ORIGINAL ARTICLE

How does knowledge about spinal cord injury-related complications develop in subjects with spinal cord injury? A descriptive analysis in 214 patients

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Study design: Monocentric cohort study.

Objective: To investigate the acquisition of knowledge about spinal cord injury (SCI)-related complications in SCI patients.

Setting: Level 1 trauma center.

Methods: All patients with a traumatic or non-traumatic SCI were included in the study. Data were collected at admission, post-admission at 1 and 3 months and post-discharge at 6, 18 and 30 months. The discharge of all patients was between 3 and 6 months post-admission. Knowledge about pressure ulcers and bladder management was tested using the 'Knowledge' score. This score has a minimum and maximum of 0 and 20 points. To detect differences across the multiple time intervals, the Friedman test was used. Differences in the number of patients with poor (0–8), average (9–12) and good knowledge (13–20) between the different age classifications (age at injury) were calculated using a χ^2 -test.

Results: A total of 214 patients were included. At discharge subjects had increased their knowledge score to 11.2 compared with 5.4 on admission ($P < 0.001$). After 30 months, however, the mean score decreased to 10.8 points. At the time of discharge, the number of patients who achieved poor, average or good knowledge were 48 (22.4%), 65 (30.4%) and 101 (47.2%), respectively. Subjects of ~50 years old and tetraplegics had better ($P < 0.001$) knowledge compared with subjects of ~50 years old and paraplegics, respectively.

Conclusion: In this study, less than 50% of SCI patients had good knowledge about bladder management and pressure ulcers after being discharged.

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Introduction

In patients with spinal cord injury (SCI), much effort has been put in attempts to evaluate SCI severity and prediction of recovery potential. In addition to the profound direct consequences of SCI, there is a heightened risk of secondary health conditions, including pressure ulcers, deep venous thrombosis and urological complications. By definition, secondary conditions are only indirectly related to the SCI and do not occur in all cases. To reduce avoidable morbidity and mortality, patients must have a basic understanding of

an SCI and SCI-related risks. Patients also need information on how to avoid these SCI-related risks.

Physicians should do their best to explain and discuss these themes with SCI patients. These SCI-related problems are not addressed in the Spinal Cord Independence Measurements (SCIM), Functional Independence Measurement and the neurological examinations according to the American Spinal Injury Association standards.^{1,2} Several studies concluded that the success of SCI rehabilitation depends not only on social-economical factors, but also on self-management.^{3–7} Our previous study showed that the combination of functional, psychological and cognitive parameters made it possible to determine the quality of a rehabilitation process in multiple dimensions.^{8,9} However, an adequate scale to measure knowledge about SCI and SCI-related complications is missing.

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The purpose of this study therefore was to analyze the development of knowledge about pressure ulcers and bladder management in SCI patients, in both the pre-discharge and post-discharge period.

Materials and methods

Since 2005, a monocentric prospective cohort study has been performed in our hospital. In this study, data about the knowledge of SCI-related problems were tested in SCI patients. Patients admitted to our hospital between January 2005 and May 2008 were enrolled consecutively into this 'Hamburg' database. Data in this database were collected at several time intervals: at the admission, and then 1 and 3 months post-admission. The discharge of all patients was between 3 and 6 months post-admission. After discharge, data were collected at 6, 18 and 30 months. Clinical assessments in our hospital were conducted by certificated neurological and rehabilitation physicians having at least 1-year experience in examining patients with SCI. Neurological examinations were conducted according to the American Spinal Injury Association standards.¹⁰

Study sample

Patients were included in the study if they had a traumatic or non-traumatic SCI. In non-traumatic patients, the date of injury was determined as the first day in which the patient experienced a motor and/or sensory deficit. Patients with a neurological level of injury of C2–T1 were considered tetraplegic subjects and patients with a neurological level of injury T2–S4–5 were considered paraplegic subjects. Only patients of 18 years and older were included in this study. Patients with an incomplete database record, severe cognitive impairment, craniocerebral injury or malignancies with short life expectancy were not included in this study. The first admission in our hospital had to last a minimum of 3 months or more.

The study protocols were approved by the local ethics committees and the subjects gave their informed consent before entering the study protocol.

Outcome measures

The SCIM II is an instrument that focuses on performing everyday tasks, and captures the disability as well as the impact of disability on the patient's overall medical condition and comfort.¹¹ The SCIM II consists of three main categories, namely, (1) self-care, (2) respiration and sphincter management, and (3) mobility.¹¹ The total SCIM II score was collected before, during rehabilitation and after discharge in each patient. The range in total SCIM II score is 0–100.

The knowledge of SCI-related problems was tested using the 'Knowledge Boberg' score. In this test, knowledge about two common SCI-related topics, pressure ulcers and bladder management, was tested. The test is shown in Box 1. The minimal and maximal score in this test were 0 and 20, respectively. The data of this test were collected at admission and during rehabilitation. In addition, data were collected after discharge from the first rehabilitation. Patients were

furthermore asked where their information came from during and after rehabilitation and how important this was to acquire more SCI knowledge.

The knowledge about these SCI-related problems was stratified for age at injury, paraplegia or tetraplegia, American Spinal Injury Association impairment scale grade A patients (complete), American Spinal Injury Association impairment scale grade B–D patients (incomplete) and 'Knowledge' score directly after admission (before the patient received any education about these SCI-related problems).

Statistics

To detect differences in total SCIM II scores and knowledge scores across multiple time intervals, the Friedman test was used. The differences in the number of patients with poor (0–8), average (9–12), and good knowledge (13–20) between the different age classifications (age at injury) were calculated using a χ^2 or Fisher's exact test as appropriate.

The differences were considered statistically significant at $P < 0.05$. Data were analyzed using SPSS software (version 15.0; SPSS, Chicago, IL, USA).

Results

In this study, the total number of patients included with complete SCIM II and Knowledge scores were 215 and 214, respectively. As expected, the total SCIM II score was significantly higher ($P < 0.001$) at discharge compared with admission. The total SCIM II score increased until a more or less steady state 18 months after discharge.

SCI patients initially showed poor knowledge about their illness. However, the subjects showed an increase ($P < 0.001$) between admission and discharge in the mean knowledge about SCI and SCI-related problems (Figures 1 and 2).

At the time of discharge, the number of patients who achieved poor, average or good knowledge were 48 (22.4%), 65 (30.4%) and 101 (47.2%), respectively. Patients aged 65 years and older achieved poor knowledge about SCI ($P < 0.001$) compared with younger patients (Table 1). Remarkably, patients of the 35–49 years age group had a higher percentage of average scores and a lower percentage of good scores compared with the 20–34 and 50–64 years age group.

Both tetraplegic and paraplegic patients showed a significant ($P < 0.001$) increase in SCI knowledge during rehabilitation (Figure 3). Although tetraplegic subjects initially had the poorest knowledge, these subject were identified to have the best knowledge compared with the other groups at discharge (Figure 3).

Of the SCI patients, 14.0% continued to improve, whereas 27.9% were identified to have scores that had diminished compared with the achieved knowledge scores during rehabilitation.

These patients with a deteriorated score were identified in both the tetraplegic and paraplegic groups (Figure 3). However, decreased scores were more identified in patients of ~65 years old and in uneducated patients.

SCI subjects in this study concluded that the clinical staff (rehabilitation physician, physiotherapist and nurse) were

Box 1 The questions about pressure ulcers and bladder management*'Knowledge Boberg'*

Question about bladder management	Answer			Points for correct answer
1. What are risk factor(s) for an urinary tract infection (UTI)? (multiple answers possible)	Yes	No	No opinion	
High voiding pressure				1
Insufficient bladder emptying				1
2. How do I recognize an UTI? (multiple answers possible)				
Abnormal urine odor				1
Hematuria color of urine				1
Increase in spasticity				1
Headaches				1
Backache				1
3. How often should my urine be tested to detect an early-phase UTI?				
Once every week				
Once every 2 weeks				
Once every 4 weeks				1
4. What is a detrusor sphincter dyssynergia?				
A coordination dysfunction between the bladder sphincter muscle and detrusor muscle				1
Bladder emptying pressure				
The development of a spastic to a hypotonic bladder				
5. What is the most hygienic way to empty the bladder?				
Continuous transurethral catheter				
Intermittent catheterization				1
Suprapubic catheter				
External urethral device				
Questions about pressure ulcers	Grade 1	Grade 2	Grade 3	
6. Which severity grade fits the following descriptions of pressure ulcers?				
Partial thickness skin loss involving epidermis, dermis or both				1
Non-blanchable erythema of intact skin				1
Full-thickness skin loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through underlying fascia				1
7. How should the following severity grades of pressure ulcers be treated?				
Relief of pressure on the skin until cured				1
Cooling of the skin				1
Surgical treatment				1
How should I try to avoid a pressure ulcer?	Yes	No	No opinion	
8. Check the skin with a mirror				
Every day				
Every week				
Every month				1
Every year				
9. Relief of skin/change sitting position				
Every minute				
Every 20 min				1
Once a day				
Not necessary				
10. Change lying position in bed				
Every 2 h				
Every 4 h				
Every 8 h				1
After individual preference				

Patients should answer yes, no or no opinion in every question. In questions 6 and 7, patients were asked to match the correct answer with the severity grade of pressure ulcers (according to the classification of the European Pressure Ulcer Advisory Panel (EPUAP), 1998). The maximal score of this test is 20 points.

the most important knowledge resources. In addition, in hospital special courses with the purpose to teach subjects about SCI were identified to be important for SCI subjects.

After discharge, the general practitioner and the physiotherapist became the most important SCI resources (Figure 4).

Figure 1 Mean total SCIM II scores during the rehabilitation and after discharge in SCI subjects.

Figure 2 Knowledge about bladder management and pressure ulcers during rehabilitation and after discharge.

Table 1 Age at injury and knowledge about bladder management and pressure ulcers in percentages during discharge in 214 patients with spinal cord injury

Age at injury (years)	Knowledge during discharge			Total (%)
	Poor (0–8 points) (%)	Fair (9–12 points) (%)	Good (13–20 points) (%)	
~ 20 (n = 9)	22.2	11.1	66.7	100
20–34 (n = 51)	5.9	29.4	64.7	100
35–49 (n = 59)	15.3	40.6	44.1	100
50–64 (n = 58)	20.3	27.2	52.5	100
~ 65 (n = 37)	59.5	24.3	16.2	100

Discussion

This study identified that 77.6% of the SCI subjects achieved an average to good knowledge about SCI. Only 47.2% of the SCI subjects achieved good SCI knowledge.

When SCI subjects develop good knowledge about their illness and SCI-related problems, these subjects are more aware of complications. For instance, the study by Rintala

*et al.*¹² tested the hypothesis that enhanced education after pressure ulcer surgery would result in fewer recurrences. Although only tested in 38 SCI subjects, the group that received individualized education was identified to have a longer average time to ulcer recurrence than SCI subjects without education.¹² It is hypothesized, however, that education alone about urinary tract infections or pressure ulcers with the primary aim to prevent these complications is insufficient.¹³ Other variables like age, neurological level of injury, functional recovery of mobility, social support and self-care also have an important role.^{14,15}

In our study, age was identified to be negatively associated with knowledge and knowledge acquisition as well. Furlan and Fehlings¹⁶ identified that older SCI subjects had worse functional recovery compared with younger patients. In our study, older subjects had less SCI knowledge compared with younger subjects. However, the proportions of good to average of the 35–49 years age group were different from those of the 20–34 and 50–64 years age group. We have no plausible explanation for the different scores in the 35–49 years age group. Generally, the aging patient has more co-morbidity, less functional reserves and/or learning abilities,

Figure 3 Knowledge about bladder management and pressure ulcers during rehabilitation and discharge stratified for spinal cord injury severity.

Figure 4 Information sources used by SCI patients and how important these were for SCI patients during discharge and 30 months after discharge (in percentages).

which could imply less efficiency in the rehabilitation process, less functional recovery and more SCI-related complications.

In our study, the general practitioner and rehabilitation physician were the most important knowledge resources for SCI patients. Although patients prefer to receive information from an SCI rehabilitation specialist, a recent study showed that the Internet is a more accessible and more currently used source for SCI patients.¹⁷ In the current trend of shorter rehabilitation stays, because of insurance limitations and the difficulty of accessing SCI specialists,¹⁸ patients and family members are required to absorb self-care information quickly while in the hospital and have to be proactive in finding

health information once they are discharged. Although the Internet was the fourth most important information source in this study, we believe that when information is easily accessible and is provided comprehensible, it may become a valuable additional SCI resource for patients after discharge. As medical issues related to SCI are the most important information topics on the Internet for individuals with SCI,¹⁷ in this study younger subjects had higher knowledge scores; however, only few had very good scores. The teaching methods used in our hospital therefore were insufficient, as less than 50% of the SCI achieved good knowledge. Moreover, the knowledge about SCI that subjects had acquired became less over time in 28% of the patients after discharge. Studies which

investigated whether better knowledge leads to less SCI-related complications and, *vice versa*, less knowledge leads to more SCI-related complications are lacking. Considering that SCI patients have a lifelong struggle with SCI and SCI-related complications, more studies are required to investigate new in-hospital and post-discharge methods to teach patients and family members about SCI. In addition, the correlation between education and SCI-related complications will have to be performed in future studies.

Our results should be interpreted in the context of specific study limitations. First, the Knowledge score has been introduced recently to test for SCI-related topics. We used pragmatically chosen cutoff points for good, average and poor knowledge, which were sufficient for this descriptive analysis. The test, however, lacks validity and more studies are required to test the reproducibility and validity. Second, we did not stratify for the type of bladder emptying. To illustrate, question five in Box 1 addresses the most hygienic way to empty the bladder. This question is irrelevant for patients who do use an external condom but do not require a catheter. Third, the discharge dates are between 3 and 6 months post-admission in this study. Differences in discharge dates could therefore lead to differences in acquired knowledge. For instance, patients discharged after 6 months are able to receive more SCI information compared with patients who are discharged earlier.

Conclusions

In this study, less than 50% of the SCI patients had good knowledge about bladder management and pressure ulcers after being discharged.

Conflict of interest

The authors declare no conflict of interest.

Acknowledgements

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