious burden and a serious impact of caregiving on their own daily activities and social life, this should be treated as a legitimate need for professional, reimbursed support. This would not necessarily be assistance or extra assistance for the person with SCI because this study showed that a wide range of needs for support exist. Partners also expressed a need for information, partner support groups or counselling. These kinds of interventions have been shown to be effective in other patient groups, especially stroke, and could be considered for partners of persons with SCI.³⁰ The kind of support that would be most applicable in a particular situation should however be discussed with the partner and the person with SCI themselves.

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