

## ORIGINAL ARTICLE

# Home aids and personal assistance 10–45 years after spinal cord injury

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**Objective:** Assessment of home aids, adaptations and personal assistance received after traumatic spinal cord injury (SCI).

**Setting:** Clinic for Spinal Cord Injuries, Denmark. Uptake area, 2.5 million inhabitants.

**Study design and methods:** Cross-sectional follow-up with retrospective data from medical files.

**Materials:** Individuals with traumatic SCI before 1 January 1991, still in regular follow-up and with sufficient medical record. In all, 279 were included, and 236 answered the questionnaire (193 men and 43 women), with a response rate of 84.6%. Mean age at follow-up was 50.5 years, and mean follow-up time, 24.1 years. One hundred and twenty-six were paraplegic and 110, tetraplegic. Responders and non-responders were comparable.

**Results:** Most common aids or adaptations reported were commode/shower chair on wheels or a seat (69%), grab bar by the toilet (41%), electrical bed (44%), special mattress (28%), lift/hoist (20%), computers (39%) and kitchen tools or cutlery with special handles (14%). In all, 7.6% of the participants reported no aids. Eighty-two percent answered 'Yes' to the question 'Have the aids, you currently or previously needed, been available to you?' The majority reported that their source of information about aid had been various journals and magazines. Twenty-one percent had personal helpers, with 60 h per week in median (range 2–168). Thirty-three percent received domestic help with 2.5 h per week in median (range 0.5–37). Eight percent had a home nurse. A total of 98.7% were living in their own homes.

**Conclusions:** This is the first study of a representative SCI population giving information on home aids. Individuals with SCI in Denmark seem to be sufficiently supplied with aids and personal assistance. *Spinal Cord* (2009) 47, 405–412; doi:10.1038/sc.2008.132; published online 11 November 2008

**Keywords:** spinal cord injury; home aids; personal assistance; paraplegia; tetraplegia

## Introduction

Throughout the later decades, cost in relation to spinal cord injuries (SCIs) is moving from acute medical care to less-acute community-based care, including the use of various aids, appliances and transportation.<sup>1</sup>

The authors have researched in the available literature, and little is known about the provision of home aids and personal assistance individuals with an SCI received years after their injury, although this topic has been studied more recently in the disabled, in general, and elderly people.<sup>2–4</sup> Information about which, and how often, home aids and personal assistance are used by individuals with SCI is highly relevant for all professionals working with SCI individuals, including those who provide and finance the services. Therefore, it can

also be beneficial for therapists, nurses and social workers in the clinical setting who, before discharge, guide and find the necessary home aids and personal assistance for SCI individuals with varying severities of disability.

Having a home that is well equipped with home aids and having sufficient personal assistance are of the utmost importance for SCI individuals.<sup>5–7</sup> Whiteneck *et al.*<sup>5</sup> found that 'help at home' was ranked third as the greatest environmental barrier, coming after barriers in the 'natural environment' and 'transportation' for people with SCI. The environmental barriers were defined as barriers that keep SCI individuals 'from functioning within the household and community, and from doing what they need or want to do'. Environmental barriers were also shown to be substantial contributors to life satisfaction.

The aim of this paper is therefore to give information about how much and which home aids and personal assistance a representative population of traumatic SCI individuals of various functional disabilities use at least 10 years after injury.

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## Materials and methods

The study includes individuals followed by the Clinic for Spinal Cord Injuries, Rigshospitalet, Denmark. The uptake area corresponds to East Denmark, with a population of 2.5 million. All patients with SCI, independent of their socio-economic status, are referred to this facility, if they are judged to be in need of specialized care and rehabilitation. Afterwards, they are followed lifelong, although those with minimal consequences of their SCI may be terminated from the follow-up regime. The treatment, rehabilitation and home modifications and aids are provided free of charge in Denmark.

The study included living individuals with a traumatic SCI contracted before 1 January 1991. They should still be in regular follow-up at Clinic for Spinal Cord Injuries, and their medical records had to be sufficient for retrieval of the historical data.

Two hundred and seventy-nine participants were included. They received a questionnaire by mail with a pre-stamped return envelope. If they did not reply to the first mail, they received a reminder after 2 months.

Two hundred and thirty-six participants answered and returned the questionnaire (84.6%), 193 men and 43 women injured during 1956–1990. Age at the time of follow-up was 50.5 years in mean (s.d. 11.2, median 50.0, range 28.4–84.5), and follow-up time was 24.1 years in mean (s.d. 8.7, median 23.7, range 10.7–45.1). One hundred and twenty-six participants were paraplegic and 110 tetraplegic, 102 complete and 134 incomplete according to Frankel *et al.*<sup>8</sup>

The non-responder group consisted of 43 participants, 35 men and 8 women injured during 1960–1990.

### Medical record data

Data concerning date of birth, gender, time of SCI, cause of SCI, neurological level and functional classification<sup>8</sup> at the time of discharge from the initial rehabilitation were collected.

A 'neurofunction' variable was used:<sup>9</sup>

- 'C<sub>1–5</sub>/A–C': neurological level C<sub>1–5</sub> and functional class A–C.
- 'C<sub>6–8</sub>/A–C': neurological level C<sub>6–8</sub> and functional class A–C.
- 'T<sub>1–6</sub>/A–C': neurological level T<sub>1–6</sub> and functional class A–C.
- '>T<sub>6</sub>/A–C': neurological level T<sub>6</sub>–L<sub>4</sub> and functional class A–C.
- 'D': all with functional class D.
- 'E': all with functional class E.

This means high and low tetra- and paraplegics with no useful motor function below the level of lesion. Class D represents a very heterogeneous group,<sup>10</sup> and is therefore kept separately. Individuals in class E are almost physically normal.

### The follow-up questionnaire

The questionnaire was part of a larger follow-up in individuals with SCI at least 10–45 years before the study,

### AIDS:

Here is a list of adaptive aids. Tick off the aids you use. You may tick off more than one.

#### Toilet and bath:

- Raised toilet seat
- Grab bar by the toilet
- Electric toothbrush
- Commode / shower chair on wheels or a seat
- Grasping tongs
- Height adjustable washbasin or special washbasin
- Others \_\_\_\_\_

#### Adaptations in the home:

- Grab handle in the home other than in the bathroom
- Electric bed
- Special mattress
- Lift / hoist
- Lounge chair
- Desk chair
- Computer
- Computer table
- Others \_\_\_\_\_

#### Kitchen adaptations:

- Wheeled table
- Kitchen tools or cutlery with special handle
- Height-adjustable kitchen worktop
- Height-adjustable cupboard
- Others \_\_\_\_\_

#### Home treatment:

- Ventilator
- CPAP/BIPAP (aids for ventilation)
- Mask for respiratory training
- Others \_\_\_\_\_

#### Practical help:

- Personal helpers  
- how many hours per week? \_\_\_\_\_
- Domestic help  
- how many hours per week? \_\_\_\_\_
- Home nurse  
- how many hours per week? \_\_\_\_\_
- Others \_\_\_\_\_

1. Have the aids you currently or previously needed been available to you?

- No, describe in details \_\_\_\_\_
- Yes

2. Do you regularly get information about new aids?

- No
- Yes, how? \_\_\_\_\_

**Figure 1** Questions from the follow-up questionnaire regarding home adaptations and aids and personal assistance. Translated from Danish.

in which the present information on home aids and personal assistance was only one among several other topics.<sup>11–14</sup> The data concerning home aids, adaptations and personal assistance at the time of follow-up are given in Figure 1.

The questionnaire was developed by professionals working in rehabilitation of SCI patients. It was tried in a pilot study including seven SCI individuals. The questionnaire was found comprehensive and easy to answer. Minor adjustments were made.<sup>11</sup>

To test the validity of the process of transferring the information from the questionnaire into the database, 10% (N=24) of the questionnaires were checked thoroughly a second time.<sup>11</sup> All data entries concerning the present publication were correct.

To investigate the reproducibility of the questionnaire, 38 randomly selected participants received a second identical questionnaire, and 86.8% responded.<sup>11</sup> For the home aids/adaptation, 97% questions, and for personal assistance, 100% questions gave exactly the same answer. Therefore, the reproducibility was satisfactory.

### Statistical methods

Fisher's exact (two-tailed) and  $\chi^2$  tests were used (<http://faculty.vassar.edu/lowry/VassarStats.html>). Level of significance was 5%.

## Results

Responders and non-responders were not significantly different regarding gender, age at SCI, cause of SCI, neurological level, functional classification, years since SCI or age at follow-up.

### Home aids/adaptations

Tables 1 and 2 show the toilet and bathroom aids reported. The most common aid reported was a commode/shower chair on wheels or a seat, used equally in the neurofunction groups ( $P=0.37$ , excluding group E), but significantly more of those injured in the later years were equipped with this aid ( $P=0.013$ ). The second most frequently reported aid was a grab bar by the toilet, which in particular was used by the paraplegics without any major motor function below the level of their lesion ( $P=0.0039$ , excluding group E), and there was a tendency for the older individuals to use it more ( $P=0.090$ ). Electrical toothbrushes were not always used due to disability. Other special bathroom equipments reported by 20 individuals included ceiling hoists and thermostatically regulated mixer taps. In all, 14% (N=34) did not report any aids for the bathroom.

Among the aids in the home outside the bathroom and kitchen (Tables 3 and 4), an electrical bed was the most common, and significantly more among the tetraplegics ( $P<0.0001$ , excluding group E). The same pattern was true for the use of special mattresses ( $P=0.012$ , excluding group E) and lift/hoist ( $P<0.0001$ , excluding group E). Computers were not always an aid due to disability. Other adaptations mentioned by 24 participants were removal of doorsteps, ramps, remote-controlled door and window openers, and two participants had elevators installed. Overall, 23% (N=55) did not mention any aids and adaptations in the home other than in the bathroom and kitchen.

**Table 1** Toilet and bathroom aids and adaptations reportedly used 10–45 years after spinal cord injury, divided by gender and neurofunction classification<sup>a</sup>

Aid/adaptation	Number %	Gender		Neurofunction classification <sup>b</sup>					E
		Female	Male	C <sub>1-5</sub> /A-C	C <sub>6-8</sub> /A-C	T <sub>1-6</sub> /A-C	>T <sub>6</sub> /A-C	D	
Raised toilet seat	56 23.7%	17.9% (10) 23.3%	82.1% (46) 23.8%	7.1% (4) 13.3%	19.6% (11) 27.5%	19.6% (11) 34.4%	26.8% (15) 21.7%	26.8% (15) 25.4%	—
Grab bar by the toilet	97 41.1%	18.6% (18) 41.9%	81.4% (79) 40.9%	5.2% (5) 16.7%	15.5% (15) 37.5%	18.6% (18) 56.3%	37.1% (36) 52.2%	20.6% (20) 33.9%	3.1% (3) 50%
Electric toothbrush	64 27.1%	21.9% (14) 32.6%	78.1% (50) 25.9%	29.7% (19) 63.3%	15.6% (10) 25%	10.9% (7) 21.9%	9.4% (6) 8.7%	29.7% (19) 32.2%	4.7% (3) 50%
Commode/shower chair on wheels or a seat	162 68.6%	16.7% (27) 62.8%	83.3% (135) 69.9%	14.2% (23) 76.7%	16.0% (26) 65%	15.4% (25) 78.1%	30.2% (49) 71.0%	22.2% (36) 61.0%	1.9% (3) 50%
Grasping tongs	43 18.2%	30.2% (13) 30.2%	69.8% (30) 15.5%	4.7% (2) 6.7%	14.0% (6) 15%	18.6% (8) 25%	39.5% (17) 24.6%	23.2% (10) 16.9	—
Height-adjustable washbasin or special washbasin	14 5.9%	28.6% (4) 9.3%	71.4% (10) 5.2%	—	35.7% (5) 12.5%	14.3% (2) 6.3%	28.6% (4) 5.8%	14.3% (2) 3.4%	7.1% (1) 16.7%
All participants	236	18.2% (43)	81.8% (193)	12.7% (30)	16.9% (40)	13.6% (32)	29.2% (69)	25.0% (59)	2.5% (6)

<sup>a</sup>Neurofunction classification (cf. text and Biering-Sørensen et al.<sup>5</sup>) is based on a combination of the neurological level and the functional class.  
The first percentage shows the distribution between genders and among the neurofunction groups, and the second percentage in the cell and the percentage in the second column give the percentage of all participants having the particular aid. Numbers are given in parentheses.

**Table 2** Toilet and bathroom aids and adaptations reportedly used 10–45 years after spinal cord injury, divided by time at injury and age at follow-up

Aid/adaptation	Number %	Time at injury			Age at follow-up			
		01.01.56–31.12.70	01.01.71–31.12.80	01.01.81–31.12.90	28–39, 9 years	40–49, 9 years	50–59, 9 years	60–84 years
Raised toilet seat	56 23.7%	21.4% (12) 19.7%	33.9% (19) 25.3%	44.6% (25) 25.0%	16.1% (9) 20.5%	32.1% (18) 24.3%	32.1% (18) 24.0%	19.6% (11) 25.6%
Grab bar by the toilet	97 41.1%	20.6% (20) 32.8%	33% (32) 42.7%	46.4% (45) 45.0%	11.3% (11) 25.0%	35.1% (34) 45.9%	32.0% (31) 41.3%	21.6% (21) 48.8%
Electric toothbrush	64 27.1%	25% (16) 26.2%	26.6% (17) 22.7%	48.4% (31) 31.0%	23.4% (15) 34.1%	31.2% (20) 27.0%	31.2% (20) 26.7%	14.1% (9) 20.9%
Commode/shower chair on wheels or a seat	162 68.6%	20.4% (33) 54.1%	32.7% (53) 70.7%	46.9% (76) 76.0%	19.7% (32) 72.7%	33.3% (54) 73.0%	30.2% (49) 65.3%	16.7% (27) 62.8%
Grasping tongs	43 18.2%	25.6% (11) 18.0%	32.5% (14) 18.0%	41.9% (18) 18.0%	2.3% (1) 2.3%	37.2% (16) 21.6%	32.5% (14) 18.7%	27.9% (12) 27.9%
Height-adjustable washbasin or special washbasin	14 5.9%	21.4% (3) 4.9%	21.4% (3) 4.0%	57.1% (8) 8.0%	28.6% (4) 9.1%	42.8% (6) 8.1%	21.4% (3) 4.0%	7.1% (1) 2.3%
All participants	236	25.8% (61)	31.8% (75)	42.4% (100)	18.6% (44)	31.4% (74)	31.8% (75)	18.2% (43)

The first percentage shows the distribution among the 'time at injury' and 'age at follow-up' groups and the second percentage in the cell and the percentage in the second column give the percentage of all participants having the particular aid. Numbers are given in parentheses.

**Table 3** Home aids reportedly used 10–45 years after spinal cord injury, divided by gender and neurofunction classification<sup>a</sup>

Aid/adaptation	Number %	Gender		Neurofunction classification <sup>a</sup>					
		Female	Male	C <sub>1–5</sub> /A-C	C <sub>6–8</sub> /A-C	T <sub>1–6</sub> /A-C	> T <sub>6</sub> /A-C	D	E
Grab handle in the home other than in the bathroom	6 2.5%	16.7% (1) 2.3%	83.3% (5) 2.6%	—	16.7% (1) 2.5%	16.7% (1) 3.1%	33.3% (2) 2.9%	33.3% (2) 3.4%	—
Electric bed	103 43.6%	18.4% (19) 44.2%	81.6% (84) 43.5%	28.2% (29) 96.7%	29.1% (30) 75.0%	11.7% (12) 37.5%	15.5% (16) 23.2%	14.6% (15) 25.4%	1.0% (1) 16.7%
Special mattress	66 28.0%	18.2% (12) 27.9%	81.8% (54) 28.0%	24.2% (16) 53.3%	19.7% (13) 32.5%	12.1% (8) 25.0%	25.8% (17) 24.6%	16.7% (11) 18.6%	1.5% (1) 16.7%
Lift/hoist	47 19.9%	23.4% (11) 25.6%	76.6% (36) 18.7%	40.4% (19) 63.3%	29.8% (14) 35.0%	2.1% (1) 3.1%	10.6% (5) 7.2%	14.9% (7) 11.9%	2.1% (1) 16.7%
Lounge chair	31 13.1%	19.4% (6) 14.0%	80.6% (25) 13.0%	—	3.2% (1) 2.5%	22.6% (7) 21.9%	38.7% (12) 17.4%	29.0% (9) 15.3%	6.5% (2) 33.3%
Desk chair	24 10.2%	25% (6) 14.0%	75% (18) 9.3%	—	—	4.2% (1) 3.1%	16.7% (4) 5.8%	70.8% (17) 28.8%	8.3% (2) 33.3%
Computer	91 38.6%	15.4% (14) 32.6%	84.6% (77) 39.9%	24.2% (22) 73.3%	25.3% (23) 57.5%	12.1% (11) 34.4%	17.6% (16) 23.2%	19.8% (18) 30.5%	1.1% (1) 16.7%
Computer table	36 15.3%	11.1% (4) 9.3%	88.9% (32) 16.6%	25% (9) 30.0%	16.7% (6) 15.0%	19.4% (7) 21.9%	13.9% (5) 7.2%	22.2% (8) 13.6%	2.8% (1) 16.7%
All participants	236	18.2% (43)	81.8% (193)	12.7% (30)	16.9% (40)	13.6% (32)	29.2% (69)	25.0% (59)	2.5% (6)

<sup>a</sup>Neurofunction classification (cf. text and Biering-Sørensen et al.<sup>9</sup>) is based on a combination of the neurological level and the functional class.<sup>8</sup>

The first percentage shows the distribution within the particular group and the second percentage in the cell and the percentage in the second column give the percentage of all participants having the particular aid. Numbers are given in parentheses.

**Table 4** Home aids reportedly used 10–45 years after spinal cord injury, divided by time at injury and age at follow-up

Aid/adaptation	Number	%	Time at injury				Age at follow-up			
			01.01.56–31.12.70	01.01.71–31.12.80	01.01.81–31.12.90	28–39.9 years	40–49.9 years	50–59.9 years	60–84 years	
Grab handle in the home other than in the bathroom	6	2.5%	—	16.7% (1)	83.3% (5)	16.7% (1)	33.3% (2)	33.3% (2)	33.3% (2)	16.7% (1)
Electric bed	103	43.6%	22.3% (23)	36.9% (38)	40.8% (42)	2.3%	19.4% (20)	2.7%	29.1% (30)	2.3%
Special mattress	66	28.0%	37.7% (13)	50.7% (23)	42.0% (30)	45.5%	43.2% (24)	43.2%	40.0%	48.8%
Lift/hoist	47	19.9%	21.3% (12)	30.7% (13)	30.0% (22)	27.3%	36.4% (24)	32.4%	21.3%	32.6%
Lounge chair	31	13.1%	25.5% (12)	27.6% (13)	46.8% (22)	21.3% (10)	27.6% (13)	17.6%	31.9% (15)	19.1% (9)
Desk chair	24	10.2%	19.7% (9)	29.0% (9)	54.8% (17)	22.7%	6.4% (2)	12.2%	20.0%	20.9%
Computer	91	38.6%	8.2% (5)	25% (6)	17.0% (13)	4.5%	16.7% (4)	33.3% (8)	25% (6)	16.3%
Computer table	36	15.3%	20.9% (19)	34.1% (31)	45.0% (41)	24.2% (22)	35.2% (32)	10.8%	30.8% (28)	9.9% (9)
All participants	236		31.1% (7)	41.3% (12)	47.2% (17)	50.0%	43.2% (11)	43.2%	37.3%	20.9%
			11.5% (6)	16.0% (7)	17.0% (10)	25.0%	14.9%	14.9%	12.0%	11.6%
			25.8% (6)	31.8% (7)	42.4% (10)	18.6% (4)	31.4% (7)	31.8% (7)	31.8% (7)	18.2% (4)

The first percentage shows the distribution within the particular group and the second percentage in the second column give the percentage of all participants having the particular aid. Numbers are given in parentheses.

Regarding kitchen aids and adaptation, 14% ( $N=33$ ) reported tools or cutlery with special handles, which in particular were used by tetraplegics ( $P<0.0001$ ,  $C_{1-8}/A-C$  vs other neurofunction groups). Wheeled tables were reported by 10% ( $N=24$ ), height-adjustable kitchen worktops by 8.5% ( $N=20$ ) and height-adjustable cupboards by 1% ( $N=3$ ). Twenty-eight participants reported other adaptations for the kitchen, that is lowered kitchen worktops by 18 and removal of base units by 15. Among men, 31.1% reported kitchen aids and adaptations, whereas it was 48.8% for women ( $P=0.033$ ).

One participant was on ventilator, seven reported the use of CPAP (Continuous Positive Airway Pressure) or BIPAP (Biphasic Intermittent Positive Airway Pressure), and five more used a mask for respiratory training.

The question 'Have the aids you currently or previously needed been available to you?' was answered by 210, and 82% reported 'Yes', and the remaining 18% ( $N=38$ ) 'No'. For 22, the remark was mainly regarding mobility aids, that is the car was not good enough or took too long to acquire ( $N=9$ ), seven were not granted a hand cycle, three-wheeled cycle, training cycle or a cabin cycle, two found their electrical wheelchair should be improved, two found they needed an extra manual wheelchair and two an electrical scooter. Four participants found that they needed some more adaptations at home, four wanted a better bed and three a computer. One participant wanted help for gardening, one a mask for respiratory training, one had just recently become aware that diapers were paid by the municipality and one reported that in the later years it was becoming increasingly difficult to get the municipality to supply the necessary aids.

The question 'Do you regularly get information about new aids?' was answered 'Yes' by 62 participants and 59 reported one or more source for their information. The majority, corresponding to 66%, reported journals, in particular the disability organizations journals, and foremost the journal from the SCI association. Twenty-four percent had information from Rehab Fair or companies, and 20% from professionals or the municipality. Other information sources reported were friends and other disabled people (12%), the workplace or colleagues (10%), and the internet.

Table 5 shows the number of aids/adaptations reported. Among those who did not report any aids, 11 participants were in Frankel groups D–E, and the remaining seven participants had low paraplegia.

**Table 5** Total number of home aids or adaptations reportedly used by the participants

Number of home aids/adaptations reported	Percentage of participants (N = 236)
0	8%
1	10%
2	8%
3	20%
4	11%
5	14%
6	12%
7–9	14%
10–12	4%

**Table 6** Personal assistance reportedly used 10–45 years after spinal cord injury, divided by gender and neurofunction classification<sup>a</sup>

Personal assistance	Number %	Gender		Neurofunction classification <sup>a</sup>					
		Female	Male	C <sub>1–5</sub> /A–C	C <sub>6–8</sub> /A–C	T <sub>1–6</sub> /A–C	> T <sub>6</sub> /A–C	D	E
Personal helpers	49 20.8%	16.3% (8) 18.6%	83.7% (41) 21.2%	40.8% (20) 66.7%	34.7% (17) 42.5%	10.2% (5) 15.6%	2.0% (1) 1.4%	10.2% (5) 8.5%	2.0% (1) 16.7%
Domestic help	78 33.1%	28.2% (22) 51.2%	71.8% (56) 29.0%	11.5% (9) 30.0%	20.5% (16) 40.0%	11.5% (9) 28.1%	30.8% (24) 34.8%	24.4% (19) 32.2%	1.3% (1) 16.7%
Home nurse	19 8.1%	52.6% (10) 23.3%	47.4% (9) 4.7%	21.1% (4) 13.3%	36.8% (7) 17.5%	5.3% (1) 3.1%	31.6% (6) 8.7%	5.3% (1) 1.7%	—
All participants	236	18.2% (43)	81.8% (193)	12.7% (30)	16.9% (40)	13.6% (32)	29.2% (69)	25.0% (59)	2.5% (6)

<sup>a</sup>Neurofunction classification (cf. text and Biering-Sørensen *et al.*<sup>9</sup>) is based on a combination of the neurological level and the functional class.<sup>8</sup>

The first percentage shows the distribution within the particular group and the second percentage in the cell and the percentage in the second column give the percentage of all participants having the particular assistance. Numbers are given in parentheses.

**Table 7** Personal assistance reportedly used 10–45 years after spinal cord injury, divided by time at injury and age at follow-up

Personal assistance	Number %	Time at injury			Age at follow-up			
		01.01.56–31.12.70	01.01.71–31.12.80	01.01.81–31.12.90	28–39.9 years	40–49.9 years	50–59.9 years	60–84 years
Personal helpers	49 20.8%	18.4% (9) 14.8%	28.6% (14) 18.7%	53.1% (26) 26.0%	30.6% (15) 34.1%	30.6% (15) 20.3%	30.6% (15) 20.0%	8.2% (4) 9.3%
Domestic help	78 33.1%	21.8% (17) 27.9%	34.6% (27) 36.0%	43.6% (34) 34.0%	11.5% (9) 20.5%	38.5% (30) 40.5%	23.1% (18) 24.0%	26.9% (21) 48.8%
Home nurse	19 8.1%	10.5% (2) 3.3%	36.8% (7) 9.3%	52.6% (10) 10.0%	15.8% (3) 6.8%	42.1% (8) 10.8%	26.3% (5) 6.7%	15.8% (3) 7.0%
All participants	236	25.8% (61)	31.8% (75)	42.4% (100)	18.6% (44)	31.4% (74)	31.8% (75)	18.2% (43)

The first percentage shows the distribution within the particular group and the second percentage in the cell and the percentage in the second column give the percentage of all participants having the particular assistance. Numbers are given in parentheses.

Specific home adaptations like removal of doorsteps, ramps, remote-controlled door and window openers and installation of elevators were not specifically asked for in the questionnaire, although some of the participants reported these.

#### Personal assistance

Personal helpers (Tables 6 and 7), mostly unskilled and employed by the participant themselves, but paid by the municipality, were available to 21, and 90% gave information about the number of h per week they had helpers, that is 77.6 in mean (median 60, range 2–168). Seven had 168 h per week corresponding to 24 h care. Personal helpers were most common among tetraplegic participants ( $P < 0.0001$ , C<sub>1–8</sub>/A–C vs other neurofunction groups) and the youngest age group ( $P = 0.042$ ).

The domestic help, usually carried out by professional health and social assistants employed in the municipality, was available to 33%, and 75 reported on the number of h per week, that is median 2.5 (range 0.5–37). Six had more than 14 h per week. Domestic help was most common for the oldest age group ( $P = 0.0055$ ) and women ( $P = 0.0052$ ).

In all, 8% ( $N = 19$ ) needed a home nurse 0.2–4 h per week (median 1 h;  $N = 13$ ), the majority being tetraplegic women. Three mentioned the need for a nurse to check for ulcers and two needed a new catheter every 3–5 weeks.

Regarding other personal assistance, 18 participants reported that they had help from their wife/husband, five from

someone they were cohabitating with, one from parents and one from children. Seven had private cleaning help, four were given escort help from the municipality, two were in a nursing home and one participant was living in a residential non-institutional location with support for activities of daily living. In total, 98.7% were living in their own homes.

#### Discussion

With no significant differences between the responders and non-responders and a high participation rate, the results are representative of individuals with traumatic SCI at least 10 years post-injury in regular control in East Denmark and can probably be generalized to the whole Danish SCI population with significant consequences of their injury. As the home aids/adaptations and personal assistance are provided in negotiation with the local municipalities, there may be certain regional differences in the services.

The questionnaire used was found reproducible over a period of 2 years. This indicates stability in the population answering the questionnaire, which may even increase the validity of the information included.

It is always a limitation to a study when it is necessary to use retrospective data and questionnaires with possible bias regarding what individuals might remember at the time of the response. As mentioned, our questionnaire did not investigate all kinds of home adaptations regarding wheel-

chair accessibility for SCI individuals such as removal of doorsteps, putting up ramps, use of remote-controlled door and window openers and installation of elevators and so on, although some of the participants reported some of these modifications. These adaptations are well described by Stiens *et al.*<sup>15</sup>

There will always be a balance regarding the number of questions and the response rate, as too many questions may give fewer answers, not least because this study was part of a larger follow-up with many other questions included.<sup>11–14</sup>

This study is, as far as we could see in literature, the first that illustrates which kind of home aids people with different severity of SCI use. This information can be of importance for a variety of professionals, including those in the municipalities, who administrate and finance home aids/adaptations and personal assistance.

Results from several studies emphasize the need for SCI individuals to be sufficiently supplied with home aids and personal assistance.<sup>5–7</sup> It is therefore very positive that we, in our study, can conclude that the SCI population in Denmark, in general, is sufficiently supplied with home aids and adaptations, as the majority answered 'Yes' to the question 'Have the aids you currently or previously needed been available to you?', and only four persons found that they needed some more aids at home. The majority of those who replied 'No' were dissatisfied with their mobility aids, and not with their aids at home. Information about which kind of mobility aids the participants of this study used is described earlier.<sup>11</sup>

Only 3 of 236 participants did not live in their own home, which is positive, because existing evidence suggests that the more independence an SCI individual has, the more quality of life and self-esteem he feels.<sup>16</sup>

In our study, the most common home aid reported was commode/shower chair, which was reported by 69%. This is similar to the results from an American study in which they found that the most commonly used home aids among patients with neurologic disorders, lower-extremity orthopaedic trauma and medically complex conditions, were commode and shower adaptations.<sup>3</sup> These results imply that SCI individuals, like the disabled in general, specifically need home aids in the bathroom.<sup>17–19</sup> A study from South Africa showed that SCI individuals, compared with patients from other diagnostic groups, who also received bath aids, used their bath seats least,<sup>20</sup> which probably was due to the absence of a backrest, which made these seats unsuitable for most individuals with SCI because of balance problems.

Sufficiently supplied and well-educated personal assistance is important and may make up for the lack of physical function caused by the SCI, that is it can improve participation in society and family life, as it helps bridge the gap between physical impairment and social function. This participation often determines the perception of life satisfaction.<sup>5,21</sup> This stresses how important sufficiently supplied and well-educated personal assistance is, and it is therefore positive that SCI individuals in Denmark seem well supplied with personal assistance.

The cervical spinal cord injured received most aids and personal assistance, which was expected, and in accordance,

with earlier studies.<sup>21–24</sup> We found that participants who used personal helpers, in average had helpers for 77.6 h per week (median 60). This number of hours of personal helpers is higher than the amount reported in earlier studies.<sup>6,25</sup> In a Finnish study, SCI people in wheelchairs on average used 61 h per week of personal assistance.<sup>6</sup> They also found that most SCI individuals lived in their own homes (91%) and that they had suitable technical aids and enough personal assistance,<sup>6</sup> which is similar to our study. On the other hand, it seems that Finnish SCI individuals used relatives for personal assistance more than the case is in Denmark. In a Canadian study, almost 70% of the SCI participants reported receiving paid or unpaid personal assistance. The participants who received personal assistance had help between 11 and 20 h weekly in median.<sup>25</sup> It has to be noticed that we in our questionnaire, in contrast to these two studies, asked the participants only about paid personal assistance. The difference in questioning makes it difficult to compare the results. These studies<sup>6,25</sup> did not give the correlation between the severity of the SCI and the amount of personal assistance needed, which, as expected, is of major importance (Table 6).

Advice regarding which aids and assistance are found necessary and suitable for the particular SCI individual will, in the initial phases, be given by the personnel in the SCI centres, and the results reported here can give some basic advice about what may be necessary for the particular individual with SCI.

Today, many new home aids and adaptations are being developed with environmental control systems for daily living, which further enhances independence, control of the home environment and quality of life. Furthermore, the environmental control system has been shown to reduce the demand for personal assistance and other help.<sup>16,26</sup> We did not specifically ask about environmental control system, but several participants mentioned themselves that some of these solutions were available at their homes, and we believe that these possibilities will be used increasingly in the years to come.

In comparison with a recent study from the United States,<sup>27</sup> where 69 % used a computer at home, school or other location, our figure of 39% of the participants having a computer at home seems low. In 2006, 85% of all homes in Denmark had a personal computer,<sup>28</sup> although to a lesser degree among those above 60 years of age, which likewise is very apparent from our results (Table 4). Reasons for the difference between the US and the Danish figures may be that our questionnaire was answered in 2000, whereas the US figure during 2004–2006, and in the last years, the increase in the purchase of computers has been very significant in Denmark.<sup>29</sup> In addition, the US population had a much lower age distribution, and the study did not specify the numbers of computers at home.

Future studies should come more in depth with the particular issues treated here, that is more detailed information on the aids and adaptations as well as unpaid and paid personal assistance used by SCI individuals, but we will also advise that information about the severity of the injury should be included, to be able to use the information in practice.

## Conclusion

The majority of SCI individuals at least 10 years post-injury have a variety of home aids and seem to be individually serviced. This is important to enable individuals with SCI to be able to live independently and hereby attain high life satisfaction.

The results give indication about the kind of home aids supplied to individuals with SCI depending on their degree of disability.

The SCI population in Denmark seems to be well supplied with home aids and personal assistance.

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