

## ORIGINAL ARTICLE

# Urinary incontinence in spinal cord injured individuals 10–45 years after injury

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**Study design:** Epidemiological follow-up study.

**Objective:** To evaluate urinary incontinence and its management in a population of individuals with long-term spinal cord injury (SCI).

**Setting:** Clinic for Spinal Cord Injuries and Department of Urology, Copenhagen University Hospital, Rigshospitalet, Denmark.

**Methods:** Retrospective data collection from the patient records and information from a follow-up questionnaire of traumatic SCI individuals at least 10 years after injury. A total of 236 patients participated (84.6% response), 82% males and 18% females, 47% tetraplegic and 53% paraplegic, injured between 1956 and 1990. Age at the time of follow-up was 28–84 years (mean 50.5 years). Years of follow-up were 10–45 years (mean 24.1 years).

**Results:** A total of 43% of the participants reported incontinence from less than once a week to daily. There was a significant linear trend across the groups of incontinence with more paraplegics reporting daily incontinence compared with tetraplegics. A higher proportion of participants using clean intermittent catheterization reported incontinence (56%) compared with participants using other bladder-emptying methods. Only 19% of the participants used medication for the management of incontinence.

**Conclusion:** Urinary incontinence is a common problem in individuals with SCI. Only a minority of individuals used medication for the treatment of incontinence.

**Sponsorship:** This study was carried out as a part of the primary author's PhD study, financed by the Medicon Valley Academy and Coloplast A/S.

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**Keywords:** paraplegia; tetraplegia; bladder-emptying method; intermittent catheterization; urinary incontinence

## Introduction

A spinal cord injury (SCI) may impair the normal function of the urinary bladder and give rise to neurogenic bladder dysfunction. Lesions above the sacral micturition centre may cause urge and reflex incontinence, and lesions peripheral to the sacral micturition centre may cause overflow incontinence. Urinary incontinence is an important aspect of bladder management in individuals with SCI. From the view of the SCI individuals, it is a most unpleasant complication, which may disable the individuals socially. Earlier studies have shown impaired bladder control to be related to lower quality of life.<sup>1,2</sup>

The aim of this study was to evaluate urinary incontinence and its management in a population of individuals with SCI,

at least 10 years after injury, to elucidate the extent of the problem and how it is handled.

## Materials and methods

The study included patients from the Clinic for Spinal Cord Injuries (CSCI) at Rigshospitalet, Denmark. The inclusion criteria were a traumatic SCI contracted before 1 January 1991 and the participant still alive at the time of mailing a follow-up questionnaire.

The exclusion criteria were: (1) not immediately transferred to CSCI after the acute admission because of the SCI, (2) follow-up terminated from the CSCI, (3) not followed in CSCI since 1990 or (4) missing medical record/insufficient data.

In all, 279 participants were included in the project. They all received a questionnaire by mail with a pre-stamped return envelope. Approximately 2 months after the first dispatch of questionnaires, a reminder with a new ques-

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tionnaire was sent to those participants, who had not answered. All together, 236 participants answered and returned the questionnaire after the first or second mailing corresponding to a response-rate of 84.6%. Among them, 193 were men and 43 women, injured from 1956 to 1990. The mean age of the participants at the time of the study was 50.5 years (range 28.4–84.5 years), and mean follow-up time was 24.1 years (range 10.7–45.1 years). Concerning level of injury, 126 participants were paraplegic and 110 tetraplegic, 102 complete and 134 incomplete according to the Frankel classification.<sup>3</sup>

The non-responder group consisted of 43 individuals, 35 men and 8 women injured from 1960 to 1990.

#### *Medical record data*

Data concerning gender, time of injury, neurological level, Frankel classification<sup>3</sup> and results from the latest urodynamic investigation carried out before follow-up were collected from the medical records. The neurological level and Frankel classification were recorded as defined at the time of discharge from the initial rehabilitation at CSCI, at which time the participants are expected to be neurologically stationary. The neurological level of the SCI was given as the most caudal normal spinal cord segment.

#### *The questionnaire*

The questionnaire concerned different aspects of late complications in individuals with SCI. The questions used in this study are seen in Table 1. Scales, questions and answer possibilities in the questionnaire were similar or comparable with earlier published standards.<sup>4</sup> Experience from an earlier study of reproducibility and validity of a questionnaire filled in by spinal cord-lesioned individuals before regular follow-up<sup>5</sup> has been used to optimize the questions. The questionnaire was further developed with the assistance of different professionals working with the treatment and rehabilitation of patients with SCI. Before the questionnaires were mailed to the participants in the main study, a pilot study was carried out including seven men with SCI (four tetraplegic and three paraplegic). The pilot study showed that the questionnaire was comprehensive and easy to answer. Owing to the experience from the pilot study, minor adjustments were made before sending the questionnaire to all the participants in the main study.

To test the validity of the process of typing the answers to the questionnaire into the database, 10% ( $n=24$ ) of the questionnaires were checked thoroughly a second time. The results showed that all data entries concerning the included data for this publication were correct.

To investigate the reproducibility of the questionnaire, 38 participants received a second questionnaire 2 years after the initial emission of the questionnaire. A total of 33 participants returned the second questionnaire (86.8%). For each of the 33 participants, the answers of the first and second questionnaire were compared and it showed a reproducibility of 92–100% concerning questions, to which the answers are expected to be the same over time, and a reproducibility of 70–81% concerning questions wherein the

answers depend on how the participant feels at the time of answering the questionnaire and therefore the answers are likely to change over time. Therefore, the reproducibility of the questions used in this presentation was concluded satisfactory and even stable over a period of 2 years.

#### *Statistical methods*

$\chi^2$ -test was used for tables.  $\chi^2$ -test for trend was used for  $2 \times k$  tables with ordered categories.<sup>6</sup> To compare the means, *t*-test was used for parametric data. Five percent was chosen as level of significance.

## **Results**

The comparison between the responder and non-responder group with regard to gender, neurological level, para-/tetraplegia, Frankel classification, age at SCI, age at the time of follow-up, years since SCI and cause of SCI showed no statistically significant difference between the two groups.

#### *Frequency of incontinence*

The frequency of incontinence within the last 3 months is seen in Figure 1.

There was no statistically significant difference in frequencies of incontinence between groups with respect to gender, time of SCI (1956–1970, 1971–1980, 1981–1990) or age at follow-up (28–39 years, 40–49 years, 50–59 years, 60–84 years). Table 2 shows frequency of incontinence divided by para- and tetraplegics. There was a significant trend across the groups of incontinence with more paraplegics reporting daily incontinence compared with tetraplegics.

In the questionnaire, the participants estimated their present bladder-emptying function compared with that at the time of the initial discharge from CSCI (three categories: better, unchanged, worse). There was no statistically significant difference in the frequency of incontinence between the participants in the three categories. When analysing data, we found that significantly more participants, who found their bladder-emptying method to be a problem, experienced incontinence. Figure 2 shows the percentage of participants reporting incontinence from less than once a week to daily in each group of different bladder-emptying methods used at follow-up.

In 55% of the participants (130), at least one urodynamic investigation was present in the medical file. There was no difference in the frequency of incontinence between participants with suprasacral and infrasacral neurogenic bladder dysfunction (Table 3).

#### *Degree of incontinence*

In the questionnaire, the participants could report the degree of incontinence by four categories: small drips, minor leak, major leak and constant leak. It was possible to mark more than one degree. Table 4 shows the highest degree of incontinence reported by each participant as percentage of frequency of incontinence. We could not show a significant difference between frequency of incontinence and degree of incontinence.

**Table 1** Questions used in the study

**1. How do you empty your bladder?**

- Normal bladder emptying – as before the spinal cord injury.
- Suprapubic tapping
- Abdominal pressure
- Crede´ manoeuvre
- Clean intermittent catheterisation
- Sterile intermittent catheterisation
- Urethral indwelling catheter
- Suprapubic catheter
- Use of condom-catheter or diaper
- Sacral-anterior-root-stimulation
- Ileal conduit a.m. Bricker
- Reservoir bladder
- Other method, which?

**2. Have you within the last 3 months experienced urinary incontinence?**

- No
- Incontinence only when urinary tract infection
- Incontinence < once a week
- Incontinence > once a week but < daily
- Incontinence daily

**- If yes, state the degree of incontinence.**

- Small drips                       Minor leak
- Major leak                         Constant leak

**3. How is the incontinence handled?**

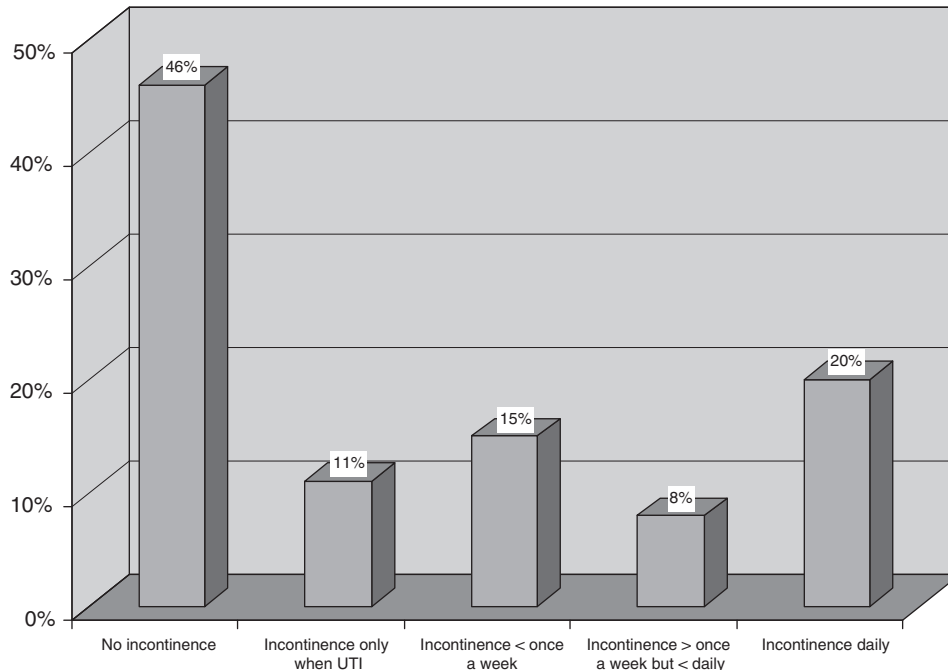
- Frequent bladder emptying
- Limited drinking
- Condom-catheter
- Diaper
- Sanitary towel
- Medication
- Problem not managed
- Other solution

**4. Do you find your bladder emptying to be a problem?**

- No                                       Yes, why ? \_\_\_\_\_

**5. How is the bladder emptying function now compared to the initial discharge from Clinic for Spinal Cord Injuries?**

- Better                                       Unchanged                                       Worse



**Figure 1** Frequency of incontinence within the last three months. ( $n = 221$ ). 15 participants did not answer the incontinence question. UTI, urinary tract infection.

**Table 2** Frequency of incontinence divided by paraplegia or tetraplegia

	No incontinence	Incontinence only when UTI	Incontinence < once a week	Incontinence > once a week and < daily	Incontinence daily
Paraplegia ( $n = 123$ )	37%	14%	15%	9%	25%
Tetraplegia ( $n = 98$ )	57%	8%	14%	6%	14%

Abbreviation: UTI, urinary tract infection.

A total of 15 participants did not answer the question. The variable 'No incontinence' is amalgamated with variable 'Incontinence only when UTI' before statistical testing.

### Management of the incontinence

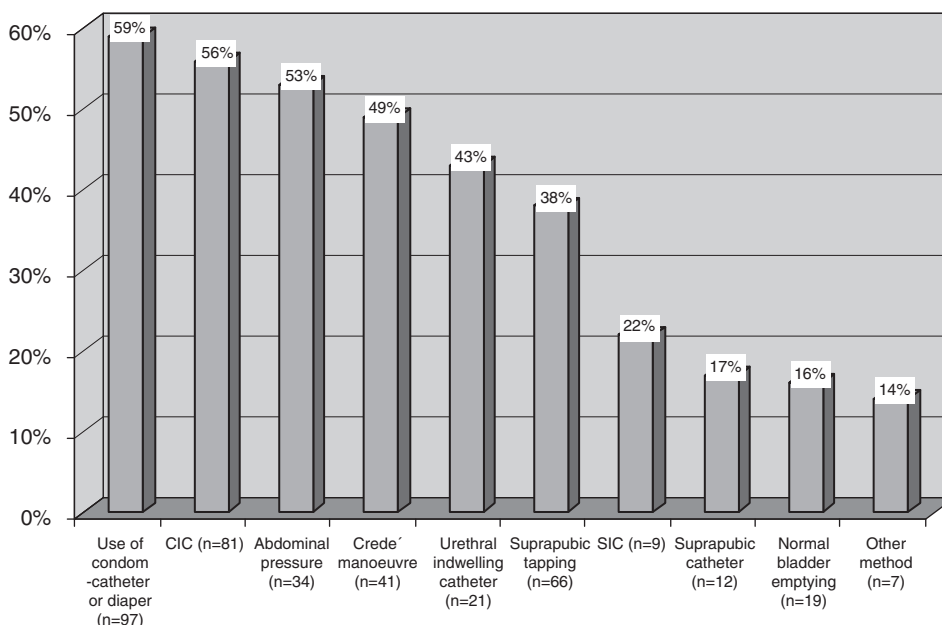
Figure 3 shows how the participants reported management of incontinence. A total of 28 participants (19%) reported use of medication. Of these, 11 used anticholinergic drugs against neurogenic detrusor overactivity, 18 used antibiotics, 13 of whom specified the use of long-term prophylaxis against urinary tract infection. Two participants used an alpha-blocker. Only three participants used two types of medication. There was no statistically significant difference in management of incontinence between groups with respect to age at the time of follow-up and how the bladder-emptying method was perceived.

### Discussion

To our knowledge, only few papers have described urinary incontinence and long-term SCI. Therefore, this study provides new information about individuals with SCI. Urinary incontinence was reported by 54% of the participants in this study, which indicates the importance of more

focus on this problem and possible solutions. An earlier study<sup>7</sup> described self-reported problems among patients with SCI more than 10 years after injury. On the basis of calculations of the data presented in the article, only 24% of the patients reported urinary incontinence. One explanation of this difference could be that data were not collected in the same way. In this study a questionnaire was filled in. In the study by Walter *et al.*,<sup>7</sup> the data were collected through a structured interview. Furthermore, they reported minor incontinence differently—with a single question for urinary incontinence.

It is important to notice that, although data from the questionnaire in this study are self-administered, the reproducibility of the data was very high, when tested 2 years after the initial emission of the questionnaire. A cross-check of the answers in a self-administered questionnaire would obviously be desirable, but unfortunately not possible in this study. Furthermore, it was not possible to obtain consistent and valid data concerning additional causes of incontinence in the participants such as prostatic or gynaecological disorders.



CIC = clean intermittent catheterisation. SIC = sterile intermittent catheterisation.  
Other method = reservoir bladder, ileal conduit a.m. Bricker, sacral-anterior-root-stimulation, haemodialysis.  
Number of participants using the different methods given in brackets ().

**Figure 2** Percent of participants reporting incontinence from less than once a week to daily in each group of the bladder-emptying methods used at follow-up. (*n* = 221). 15 participants did not answer the incontinence question. Notice that each participant may use more than one method of bladder emptying. CIC, clean intermittent catheterization. SIC, sterile intermittent catheterization. Other methods used are reservoir bladder, ileal conduit a.m. Bricker, sacral-anterior-root-stimulation, haemodialysis. Number of participants using the different methods is given in brackets.

**Table 3** Degree of incontinence divided by type of neurogenic bladder dysfunction found at the latest urodynamic investigation before follow-up

Neurogenic bladder dysfunction	No incontinence	Incontinence only when UTI	Incontinence < once a week	Incontinence > once a week and < daily	Incontinence daily
Suprasacral bladder ( <i>n</i> = 103)	46%	11%	14%	10%	20%
Infrasacral bladder ( <i>n</i> = 27)	37%	11%	19%	15%	19%

Abbreviation: UTI, urinary tract infection.

A total of 91 participants did not answer the incontinence question and/or did not have at least one urodynamic examination done. Of the remaining 145 participants, 15 had an inconclusive result of the urodynamic investigation. The variable 'No incontinence' is amalgamated with variable 'Incontinence only when UTI' before statistical testing.

**Table 4** Frequency of incontinence divided by degree of incontinence

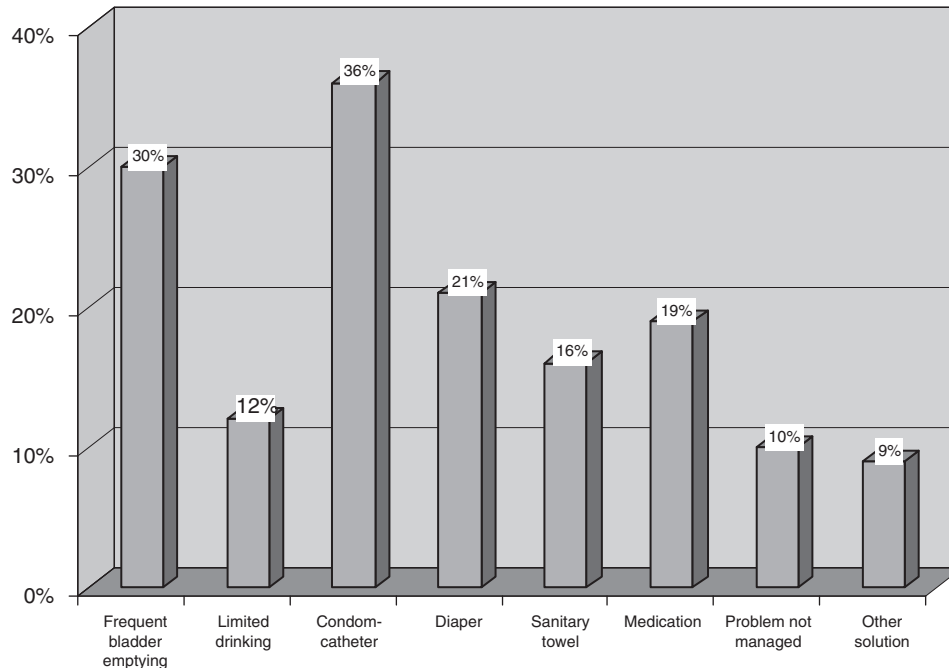
	Incontinence only when UTI	Incontinence < once a week	Incontinence > once a week and < daily	Incontinence daily
Small drips ( <i>n</i> = 23)	22 %	39 %	9 %	30 %
Minor leak ( <i>n</i> = 41)	27 %	24 %	20 %	29 %
Major leak ( <i>n</i> = 25)	12 %	20 %	20 %	48 %
Constant leak ( <i>n</i> = 12)	8 %	25 %	0 %	67 %

Abbreviation: UTI, urinary tract infection.

The participants, who were incontinent only when having a urinary tract infection, are left out when testing the table statistically. *n* = 101. Each participant is represented with the highest degree of incontinence reported in the follow-up questionnaire.

The majority (63%) experienced small drips or minor leak. Although there were no significant differences in frequency of incontinence in relation to degree of incontinence, there

seems to be a trend towards more frequent incontinence related to a higher degree of incontinence. Concerning bladder-emptying methods and incontinence, Figure 2



**Figure 3** Management of the incontinence. ( $n=151$ ). Notice that the participants may use more than one management method.

shows that 56% of the participants using clean intermittent catheterization (CIC) reported some kind of incontinence. This is nearly the same as found by Gray *et al.*,<sup>8</sup> who reported that 53% of individuals carrying out CIC experienced at least occasional leakage. CIC having the highest percentage of incontinence compared with the other bladder-emptying methods in this study could be because of selection, that is, those with severe incontinence problems are also those who change to CIC to decrease or eliminate the incontinence. Only 22% of participants using sterile intermittent catheterization reported some kind of incontinence compared with 56% of participants using CIC. One possible explanation is the limited number of participants using sterile intermittent catheterization. Another explanation could be that if sterile intermittent catheterization is needed as bladder-emptying method, the reason is most likely limited hand function, indicating tetraplegia. As mentioned earlier, we found a trend across the groups of incontinence with more paraplegics reporting daily incontinence compared with tetraplegics. In this study, we found no difference in the frequencies of incontinence between participants with suprasacral and infrasacral bladder dysfunction. The suprasacral bladder dysfunction is most likely related to neurogenic detrusor overactivity resulting in urge or reflex incontinence. The infrasacral bladder dysfunction is known to be related to detrusor areflexia and results in overflow incontinence.<sup>9</sup>

A total of 16% of the participants with normal bladder emptying reported incontinence. This is possibly because normal bladder emptying is not the same as normal bladder function. The incontinence reported by participants using urethral indwelling catheter or suprapubic catheter could be because of the catheter blocks, or bypasses and leaks.

The significant relation between perception of bladder-emptying method as a problem and incontinence was not unexpected. Earlier studies have shown neurogenic bowel and bladder problems to be associated with lower quality of life.<sup>1,2,10</sup>

The incontinence in this study is most often managed by condom-catheter (men only), frequent bladder emptying or the use of diaper/sanitary towel. Only 19% of the participants reported the use of medication, and in more than half of the cases the medicine was antibiotics as treatment or prophylaxis of urinary tract infection. An earlier study by Gray *et al.*<sup>8</sup> found pharmacotherapy to be the most common method to prevent leakage among spinal cord injured. Another study<sup>11</sup> showed the effect of anticholinergics in association with CIC or suprapubic catheters to avoid high intravesical pressure and upper tract damage. Both the high proportion of participants with incontinence and the limited percentage using pharmacotherapy against urinary incontinence in this study could be because of a reluctant or conservative approach by the health care professionals or insufficient urological follow-up of these patients. Individuals with SCI have urological investigations done routinely every second year, as part of their urological follow-up. It is possible that the focus of follow-up is on the results of these investigations, rather than the symptoms experienced by the patient.

## Conclusion

Urinary incontinence is common in both para- and tetraplegics, and in most methods of bladder management. Only a minority of individuals used medication against incontinence. The study indicates a need for larger attention towards incontinence to solve the problem.

## Acknowledgements

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