

**Urological complications  
10 - 45 years after  
a traumatic spinal cord injury.  
A follow-up study**

**Ph.D. thesis**

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## ARTICLES

This Ph.D.-thesis is based on the following articles:

Paper 1:

Hansen RB, Biering-Sørensen F, Kristensen JK. Bladder emptying over a period of 10 – 45 years after a traumatic spinal cord injury.

Submitted for publication.

Paper 2:

Hansen RB, Biering-Sørensen F, Kristensen JK. Urinary incontinence in spinal cord injured individuals 10 – 45 years after injury.

Submitted for publication.

Paper 3:

Hansen RB, Biering-Sørensen F, Kristensen JK. Urinary calculi following traumatic spinal cord injury.

Submitted for publication.

## PREFACE

This Ph.D. thesis is based on studies undertaken while I was a research fellow at Clinic for Para- and Tetraplegia, Rigshospitalet, Copenhagen University Hospital, Denmark.

The Ph.D. study is carried out under guidance from primary supervisor Fin Biering-Sørensen MD, DMSc, chairman of Clinic for Para- and Tetraplegia and supervisor Jørgen Kvist Kristensen MD, DMSc, chairman of Department of Urology, Rigshospitalet, Copenhagen University Hospital, Denmark. I am very grateful to both my advisors for all their inspiration and support through the whole project.

The great participation from the population of traumatic spinal cord injured has been an encouragement and an inspiration for me. I have had a good co-operation with the spinal cord injured patient association, former Paraplegikerkredsen, now RYK, which has contributed to this project especially concerning the follow-up questionnaire.

Further I would like to thank the medical doctors, physiotherapists, occupational therapists and nursing staff at Clinic for Para- and Tetraplegia for inspiration and help with developing the questionnaire.

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## INTRODUCTION

In 1994 the number of traumatic and non-traumatic spinal cord injured in Denmark was estimated to be 2500 - 3000 individuals with 90 - 130 newly injured individuals per year<sup>1</sup>. Approximately half of the traumatic spinal cord injuries were due to traffic accidents. The non-traumatic spinal cord lesions were the result of herniated discs, infections, tumours, a.v.malformations, myelomeningocele, etc. The spinal cord injury (SCI) incurs paresis/paralysis and reduced or absent sensibility below the level of injury. Apart from these complications there are also complications from other parts of the body e.g. the cardiovascular, pulmonary, urinary and gastrointestinal system, the skin and the muscles. Some of the complications occur immediately after the injury (primary complications) e.g. impaired bladder emptying and impaired respiration. Other complications occur over time after the injury (secondary complications) e.g. decreased renal function and pressure sores. The improved acute treatment and follow-up regimens for the spinal cord injured during the last 50 years have increased life expectancy for the population of spinal cord injured<sup>2</sup>. But how will the secondary complications develop with the increased lifetime? Earlier studies from other countries than Denmark have described different secondary complications years after a SCI<sup>3-10</sup>. In Denmark a similar study has not previously been done.

A SCI compromises the normal function of the urinary bladder. Different types of neurogenic bladder dysfunction result from SCI, depending on the localisation and completeness of the spinal cord lesion. The impaired bladder function incurs a risk of developing various urological complications, e.g. urinary tract infections, urinary stones, urinary incontinence and impaired renal function. Biering-Sørensen et al. have previously investigated the urological situation in Danish spinal cord injured five years after the SCI<sup>11</sup>. Bladder emptying in the normal population is done several times a day mostly without giving it much thought. In the population of SCI individuals, bladder emptying is a challenge to normal daily living. Hicken et al.<sup>12</sup> have reported impaired bladder control after spinal cord injury to be related to lower quality of life. Westgren et al.<sup>13</sup> earlier found neurogenic bladder problems to be associated with lower quality of life scores. Therefore bladder emptying is a very important issue for SCI individuals.

## **AIM**

The aim of this Ph.D.-study has been to investigate the urological situation for spinal cord injured 10-45 years after a traumatic SCI with emphasize on bladder emptying methods, urinary incontinence and urinary calculi. The data collection did also include information on the gastrointestinal system, pressure sores, pain, spasms, sexual function and aids. These data are to be analysed in the continuation of the Ph.D.-study.

## **MATERIAL**

The study included patients from the Clinic for Para- and Tetraplegia, Rigshospitalet, Copenhagen University Hospital, Denmark (CPT). The department has existed since November 1952. Initially the department rehabilitated polio victims, and over the year's patients with juvenile rheumatoid arthritis, Calve-Leg-Perthes disease, brain injuries, stroke and spinal cord lesions have been admitted. The emphasis has gradually changed, and during recent years CPT has only received patients with spinal cord lesions.

## **Inclusion**

The inclusion criteria were:

- 1) A traumatic SCI contracted before 1<sup>st</sup> of January 1991.
- 2) Participants still alive at the time of receiving a follow-up questionnaire.

Because of no complete list over the patients of the CPT, it was necessary to go through the medical archives manually. This was done twice with months in between to avoid missing files being out of the archive in connection to an admission or an examination. In addition old lists consisting names and date of birth of patients admitted to the CPT have been reviewed. In relation to another study at CPT, the medical files were revised by another investigator, who did not find additional traumatic spinal cord injured. 643 patients fulfilled the first inclusion criteria, 506 men and 137 women.

## **Exclusion**

Of the 643 patients, 364 patients were excluded from the project due to the following exclusion criteria:

- 1) The initial admission at CPT not in continuation of the acute admission (due to the SCI) at an orthopaedic or neurosurgical department (N=58).

This first criterion covered participants where the initial admission to the CPT was not a direct transfer from the emergency department, e.g. a neurosurgery department where the patient was initially admitted for the SCI.

2) Follow-up terminated from the CPT (N=264).

This criterion covered participants, who had their follow-up terminated from the CPT either due to completion of treatment as normal or near normal functioning, transfer to another hospital, emigration, or the participants did not wish to be followed at CPT.

3) Not followed at CPT since 1990 (N=32).

This criterion covered participants, who had not been followed at CPT since 1990 for unknown reasons.

4) Missing medical record (N=10).

This criterion covered participants, where the data missing in the medical record was so extensive, that it was insufficient for retrieval of the historical data found to be necessary for participation in the project.

## **Participants**

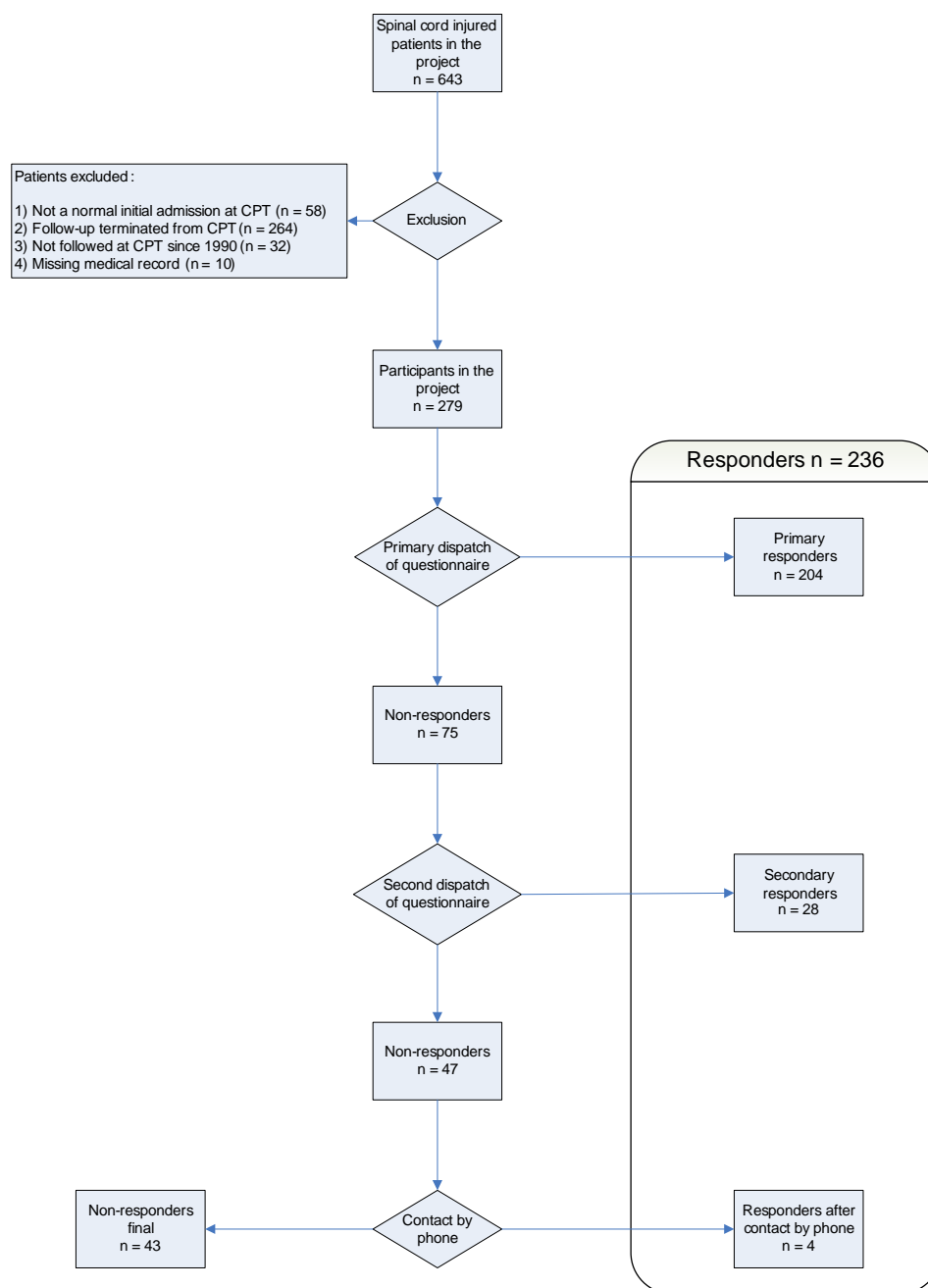
In all 279 (643-364) participants were included in the project, 228 men and 51 women injured between 1956 and 1990. They all received a questionnaire by mail with a pre-stamped return envelope. Approximately 2 months after the first dispatch of questionnaires a reminder with a new questionnaire was sent to those participants, who had not answered. 204 participants answered and returned their questionnaire after the first mailing, 28 participants after the second mailing.

Approximately 7 month after the primary dispatch of questionnaires, the patients who had not answered the questionnaire or given a reason for not answering (39 participants), were tried contacted by phone to elaborate the reasons why the questionnaire was not answered. Contact was achieved with 26 of the participants. During the telephone conversation the patients were not encouraged to participate in the project. Still 5 patients asked for and had a new questionnaire sent, and 4 of these patients answered and returned their questionnaire. In table 1 the reasons for not answering the questionnaire are shown and Figure 1 shows a flow chart of participants in the study.

**Table 1. Reasons for not answering the questionnaire.**

N=43

<b>Reasons for not answering the questionnaire</b>	<b>Number of patients</b>
Did not wish to participate, no specific reason	8
Laziness	4
The questions were too difficult	3
The questions were too personal	3
Had not received a questionnaire	3
Had submitted a questionnaire not received by the project	1
Had forgotten to answer the questionnaire	1
Found the questionnaire not relevant	1
Could not answer the questionnaire due to language problems	1
Could not answer the questionnaire due to mental problems	1
Did not receive the questionnaire because of missing address	4
Reason unknown, did not obtain contact via telephone	13



**Figure 1. Flow chart of participants in the study**

### Responders and non-responders

All together 236 participants answered and returned the questionnaire, 193 men and 43 women (82% / 18%) injured from 1956 to 1990, corresponding to a response-rate of 84.6 %. 86 % of these answered the first mailing, 12 % answered the second mailing and 2 % answered after the phone interview.

The age at the time of the study was 50.5 years in mean (SD 11.2, median 50.0, range 28.4-84.5), and follow-up time was 24.1 years in mean (SD 8.7, median 23.7, range 10.7-45.1). Concerning level of injury 126 participants were paraplegic and 110 tetraplegic, 102 complete and 134 incomplete according to Frankel et al.<sup>14</sup>.

The non-responder group consisted of 43 participants (279-236), 35 men and 8 women injured from 1960 to 1990. Table 2 shows the data for the responder and non-responder group regarding gender, para- or tetraplegia, neurological level of injury, complete- or incompleteness of injury, Frankel classification<sup>14</sup>, age at SCI, age at the time of the project, years since injury at the time of the project and cause of injury. None of these were found to be statistically significantly different between the responders and non-responders.

**Table 2. Comparison of the responder and non-responder group with regard to gender, neurological level, age at injury, age at the time of the project, years since injury, Frankel classification and cause of injury.**

		Responders N=236	Non-responders N=43	Statistic method	Significance value
Male / Female		193 / 43	35 / 8	$\chi^2$ test	P = 0.89
Paraplegia / Tetraplegia		126 / 110	25 / 18	$\chi^2$ test	P = 0.68
Neurological level	C1-C4	17	4	$\chi^2$ test (d.f.=2)	P = 0.72
	C5-C8	93	14		
	T1-T11	78	14		
	T12-S5	48	11		
Complete / Incomplete		102 / 134	21 / 22	$\chi^2$ test	P = 0.60
Frankel classification	A	102	21	$\chi^2$ test (d.f.=2)	P = 0.74
	B	48	7		
	C	21	2		
	D	59	13		
	E	6	0		
Age at SCI		Mean: 26.3, SD: 10.9	Mean: 25.6, SD: 10.2	T-Test	P = 0.7
Age at the time of the project		Mean: 50.5, SD: 11.2	Mean: 47.1, SD: 11.2	T-Test	P = 0.08
Years since SCI		Mean: 24.1, SD: 8.7	Mean: 21.5, SD: 8.1	T-test	P = 0.07
Cause of injury	Traffic accident	135	19	$\chi^2$ test (d.f.=3)	P = 0.20
	Fall to a level below	27	9		
	Fall on the same level	2	1		
	Hit by moving object	4	0		
	Crushing accident	12	1		
	Diving into shallow water	32	3		
	Sporting accident	10	4		
	Attempted suicide	7	3		
	Violence	2	1		
	Other	5	2		

The complete- or incompleteness of the lesion is defined according to the Frankel classification<sup>14</sup>: "A" is defined as a complete lesion. "B", "C", "D" and "E" are defined as incomplete lesions.

Concerning neurological level of injury, level C1-C4 was added to level C5-C8 to obtain values >4 per cell in Table 2.

Concerning Frankel classification, Frankel C, D and E were added up to obtain values >4 per cell. Regarding cause of injury "fall to a level below" and "fall on the same level" were added up, "diving into shallow water" and "sporting accident" were added up and "hit by moving object", "crushing accidents", "attempted suicide", "violence", and "other" were added up to obtain values >4 per cell.

## METHODS

### Data from medical files

First stage of the project was to review the medical files of all the included patients, primarily the medical records, the discharge letters and the results from investigations of the kidney and urinary tract. In some files copies of records of admissions at other departments were available and reviewed.

### *Pilot study*

The final information retrieved from the files was preceded by a pilot study of first 20 medical files, and later additional 50 medical files. It became obvious that a lot of the information expected to be available in the files was not so due to missing data or the fact that data could only be found in some of the files. One example is data concerning pressure sores. Seldom were the procedures of handling the pressure sores included in the medical record. Therefore it was decided that information concerning pressure sores should only be collected from the questionnaire. Another example is data concerning dislocation of vertebrae in connection to the spinal cord injury, which were not consistent in the files.

### *Data quality*

The varying existence and quality of data demanded a division of data into groups. Data were divided into three groups.

1) Data, which are present in most patient files, often in more than one connection for instance both in the medical record and the discharge letter. This gives a possibility of control and these data are therefore considered good and reliable:

Date of the initial admission at CPT

Diagnosis

Date of SCI

Cause of SCI

Date of admissions related to the SCI prior to admission at CPT

Level of fracture, if any

Date and type of operation of the SCI, if any

Other lesions at time of SCI

Investigations of the urinary tract and kidneys

Transfer to other departments during the initial admission at CPT

Serum creatinine at the initial discharge from CPT

Date of discharge

Discharge normal/not normal

2) Data, which are subject to some uncertainty because of inconsistency in appearance in the files and some discrepancy between discharge letter and medical record. Data are usable in analyses, but only when aware of the restrictions bound to these data:

Dislocation of vertebrae

Problems with respiration

Utilization of catheter or intermittent catheterisation at the initial admission at CPT

Utilization of catheter or intermittent catheterisation at the initial discharge from CPT

Urinary tract infections during the primary admission at CPT

Bladder emptying method at the initial discharge from CPT \*.

Bowel emptying method and use of laxative at the initial discharge from CPT \*.

\* = Data often only present in the discharge letter. When also present in the medical file it became obvious that the discharge letter often only mentioned the main procedure and not associated procedures. Therefore the main procedure concerning bladder and bowel emptying is reliable, but the possibility of missing some associated procedures used seldom by the participants is present.

3) Data, which are not present in all the files they are supposed to be in. These data are therefore considered not usable in analyses:

Skull traction treatment, if any

Cervical collar treatment, if any

Corset treatment, if any

Urinary tract infections after the SCI and prior to admission at CPT.

Additionally it was necessary to make rules to standardize the interpretation of the information from the medical files (Appendix 1).

Example 1: If the medical record says “ A normal urography prior to admission at the CPT” without stating the time of the examination, the examination time is set to be the day before the admission to CPT.

Example 2: If the result of an isotope renography examination was “equal function of the kidneys” the right/left percent is set to 50 %.

Until the beginning of the 1990-ies the routine urological follow-up at CPT included intravenous urography (IVU), which at that point changed to plain radiography of the abdomen and isotope renography. All investigations were recorded from the time the participants had their SCI to the time of the study. 70 % of the participants had a regular urological follow-up done every year or every second year. The remaining 30 % of the participants had the urological investigations done more irregularly i.e. years in between without investigations.

### **Data from the questionnaire**

The purpose of the questionnaire was to relate data from the medical files of the first admission at the CPT to present data and hereby give indications of how secondary complications develop. The experiences with the medical files mentioned above were important in developing the questionnaire because the data should relate to each other. Before composing the questionnaire, various aspects of secondary complications were discussed and the items for the questionnaire were chosen.

The construction of the questionnaire was based on the SCI base<sup>15</sup>, an electronic patient record and database containing information about the patients´ primary admission, status at discharge, nursing status, status at routine follow-up, physiotherapy status, occupational therapy status etc. Appropriate items from the SCI base were used to create the questionnaire.

As far as possible scales, questions and answer possibilities in the questionnaire were made similar or comparable to previously published standards<sup>16</sup>. Given the fact that the questionnaire in this study is self-reported, the published standards could not be followed completely as they are designed for an interview situation. Additionally some answer

possibilities were made slightly different. Experiences from an earlier study of reproducibility and validity of a questionnaire filled in by spinal cord lesioned individuals before regular follow-up<sup>17</sup> have been used to optimise the questions.

The questionnaire was further developed with assistance of different professionals working with rehabilitation of spinal cord injured patients. It was important that the questionnaire was easy to answer and easy to transfer into the database for further analyses.

The answers to the questions are mostly yes/no, a number or ticking off one or more answers possibilities. This construction makes the analyses simple and useful. The questionnaire is found in Appendix 2.

#### *Pilot study of the questionnaire*

Before the questionnaires were mailed to the participants in the main study, a pilot study was carried out including seven men with SCI (4 tetraplegic and 3 paraplegic). The results of the pilot study showed that the questionnaire was comprehensive to the patient group and easy to answer. In addition the questionnaire was presented to one female with SCI. Due to experiences from the pilot study and from the female with SCI, minor adjustments were made before sending the questionnaire to the participants. An electronic edition of the questionnaire was made in case some patients wanted to answer in that way. Only two participants used this possibility.

#### *The data transfer from the questionnaires*

All data from the questionnaires were transferred manually into the SCI-base in a data window resembling the questionnaire. In addition the Frankel classification of the patients<sup>14</sup> and the neurological level of injury at the time of the primary discharge from CPT were typed in the SCI base. The definition of the neurological level of the spinal cord injury is given as the last preserved segment.

The author was the keyboarder at all times. The questionnaires were typed in one time each. Various validation procedures were included in the data entry schemes to avoid mistakes in the typing process.

Example 1: It was only possible to type either yes or no to questions with yes/no answers.

Example 2: If there was a remark to an answer, it was only possible to type in the remark if the answer was typed in or ticked off.

Example 3: If an answer was a number, it was not possible to type in letters and it was restricted how many digits could be typed in.

Example 4: If questions were related like “If yes in question 4, what about...”, it was not possible to type in the answer to the question, if question 4 was not answered with a yes.

It was necessary to make different rules to standardize interpretation of answers out of the ordinary (Appendix 3).

Example 1: If noted defecation daily, it is typed as 3-7 times a week.

Example 2: If noted urinating every second hour it is typed as 8 times a day because normally a person is awake 16 hours per day.

#### *Validity of the process of typing data into the database*

Concerning the validity of the process of typing in the answers of the questionnaire into the database, 10 % (n=24) of the questionnaires were checked thoroughly a second time. The results showed that there were no wrong ticking of when comparing the questionnaires with the database. In one questionnaire a ticking off in question number 8 under bladder management was missing in the database. In three cases one remark to a ticking off in the questionnaire was not typed in the database, twice in the remark to question number 8 under bowel management and once in the remark to question number 2 under bladder management. In one remark under help at home in the questionnaire a wrong remark was typed in the database. In conclusion all questions except question number 8 in bladder management are valid, but if one would like to use the remarks to some of the questions, it would imply a thorough check of all the questionnaires. All data entries concerning the included data for the publications in this thesis were correct.

#### *Reproducibility of the questionnaire*

To investigate the reproducibility of the questionnaire an identical questionnaire was sent out approximately 2 years after the primary dispatch to 38 randomly chosen participants,

who had answered the first questionnaire initially. 33 participants responded (87 %, 24 males, 9 females). The answers from the second identical questionnaire were valued either to be or not be in accordance with answers from the first questionnaire. Answers in exact accordance were exactly the same in the two questionnaires. Answers with approximate accordance were answers, which were partly the same, e.g. an additional bladder emptying method ticked off or one bladder emptying method less ticked off or answers changed due to actual changes e.g. change of bladder emptying method noted by the participant.

We calculated how many answers from the second questionnaire, which were in accordance with answers to the first questionnaire. The results are given in percent. Kappa coefficients have often been used in contexts like this, but they may be misleading and are difficult to interpret<sup>18;19</sup>. Table 3 shows the results of the reproducibility test of the questionnaire for data used in this thesis including the three separate papers.

**Table 3. Reproducibility of the questionnaire concerning data used in the thesis.**

Questions in bladder management	In accordance with the first questionnaire		Not in accordance with the first questionnaire
	Exact	Approximate	
2. How do you empty your bladder? N=33	73%	27 %	0 %
3. If use of catheter please state type and numbers used per day. N=11	100 %	0 %	0 %
4. Do you find your bladder emptying to be a problem? N=30	70 %	0 %	30 %
5. Have you within the last 3 months experienced urinary incontinence? N=31	61 %	10 %	29 %
5a Degree of incontinence N=12	75 %	17 %	8 %
6. How is the incontinence handled? N=17	35 %	59 %	6 %
9. Have you changed bladder emptying method since your initial discharge from CPT? N=30	80 %	10 %	10 %
10. How is the bladder emptying function now compared to the initial discharge from CPT? N=31	65%	16 %	19 %

Question 2 was 100 % reproducible. Of the answers approximately in accordance, three answers changed to include clean intermittent catheterisation (CIC), which was described by the participants, five answers had the same method/methods ticked off but in combination with a new method and one answer was mistakenly placed in the wrong box. (Sterile intermittent catheterisation (SIC) instead of CIC, which was an obvious mistake, since the participant did not need any assistance and had no helpers). None of the answers were completely different from each other.

The answers to questions 4, 5, 5a and 10 depended on how the participant felt at the time of answering the questionnaire and were therefore likely to change over time.

In question 4 the answer possibility was yes or no. 9 participants answered completely different in the two questionnaires.

In question 5 the answer possibilities were a grading of the frequency of incontinence. Three answers were approximately the same. Nine answers were completely different.

In question 5a the answer was ticking off one or more different degrees of incontinence. 9 participants ticked off exactly the same, two participants ticked off partly the same and one participant ticked off completely different from first questionnaire.

In question 6 different management methods of incontinence were to be ticked off. 6 participants answered exactly the same, 10 participants ticked off partly the same methods as initially and one participant ticked off completely different from initially.

In question 9 three changed answers were due to real changes and three changed answers were completely different from the first questionnaire.

In question 10 five changed answers were due to real changes and six changed answers were completely different from the first questionnaire.

In the process of investigating the reproducibility of the questionnaire it became obvious that some of the participants did not always answer a yes in “drainage in condom-catheter or diaper” in bladder emptying method although they answered that they used condom-catheters or diapers in relation to incontinence. Therefore, to make the data uniform we consistently changed the answers for the relevant participants (N=59) with a yes to “drainage in condom-catheter or diaper” as bladder emptying method if the participant reported use of condom-catheter or diaper concerning incontinence. Consequently we changed the term to “ *use of condom-catheter or diaper*”, which then is more correct.

In the questionnaire the participants were asked if their bladder emptying method had changed since their initial admission at CPT and 47 % (N=109) reported that they had changed method, 53 % (N=123) reported that they had not changed method.

The answers to this question were compared to the data on bladder emptying method from the initial discharge and from the questionnaire. The result showed agreement in 95 % of the participants, who reported they had changed method and in 79 % of the participants

who reported that they did not change bladder emptying method since the initial rehabilitation. When considering the time span of 10-45 years this is to be considered a satisfactory recall.

One question in the questionnaire was taken out of analysis because of problems in understanding the question the way it was intended. The question was "Do you manage the bladder emptying yourself or do you need help?" If the answer was positive there was an elaborate question where the participants were asked to define the help they needed. When analysing the answers it became obvious that some patients understood help as assistance from another person, which was the intention but others understood help as anything that was used in the process e.g. a catheter. Of the 47 participants who answered positive to the question 57 % (N=27) showed that they understood the question as assistance from another person through the explanatory question, but 43 % (N=20) participants had obviously misunderstood the question or it was not clear how they understood the question. It was concluded that this question could not be used in this project.

The question concerning frequency of incontinence (in the questionnaire) has the following answer possibilities: no incontinence, only incontinence when urinary tract infection (UTI), incontinence < once a week, incontinence > once a week, but less than daily and incontinence daily. Obviously there is no answer for incontinence exactly once a week. This was discovered too late to make the appropriate changes, but fortunately no participants have reported any difficulties in answering the question.

43 % of the participants using urethral indwelling catheter reported daily incontinence. This could be due to incontinence along the catheter or maybe some of these participants interpret the function of the permanent catheter as incontinence. This illustrates clearly the interpretation problems in questionnaires, where the challenge for the constructor is to make the questions and answer possibilities simple and easy.

Four participants answered that they had an artificial bladder. When checking this information we found that one participant did not have an artificial bladder though reporting

this. This participant had reported numerous other methods and may have thought that the bladder was artificial because he/she did not have normal bladder emptying. The remark on artificial bladder was removed.

### **Statistics**

Chi squared test was used for tables (d.f = degrees of freedom). To compare means t-test was used. Five percent was chosen as level of significance.

In Paper 2 Chi squared test for trend was used for  $2 \times k$  tables with ordered categories. In Paper 3 the Kaplan-Meier method of cumulative calculus-free probabilities and the hazard rates (instantaneous probability rate) of both the first renal calculus and the first bladder calculus of all participants were estimated in accordance to standard life-table measures<sup>20</sup>.

## MAIN RESULTS

### Paper 1

#### **Bladder emptying over a period of 10 – 45 years after a traumatic spinal cord injury.**

*Objective:* To examine the bladder emptying methods at least 10 years after a traumatic spinal cord injury (SCI).

*Method:* Retrospective data collection from patient records and data collected with a follow-up questionnaire.

*Results:* The proportion of participants using suprapubic tapping fell from 57 % after the initial rehabilitation to 31 % at the time of follow-up, while intermittent catheterisation (Clean-(CIC)/Sterile-(SIC)) procedure increased from 13 % to 39 % during the same period. The proportion of participants using Credé manoeuvre rose from 5 % to 20 %. CIC was the most common method of bladder emptying at the time of follow-up. 46 % had completely changed bladder emptying method during follow-up, 25 % used the initial method in combination with one or more new methods and 29 % had not changed method. The results showed the following trends in change of method: a high proportion of discontinuation in normal bladder emptying, suprapubic tapping and abdominal pressure and a high proportion of continuation when using CIC. 28 % of the participants found their bladder emptying method to be a problem; significantly more of these were tetraplegics. The reasons for bladder management to be a problem were mainly related to finding and using toilets outside the home or incontinence problems. Of the participants using CIC, 89 % reported using hydrophilic-coated catheters.

*Conclusions:* Change of bladder emptying method among SCI individuals over time is common. Some of the changes in bladder emptying method are due to new knowledge in the area. CIC alone or in combination with another bladder emptying method is the most frequently used method of bladder emptying at the time of follow-up.

## **Paper 2**

### **Urinary incontinence in spinal cord injured individuals 10-45 years after injury.**

*Objective:* To evaluate urinary incontinence and management of the incontinence in a population of spinal cord injured (SCI) individuals.

*Methods:* Retrospective data collection from patient records and information from a follow-up questionnaire of traumatic SCI individuals at least 10 years after the injury.

*Results:* 43 % of the participants reported incontinence from less than once a week to daily, 11 % experienced only incontinence when having a urinary tract infection and 46 % experienced no incontinence. Significantly more paraplegics experienced some degree of incontinence compared to tetraplegics. Significantly more participants, who found their bladder emptying method to be a problem, experienced incontinence. 56 % of the participants, who used clean intermittent catheterisation as bladder emptying method reported some degree of incontinence. Based on 130 participants, classification of neurogenic bladder dysfunction found at the latest urodynamic investigation before follow-up showed no significant differences between types of neurogenic bladder dysfunction (suprasacral/infrasacral) concerning frequency of incontinence. 19 % used medication for management of the incontinence. Management of the incontinence divided by time of SCI showed that among the male participants injured between 20-30 years before follow-up there were significantly more who used condom-catheter when comparing with participants injured more than 30 years or less than 20 years before follow-up

*Conclusion:*

Urinary incontinence is a common problem in spinal cord injured individuals. More paraplegics compared to tetraplegics reported some degree of incontinence. The perception of bladder emptying as a problem is associated with incontinence. A higher proportion of participants using CIC as bladder emptying method reported incontinence compared to participants using other bladder emptying methods. A minority of participants used medication against incontinence.

### **Paper 3**

#### **Urinary calculi following traumatic spinal cord injury.**

*Objective:* To investigate the occurrence of renal and bladder calculi following a traumatic spinal cord injury and the possible relation to bladder emptying method.

*Method:* Retrospective data collection from patient records and a questionnaire follow-up of traumatic SCI individuals at least 10 years after the injury.

*Results:* 47 participants had at least one episode of renal calculi and 32 participants had at least one episode of bladder calculi during follow-up. The risk of first renal calculus and first bladder calculus was highest within the first 6 months post injury. The cumulative proportion of calculi-free participants 45 years post injury were 62 % concerning renal calculi and 85 % concerning bladder calculi. If no renal calculi within the first 2 years post injury, the risk of having the first renal calculi within the next 43 years is 34 %. For bladder calculi the corresponding risk of having the first bladder calculi within the next 43 years is 5 %. No significant differences were found regarding bladder emptying method and renal or bladder calculi. Participants with renal calculi or bladder calculi were not statistically significantly different from the remaining study group concerning gender, para- or tetraplegia and Frankel classification.

*Conclusions:* The risk of renal and bladder calculi is higher in the SCI population compared to the normal population. Bladder calculi appear primarily early post injury and renal calculi appear both initially and years after injury. Therefore it is important to follow SCI individuals with regularly urological investigations, already from the time of injury and life-long to avoid complications.

## DISCUSSION

### Material

As many as 364 individuals, corresponding to 57 %, were excluded from the project due to the exclusion criteria mentioned. The exclusion criteria are made in consideration of the study being a follow-up study, which requires a certain amount of data in the medical files during follow-up. Nevertheless the choice of excluding these individuals may have interfered with the representativeness of the material towards the entire population of traumatic spinal cord injured at CPT. The majority of the individuals were excluded due to termination of follow-up at CPT for different reasons. The individuals, who did not wish to be followed at CPT may be SCI patients with severe late complications. This is unknown but important to be aware of when interpreting the results.

Many studies have found that there are marked differences between those who do or do not respond to a questionnaire<sup>21</sup>. The comparison between the responder and non-responder group in this thesis with regard to gender, neurological level, para-/tetraplegia, Frankel classification<sup>14</sup>, age at SCI, age at the time of follow-up, years since SCI and cause of SCI showed no statistically significant differences between these two groups. The analysis of reasons for not answering the questionnaire in the non-responder group did not indicate any specific problems concerning the questionnaire.

The response rate in the main study was 84.6 %, which is very satisfactory but may also be related to the selection made with only those followed regularly being included.

Previous studies investigating traumatic spinal cord injured have reported similar gender ratio<sup>5-7;9;13;22-24</sup>, para-/tetraplegia ratio<sup>9;11;13;22-24</sup>, complete/incomplete ratio<sup>9;11;22-24</sup> and mean age at injury<sup>7;9;11;24</sup> as in this study.

Cause of injury in this study (Table 3) is comparable to a previous study on the same population<sup>25</sup> and to studies from other countries with a lifestyle similar to the Danish<sup>3;26</sup>. In all these studies traffic accidents are shown to be the most frequent cause of spinal cord injury. The percent of traffic accidents as cause of injury in Denmark has declined since 1975. This may be an effect of introduction of general speed limits in 1973 and compulsory use of seat belts on the front seats in 1976<sup>25</sup>.

A follow-up period of 10 to 45 years has the possibility of providing interesting data, but given the fact that some participants have only been followed for 10 years, it is an

important bias, when investigating incidents that may not appear until years after injury i.e. renal calculi, because some of the participants with the shortest follow-up period may not have had enough time to develop the calculi.

When all the above-mentioned comments are taken in consideration, the material is found to be representative for the population of traumatic spinal cord injured in Denmark following the regular follow-up regime.

## **Methods**

The existence and quality of data in the medical files was more limited than expected. The necessity to have different rules of standardization when handling data is mentioned. This of course restricted the results, because inevitably some of the standardizations changed some data. Yet it was the best solution but important to remember when interpreting the results.

Pilot studies are recommended in epidemiological literature<sup>21;27</sup>. In this study the two pilot studies were of crucial importance for the quality of data. Retrospective data concerning results of investigations were recorded only from the medical files at CPT. There may have been participants with investigations from other hospitals not described in the medical files at CPT. As mentioned 30 % of the participants had irregular urological follow-up according to the medical files at CPT. Therefore there may be episodes of urinary calculi, which have not been registered in the medical files at CPT. Consequently the numbers of urinary calculi in this study are to be viewed as minimum figures.

The questionnaire used in this thesis was developed for this study with the use of previous experience<sup>15-17</sup> and guidance from epidemiological literature<sup>21;27;28</sup>. Concerning the reproducibility of the questionnaire, the nature of the questions had to be taken into consideration, but both the validity of the process of typing into the database and the reproducibility of the questionnaire can be concluded to be satisfactory. Another study of the reliability of a self-reported measure of disease, impairment and function in patients with spinal cord dysfunction<sup>29</sup> showed a high reliability. The change of data concerning drainage in condom-catheter or diaper was found necessary in this study.

In conclusion both the retrospective data collection and the follow-up questionnaire have provided the study with reliable data, when making an appropriate selection of the data to be used as described above.

## Results

The participants in this study reported a large variety of different methods of bladder emptying. More than half of the participants (56 %) used a combination of methods, which indicates that the optimal bladder emptying regime in the daily routine sometimes demands combinations of more than one method. During follow-up 46 % completely changed bladder emptying method and 25 % partly changed method. This is in agreement with an earlier study<sup>11</sup>, which found an even higher percentage (58%) of complete change within a follow-up period of only five years. These changes of method could be due to advice from the professionals towards more appropriate methods, but there could also be individuals for whom the bladder emptying method used during admission was not suitable when returning to the daily environment. This indicates the importance of professional guidance of SCI individuals concerning choice of bladder emptying method, especially during the initial admission at a rehabilitation centre to find the optimal bladder emptying method for the daily routine at home, but also during the lifelong follow-up.

The most frequently used bladder emptying method at follow-up was CIC, which was also observed in previous studies<sup>3;11;30</sup> and is in agreement with recommendations<sup>31;32</sup>. The high continuation of CIC, (77 % remained on this method) during follow-up found in this study was surprising and not in agreement with earlier studies. One study of urological follow-up five years post injury<sup>11</sup> found a trend towards less intermittent catheterisation. Another study with 5 – 40 months of follow-up<sup>33</sup> found 52 % discontinuing CIC. 15 years of follow-up data from the Model Systems<sup>34</sup> showed use of intermittent catheterisation declining from 36% / 39% (male/female respectively) at discharge to 7% / 19% at 15 years of follow-up. One reason could be the longer time span in the present follow-up and the time passed since the other studies were carried out i.e. the acceptance of CIC is gradually increasing both among the SCI individuals and among the health care personnel. In addition, catheters are becoming easier to use, e.g. hydrophilic-coated catheters. The proportion of participants using Credé manoeuvre raised from 5 % to 20 %, most probably reflecting that it is an easy procedure when seated in a wheel chair. Still the professionals discourage it. One study found the Credé manoeuvre not to be safe for long-term use in spinal cord injury patients<sup>35</sup>. The high proportion of participants using hydrophilic-coated catheters in this study is positive. A recent study has shown that use of hydrophilic-coated catheters is associated with less hematuria and a significant

decrease in the incidence of urinary tract infections compared to use of conventional plastic catheters<sup>36</sup>.

Urinary incontinence from less than once a week to daily was found in 43 % of the participants in the present study. A previous study<sup>37</sup> on self-reported problems among SCI patients more than 10 years after injury, found 24 % (based on calculations of the data presented in the article) of the patients reporting urinary incontinence. One explanation to this difference could be that data were not collected in the same way. In the study by Walter et al.<sup>37</sup> data were collected through a structured interview. More than half of the participants using CIC (56 %) in the present study reported incontinence. This was the method with the highest rate of incontinence when not considering condom-catheter or diaper, which are incontinence devices. Gray et al.<sup>38</sup> found nearly the same as they reported 53 % of individuals performing CIC experiencing at least occasional leakage. Wyndaele et al.<sup>39</sup> found only 37 % of patients (calculated from figures mentioned in the paper) performing CIC for a mean of 7 years to be incontinent. CIC having the highest percentage of incontinence compared to the other bladder emptying methods in this study could be due to selection i.e. those with severe incontinence problems are also those who change to CIC to decrease or eliminate the incontinence or to decrease the potential complications related to high intravesical pressure due to neurogenic detrusor overactivity and / or detrusor sphincter dyssynergia.

Only one out of five (19 %) used medication against incontinence, which may be due to the side effects, which force the participants to use other management methods. This was surprising compared to another study<sup>38</sup> which found pharmacotherapy, used by 69 %, to be the most common method to prevent leakage among SCI individuals.

Ruutu et al.<sup>40</sup> found that the patients with mixed lesions and low compliance bladders, all paraplegics had the most severe incontinence problems, which is in line with the present study where significantly more paraplegics experienced some kind of incontinence. The significant relation between perception of bladder emptying method as a problem and incontinence was not unexpected. Likewise previous studies have shown neurogenic bowel and bladder problems to be associated with lower quality of life<sup>12;13;41</sup>

In the normal population in Denmark (and Scandinavia) 10-20 % of all males and 3-5 % of all females are expected to experience renal calculi during their lifetime<sup>42</sup>. In our study the risk of renal calculi was much higher than in the normal population, even though we did not

have life-long follow-up. The risk of first renal calculus was highest within the first 6 months post injury. This may well be related to the demineralisation in the months post injury<sup>43</sup>, corresponding to the finding of hypercalciuria in this period<sup>44;45</sup>. The hazard rate of renal calculi in our study is similar to hazard rates from previous studies on renal calculi<sup>46;47</sup>, when comparing the first 10 years and 8 years post injury respectively, which are the follow-up periods of the mentioned studies. Kohli et al.<sup>48</sup> earlier examined factors that might influence kidney stone formation in SCI patients and found no relationship between kidney stone formation and methods of urinary drainage, which corresponds to the results in this study.

The risk of bladder calculi was higher compared to the normal population because bladder calculi are not expected to develop in the normal population, but only in patients with bladder outlet obstruction<sup>49</sup>. The risk of first bladder calculus is highest within the first 6 months post injury. The hazard rate peak of bladder calculi in this study is much higher after the first 6 months post injury (0.131, 95% CI=0.11 - 0.16) compared to the study by DeVivo et al.<sup>50</sup>. They found the hazard rate peak, estimated from the Figure in the paper, to be approximately 0.047 after 3 months, declining hereafter. An earlier study<sup>50</sup> has showed that an indwelling Foley catheter at the time of discharge makes the patient 6.1 times more likely to develop bladder stones within 2 years of discharge compared to patients with normal micturition. In our study there was likewise a non-significant trend towards more participants with bladder calculi using indwelling catheters.

The cumulative proportion of participants without renal calculi 10 years post injury was 90% (SE=2%), which is comparable to other studies with 8 and 10 years of follow-up<sup>46;47</sup> respectively. Bladder calculi appear primarily in the early years post injury and renal calculi appear both initially and years after injury. This emphasizes the importance of following the SCI individuals with urological investigations already immediately after the injury and life-long to avoid complications.

## CONCLUSION

The material in this study was found to be representative for the population of traumatic spinal cord injured in Denmark following the regular follow-up regime. Both the retrospective data collection and the follow-up questionnaire have provided the study with reliable data. The results showed that changing of bladder emptying method among SCI individuals over time is common. Some of the changes are due to new knowledge in the area i.e. the recommendation of CIC as bladder emptying method, but still some changes are against recommendations. Therefore it is important to give spinal cord injured individuals as much information as possible on this issue to limit the possibility of complications. The most frequently used bladder emptying method in the SCI population was CIC, which is in agreement with recommendations. Further was there a high continuation of CIC during follow-up, which is unique, when comparing with other studies. Urinary incontinence was in this study found to be a common problem in the SCI population. The use of CIC as bladder emptying method was related to a higher rate of incontinence compared to the other bladder emptying methods. Only a limited part of the participants in this study used medication against incontinence. More paraplegics compared to tetraplegics reported some degree of incontinence. Not surprisingly the perception of bladder emptying as a problem was associated with incontinence. The risk of renal and bladder calculi is higher in the SCI population compared to the normal population. Bladder calculi appear primarily in the early years post injury and renal calculi appear both initially and years after injury. Therefore it is important to follow SCI individuals with regularly urological investigations, already from the time of injury and life-long to avoid complications.

## PERSPECTIVES

The large variety of bladder emptying methods, the frequency of urinary incontinence and the risk of having urinary calculi post injury emphasizes the necessity of the urological follow-up of spinal cord injured life-long.

The high frequency of incontinence among participants using CIC as bladder emptying method should be further investigated to understand and maybe avoid the problem.

Management of incontinence is another interesting subject for further evaluation.

Especially concerning the limited number of participants using medication to manage incontinence. It could be interesting to study the group of participants with incontinence with regard to use of medication. Treatment of incontinence in the SCI population with neurogenic detrusor overactivity with botulinum-A toxin injected into the detrusor muscle may provide a better solution to the incontinence problem for this group of SCI individuals<sup>51;52</sup>.

This study contains more information than the urological data presented. The participants have also been asked about bowel emptying, spasms, pain, pressure ulcers, sexual function and aids. It is obvious to use these data in further analysis.

The 264 individuals excluded from this study due to termination of follow-up at CPT, could be an interesting group to investigate. The characteristics of this group is unknown, because they are no longer connected to CPT. It could be interesting to see which complications these individuals have, but also how many of these individuals having normal or near normal bladder function.

## SUMMARY

The spinal cord injury incurs paresis/paralysis and reduced or absent sensibility below the level of injury. Apart from these complications there are also complications from other parts of the body occurring either immediately or over time after the injury. The aim of this Ph.D.-study has been to investigate the urological situation for spinal cord injured 10-45 years after a traumatic SCI with emphasize on bladder emptying methods, urinary incontinence and urinary calculi.

The methods were retrospective data collection from patient records and a follow-up questionnaire of traumatic spinal cord injured individuals at least 10 years after the injury. 279 participants were included in the project. They all received a follow-up questionnaire. In all 236 spinal cord injured individuals answered the questionnaire, corresponding to a response-rate of 84.6 %, 82 % (193) men and 18 % (43) women, injured from 1956 to 1990.

The material in this study was found to be representative for the population of traumatic spinal cord injured in Denmark following the regular follow-up regime. Both the retrospective data collection and the follow-up questionnaire have provided the study with reliable data. The results showed that changing of bladder emptying method among SCI individuals over time is common. Some of the changes are due to new knowledge in the area i.e. the recommendation of CIC as bladder emptying method, but still some changes are against recommendations. Therefore it is important to give spinal cord injured individuals as much information as possible on this issue to limit the possibility of complications. The most frequently used bladder emptying method in the SCI population was CIC, which is in agreement with recommendations. Further was there a high continuation of CIC during follow-up, which is unique, when comparing with other studies. Urinary incontinence was in this study found to be a common problem in the SCI population. The use of CIC as bladder emptying method was related to a higher rate of incontinence compared to the other bladder emptying methods. Only a limited part of the participants in this study used medication against incontinence. More paraplegics compared to tetraplegics reported some degree of incontinence. The perception of bladder emptying as a problem was not surprisingly associated with incontinence.

The risk of renal and bladder calculi is higher in the SCI population compared to the normal population. Bladder calculi appear primarily in the early years post injury and renal

calculi appear both initially and years after injury. Therefore it is important to follow SCI individuals with regularly urological investigations, already from the time of injury and life-long to avoid complications.

## DANISH SUMMARY/DANSK RESUME

En rygmarvsskade medfører, at der under niveauet for skaden kommer hel eller delvis lammelse af kroppens ekstremiteter og påvirket sensibilitet. Udover disse komplikationer opstår også komplikationer fra andre dele af kroppen, enten umiddelbart efter skadens opståen eller senere. Formålet med dette Ph.d.-studie var at undersøge den urologiske situation for rygmarvsskadede 10 – 45 år efter en traumatisk rygmarvsskade med hovedvægten lagt på blæretømningsmetoder, urin inkontinens og sten i urinvejene.

I studiet indgik dels retrospektive oplysninger fra patientjournaler, dels besvarelserne af et spørgeskema.

279 deltagere med en traumatisk rygmarvsskade mindst 10 år tidligere fik tilsendt et spørgeskema. I alt besvarede 236 rygmarvsskadede spørgeskemaet, svarende til 84.6 %, 82 % (n=193) var mænd og 18 % kvinder (n=43), tilskadekommet i perioden fra 1956 til 1990. Deltagerne i dette studie fandtes repræsentative for populationen af traumatisk rygmarvsskadede i Danmark, som følger det almindelige kontrol regime for rygmarvsskadede. Både den retrospektive dataindsamling og spørgeskemaet vurderedes at give pålidelige data.

Resultaterne viste at skift i blæretømningsmetode hos rygmarvsskadede i årene efter skaden er almindelige. Nogle af skiftene skyldes ny viden indenfor området, som for eksempel anbefalingen af intermitterende kateterisation som blæretømningsmetode, men nogle skift er imod de normale anbefalinger for rygmarvsskadede. Det er således fortsat vigtigt at give rygmarvsskadede så meget information som muligt for at begrænse risikoen for komplikationer mest muligt. Den hyppigst anvendte blæretømningsmetode blandt de rygmarvsskadede var ren intermitterende kateterisation, hvilket er i overensstemmelse med de almindelige anbefalinger. Der fandtes også at mange fortsatte brugen af ren intermitterende kateterisation, hvilket er et overraskende positivt resultat for dette studie sammenlignet med tidligere studier.

Urin inkontinens viste sig at være et almindeligt problem blandt rygmarvsskadede. Brugen af ren intermitterende kateterisation som blæretømningsmetode var relateret til flere inkontinente rygmarvsskadede sammenlignet med de andre blæretømningsmetoder. Kun et begrænset antal af deltagere i studiet brugte medicinering mod inkontinens. Flere paraplegikere sammenlignet med tetraplegikere rapporterede inkontinens. Opfattelsen af blæretømningen som et problem var ikke overraskende relateret til inkontinens.

Risikoen for at få nyre- og blæresten var højere i populationen af rygmarvsskadede i forhold til normal befolkningen. Blæresten opstod oftest i de første år lige efter rygmarvsskadens opståen, hvorimod nyresten opstod både initialt og i årene efter. Det er derfor vigtigt at kontrollere nyrer, blære og urinveje hos de rygmarvsskadede fra lige efter rygmarvsskadens opståen, men også livslangt grundet risikoen for urinvejssten, urininkontinens mv. for om muligt at følge op med nødvendige tiltag i relation hertil.

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## APPENDICES (In Danish)

### Appendix 1

Rules of standardization of data transfer from patient files to the SCI-base.

1. Oversættelse: Forår: marts-maj  
Sommer: juni-august  
Efterår: september-november  
Vinter: december-april  
Indlæggelse efterår 1995 = 1/9-95  
Seponering af kateter sommer = 1/7.
2. Ved angivelse af måned eller år skrives altid den 1. i måneden eller 1/1 i året.
3. Tilskadekomst mellem den 25. og 26. medfører datoen sættes til den 26.
4. Kateter seponeret efter 2-3 måneder registreres som 2 måneder.
5. Dato for undersøgelser i journalerne er ud fra det dikterede svar's dato, da undersøgelsesvar ikke foreligger i journalen.
6. Ved seponering af kateter før indlæggelse på Fysiurgisk Hospital i Hornbæk (FHH, nu CPT) uden nærmere datoangivelse angives seponeringsdatoen til dagen før indlæggelsen på FHH.
7. Hvis der ikke findes et serum-creatinin svar på blodprøvearket i journalen med den præcise dato for undersøgelsen, tages det serum-creatinin svar, der er anført i epikrisen samt datoen for udskrivelse.
8. Når der ikke står andet end stikpille samt afføring hver 2. dag registreres dette som "normal afføring" med brug af stikpille.

9. Hvis der i den neurokirurgiske journal blot står "urografi viser normale forhold" uden datoangivelse, fastsættes datoen for undersøgelsen til dagen før overflytning til FHH.
10. Efter få dage tolkes som efter 3 dage.
11. Hvis cystoskopi med stenfjernelse er på en angivet dato og den forudgående iv-urografi som viser blæresten, er uden angivet dato, sættes datoen for iv-urografien til 1 uge før cystoskopian.
12. Opstartet intermitterende kateterisation ved personale under den neuro-/ortopæd kirurgiske indlæggelse uden angivet dato sættes datoen til dagen før indlæggelsen på FHH.
13. Alle prøvesvar samt journalnotater om prøvesvar registreres. Resumemarket er kun anvendt i det omfang den pågældende undersøgelse kan ses i journalen og hvor svaret ikke kan findes andre steder.
14. Hvis der i et renografisvar står angivet ligelig fordeling af nyrerne angives funktionsfordelingen til at være 50 %.
15. Ved seponering af kateter under indlæggelsen på FHH uden nærmere dato angivet, sættes datoen til dagen før udskrivelse fra FHH.

## Appendix 2

The follow-up questionnaire

### VANDLADNING:

1. Klarer du selv vandladningen eller har du brug for hjælp ?

- Klarer selv vandladningen
- Har brug for hjælp til vandladningen. Hvilken hjælp ? \_\_\_\_\_

2. Hvordan lader du vandet ? Du må gerne sætte flere krydser. Til højre kan du skrive hvornår eller i hvilke situationer, du bruger den angivne vandladningsmetode.

Hvornår

- |  |       |
|--|-------|
| <input type="checkbox"/> Normal vandladning - som før rygmarvsskaden.                      | _____ |
| <input type="checkbox"/> Bankeblære (ved bankning på maven evt. en finger i endetarmen)    | _____ |
| <input type="checkbox"/> Bugpres (dvs. bruger mavemusklernerne)                            | _____ |
| <input type="checkbox"/> Presseblære (tryk på maven med f.eks. hånden)                     | _____ |
| <input type="checkbox"/> Selvkateterisation (RIK)  | _____ |
| <input type="checkbox"/> Kateterisation ved hjælper (RIK/SIK)                              | _____ |
| <input type="checkbox"/> Fast kateter igennem urinrøret                                    | _____ |
| <input type="checkbox"/> Topkateter (kateter sat ind i blæren gennem huden over skambenet) | _____ |
| <input type="checkbox"/> Lader vandet / løber af sig selv f.eks. i ble eller uridom        | _____ |
| <input type="checkbox"/> Brindley stimulator (tømming ved elektrisk stimulation)           | _____ |
| <input type="checkbox"/> Brickerblære (urinen ført ud i siden på maven med pose henover)   | _____ |
| <input type="checkbox"/> Kunstig blære (indvendig tarmlære, tømmes med kateter)            | _____ |
| <input type="checkbox"/> Anden metode, hvilken ? _____                                     | _____ |

3. Hvis du bruger kateter angiv da:

Type/typer \_\_\_\_\_

Hvor mange bruger du til daglig ? \_\_\_\_\_

4. Opfatter du din vandladning / måde at tømme blæren på som et problem ?

Nej  Ja, hvorfor ? \_\_\_\_\_

5. Har du indenfor de sidste 3 måneder været utæt for urin (inkontinent) ?

Nej

Ja, kun i forbindelse med blærebetændelser

Ja, mindre end 1 gang pr. uge i gennemsnit

Ja, mere end 1 gang pr. uge, men mindre end 1 gang dagligt i gennemsnit

ja, dagligt

- Hvis ja, angiv graden af utæthed.

Du må gerne sætte flere krydser.

Små dryp

Mindre siven af urin

Mere siven af urin

Konstant siven af urin

6. Hvordan håndterer du utæthed for urin ?

Du må gerne sætte flere krydser.

Meget hyppige blæretømninger, hvor mange gange dagligt i gennemsnit ? \_\_\_\_\_

Begrænset væskeindtagelse

Anvender uridom, - hvis ja, hvor mange dagligt i gennemsnit ? \_\_\_\_\_

Anvender ble, - hvis ja, hvor mange dagligt i gennemsnit ? \_\_\_\_\_

Anvender bind / dråbesamler, - hvis ja, hvor mange dagligt i gennemsnit ? \_\_\_\_\_

- Tager medicin, - hvis ja, hvilke præparater ? \_\_\_\_\_
- Problemet ikke løst
- Andet - hvordan ? \_\_\_\_\_

7. Hvor mange gange har du været i behandling med antibiotika (penicillin, sulfa eller andet) imod blærebetændelse indenfor de sidste 3 måneder ?

Antal: \_\_\_\_\_

8. Har du indenfor de sidste 3 måneder været i langtidsbehandling med antibiotika imod blærebetændelser ?

Nej

Ja

- Hvis ja, hvilken medicin ? \_\_\_\_\_

9. Har du ændret vandladningsmetode siden du første gang blev udskrevet fra Fysiurgisk Hospital i Hornbæk ?

Nej

Ja, beskriv \_\_\_\_\_

---

10. Set i forhold til da du første gang blev udskrevet fra Fysiurgisk Hospital i Hornbæk hvordan fungerer vandladningen nu ?

Bedre

Uændret

Dårligere

**TARMTØMNING (AFFØRING):**

1. Klarer du selv tarmtømningen eller har du brug for hjælp ?

- Klarer selv tarmtømningen
- Har brug for hjælp til afføring, hvilken ? \_\_\_\_\_

2. Hvilken afføringsmetode anvender du ?

Du må gerne sætte flere krydser

- Normal tømning, som før rygmarvsskaden
- Tømning efter stimulation med finger eller bankning
- Bugpres (dvs. bruger mavemusklerne)
- Presse uden på maven, f.eks. med hånden
- Tømning med finger
- Ukontrolleret, kommer af sig selv
- Stomi (tarmen tømmes gennem huden på maven i en pose)
- Tarmskylning med kateter nedefra - Højt skyl (transanal irrigation)
- Brindley stimulator (tømning ved elektrisk stimulation)
- Anden metode, hvilken ? \_\_\_\_\_

3. Opfatter du din afføringsmetode som et problem ?

- Nej
- Ja, hvorfor ? \_\_\_\_\_

4. Hvor ofte har du haft afføring i gennemsnit over de sidste 3 måneder ?

- 0-2 gange pr. uge
- 3-7 gange pr. uge
- Mere end 7 gange pr. uge



- Hvis ja, hvordan håndterer du hård afføring ?

Du må gerne sætte flere krydser.

- Drikker mere end normalt
- Ændrer kosten
- Anvender medicin kortvarigt i perioder, hvilken medicin ? \_\_\_\_\_
- Problemet ikke løst
- Andet - hvordan ? \_\_\_\_\_

8. Har du indenfor de sidste 3 måneder dagligt anvendt medicin til regulering af tarmtømningen ?

- Nej
- Ja

- Hvis ja, hvilken medicin (såvel tabletter, kapsler, stikpiller, klyx og klysma) ? \_\_\_\_\_

---

9. Har du nogensinde fået konstateret hæmorider af en læge eller sygeplejerske ?

- Nej
- Ja

10. Set i forhold til første gang du blev udskrevet fra Fysiurgisk Hospital i Hornbæk, er den tid, du nu bruger på at komme af med afføringen blevet:

- Kortere
- Uændret
- Længere

11. Set i forhold til første gang du blev udskrevet fra Fysiurgisk Hospital i Hornbæk, hvordan fungerer tarmtømningen nu ?

- Bedre
- Uændret
- Dårligere

**SÅR:**

1. Har du indenfor det sidste år haft et eller flere ligge- eller siddesår opstået på grund af tryk (tryksår) ?

Nej  Ja

- Hvis ja, har det pågældende sår haft konsekvenser i form af:

Du må gerne sætte flere krydser

- Behov for aflastning
- Regelmæssig kontrol ved sygeplejerske
- Hindring af dine normale dagligdagsaktiviteter
- Indlæggelse
- Operation
- Andet, hvad ? \_\_\_\_\_

2. Hvad gør du for at undgå at få tryksår ? Du må gerne sætte flere krydser.

- Stemmer op fra stolen flere gange dagligt
- Aflaster i seng mindst 1 gang i løbet af dagen
- Kontrollerer huden bagpå dagligt
- Gør ikke noget
- Andet - hvilket ? \_\_\_\_\_

3. Har du nogensinde haft problemer med tryksår ?

Nej  Ja

- Hvis ja, er problemerne med tryksår over årene blevet:

Bedre  Uændret  Værre

**SPASMER:**

1. Har du spasmer ?

 Nej                       Ja

- Hvis ja, er spasmerne så kun til stede i forbindelse med blærebetændelse, sår eller andre specielle forhold ?

 Nej                       Ja

2. Kan du bruge spasmerne i dagligdagen ?

 Nej                       Ja

3. Får du behandling mod spasmerne ?

 Nej                       Ja

- Hvis du får behandling, udfyld da nedenstående ud fra et gennemsnit over de sidste 3 måneder

	Effekt			Antal
	god	middel	dårlig	
<input type="checkbox"/> Udspændinger				
gange pr. uge _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<input type="checkbox"/> Ståbord / ståstøttestol / stativer				
Antal timer pr. uge _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<input type="checkbox"/> Medicin, hvilken ? _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<input type="checkbox"/> Andet, hvad ? _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

4. Har du nogensinde haft problemer med spasmer ?

 Nej                       Ja

- Hvis ja, er problemerne med spasmer over årene blevet:

 Bedre                       Uændret                       Værre

**SMERTER:**

1. Har du smerter ?

- Nej  Ja

- Hvis ja, hvor ofte er smerterne til stede ?

- Mindre end 1 gang om ugen i gennemsnit
- Mere end 1 gang om ugen, men mindre end 1 gang dagligt i gennemsnit
- Dagligt

2. Kryds af hvor du har smerter og om du får behandling mod smerterne. Du må gerne sætte flere kryds.

	<u>Får du behandling mod smerterne ?</u>	
	Ja	Nej
<input type="checkbox"/> Nakken	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Skuldre	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Albuer	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Håndled	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Brystkasse	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Mave	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Hofter	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Endeballer	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Lår	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Knæ	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Skinneben	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Fødder	<input type="checkbox"/>	<input type="checkbox"/>

<input type="checkbox"/> Ryg	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Andre steder: _____	<input type="checkbox"/>	<input type="checkbox"/>

- Hvis du får behandling, udfyld da nedenstående ud fra et gennemsnit over de sidste 3 måneder.

		<u>Effekt</u>		
		god	middel	dårlig
Fysioterapi:				
Hvilken form ?	Hvor ofte ?			
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicin:				
Navn				
_____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andet, hvilken behandling ?				
_____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Har du nogensinde haft problemer med smerter ?

Nej                       Ja

- Hvis ja, er problemerne med smerter over årene blevet:

Bedre                       Uændret                       Værre

**SEXUALFUNKTIONEN:**De næste spørgsmål 1-7 skal kun besvares af mænd

1. Kan du få rejsning (erektion) ?

 Nej
  Ja
  Ej forsøgt

- Hvis ja, er rejsningen da:

 Spontan/ufrivillig
  Bevidst

2. Hvordan er rejsningen ?

 Hård (normal)
  Blød

3. Anvender du eller har du anvendt nogle af følgende hjælpemidler for at opnå rejsning ?

Du må gerne sætte flere krydser. Til højre er der plads til kommentarer med hensyn til effekten.

Kommentarer til effekten

<input type="checkbox"/> Pubesring	_____
<input type="checkbox"/> Viagra - tabletter/piller	_____
<input type="checkbox"/> Vibration	_____
<input type="checkbox"/> Indsprøjtning i penis (Caverject eller lign.)	_____
<input type="checkbox"/> Vakuumpumpe	_____
<input type="checkbox"/> Andet	_____

4. Kan du få sædudtømmning (ejakulation) ?

 Nej
  Ja
  Ej forsøgt

5. Har du nogensinde fået sædudtømning ved hjælp af nedenfor nævnte hjælpemidler ? Du må gerne sætte flere krydser. Til højre er der igen plads til kommentarer med hensyn til effekten.

	Kommentarer til effekten
<input type="checkbox"/> Vibration	_____
<input type="checkbox"/> Elektrostimulation	_____
<input type="checkbox"/> Andet	_____

6. Har du efter skaden gjort en kvinde gravid ?

Nej                       Ja

- Hvis nej, skyldes det at du på grund af rygmarvsskaden havde problemer med at gøre din partner gravid ?

Nej                       Ja

- Hvis ja, havde du behov for speciel hjælp til at gøre din partner gravid ?

Nej                       Ja, hvilken ? \_\_\_\_\_

7. Er du tilfreds med dit sexullev ?

Ja

Nej, hvorfor ikke ? \_\_\_\_\_

\_\_\_\_\_

**SEXUALFUNKTIONEN:**

De næste spørgsmål 1-5 skal kun besvares af kvinder

1. Hvordan er din menstruation ?

Regelmæssig       Uregelmæssig       Ingen menstruation

2. Har du problemer med at være meget tør i skeden ?

Nej                       Ja

3. Får du nogen form for behandling i relation til eventuelle problemer med menses og skedeseekretion ?

Nej

Ja, hvilken ? \_\_\_\_\_

4. Har du efter skaden født børn ?

Nej                       Ja

- Hvis ja, har du da fået ekstra hjælp fra de sociale myndigheder i relation til barnet ?

Nej

Ja, hvilken ? \_\_\_\_\_

5. Er du tilfreds med dit sexualliv ?

Nej, hvorfor ikke ? \_\_\_\_\_

Ja

**HJÆLPEMIDLER:**

Her er en liste over hjælpemidler. Sæt kryds ud for det du bruger. Du må gerne sætte flere krydser.

**Mobilitet:**

- Stok/stokke
  - Rollator
  - Glidebræt ("Banan")
  - Hjulbeskytter ved forflytninger ("Reje")
  - Manuel kørestol
  - Elektrisk kørestol
  - 3-hjulet el-køretøj (Minicrosser eller lignende)
  - Håndcykel
  - Ståbord
  - Ståstøttestol
  - Skinner til arme
  - Skinner/stativer til ben, herunder dropfodsskinne
  - Elektrisk stimulering til forbedring af gangfunktionen
  - Andet \_\_\_\_\_
- 

**Toilet og bad:**

- Toiletforhøjer
- Støttegreb i badeværelse
- Elektrisk tandbørste
- Badestol / brusesæde

- Gribetang
  - Højdeindstillelig håndvask eller specialhåndvask
  - Andet \_\_\_\_\_
- 

**Indretning i hjemmet:**

- Støttegreb i hjemmet udover i badeværelset
  - Elektrisk seng
  - Special madras
  - Lift
  - Hvilestol
  - Arbejdsstol
  - Computer
  - Computerbord
  - Andet \_\_\_\_\_
- 

**Køkkenændringer:**

- Rullebord
- Køkkenværktøj eller bestik med specialgreb
- Hæve / sænke-køkkenbord
- Hæve / sænke-skabe
- Andet \_\_\_\_\_

**Hjemmebehandling:**

- Respirator
- CPAP/BIPAP ( hjælpemiddel til vejrtrækningen )
- Maske til vejrtrækningstræning
- Andet \_\_\_\_\_
- 

**Praktisk hjælp:**

- Hjælpere  
- hvor mange timer pr. uge ? \_\_\_\_\_
- Hjemmehjælp  
- hvor mange timer pr. uge ? \_\_\_\_\_
- Hjemmesygeplejerske  
- hvor mange timer pr. uge ? \_\_\_\_\_
- Andet \_\_\_\_\_
- 

**Transport:**

- Kassebil                       Med servostyring
- Anden bil                       Uden servostyring

Andre specialændringer ved bilen: \_\_\_\_\_

---

- Handicaptransport, HT, DSB eller lign.
- Andet \_\_\_\_\_
-

1. Har du fået de hjælpemidler du har eller har haft behov for ?

Nej, beskriv nærmere \_\_\_\_\_  
\_\_\_\_\_

Ja

2. Får du løbende oplysninger om nye hjælpemidler ?

Nej

Ja, hvorfra ? \_\_\_\_\_

### **GENERELT:**

1. Hvordan vil du selv beskrive din helbredsmæssige tilstand ?

God                       Middel                       Dårlig

2. Er din helbredstilstand inden for de sidste 10 år blevet:

Bedre                       Uændret                       Dårligere

3. Hvad mener du aktuelt er dit største helbredsmæssige problem ?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**BEMÆRKNINGER I ØVRIGT TIL SPØRGESKEMAET:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Appendix 3

Rules of standardization of data transfer from questionnaire to the SCI-base.

- 1) Når der står 8-10 skriver jeg 9. Når der står 5-8 skriver jeg 7. Altid den højeste ved valg mellem to tal.
- 2) Hvis svaret er "hver time" er dette tolket som 15 gange, idet døgnet er 24 timer minus gennemsnitlig 8 timers søvn. Hver anden time tolkes som 8 gange dagligt. Hver 1-2 time tolkes som 10 gange dagligt.
- 3) Hvis der står noget under "andet" som passer med mulige afkrydsningsmuligheder ovenover, retter jeg i afkrydsningen.
- 4) Hvis en patient har afføring dagligt registreres det som 3-7 gange dgl. i spørgsmål 4 under Tarmtømning.
- 5) Hvis der under "Smerter" er afkrydset behandling ja/nej ud for en kropsregion, forudsætter jeg at deltageren har smerter i den pågældende kropsregion.