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ORIGINAL ARTICLE

Long-term follow-up of patients with spinal cord injury with a new ICF-based tool

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Study design: To develop a computer program that supports the overview of a follow-up care process in people with spinal cord injury (SCI) in daily clinical practice.
Objectives: To create a new electronic tool based on the International Classification of Functioning, Disability and Health (ICF) that enables information to be registered and visualized, including the use of a net-diagram ('spider') to show a patient's long-term development. This diagram helps the clinician to recognize predispositions over time, as well as making information accessible to the patient, so as to involve him as a participant in defining current and future treatment options. Furthermore, guidelines for the prevention of common diseases, based on the recommendations of internal medicine, rehabilitation medicine and findings in the SCI literature, were implemented to provide enhanced health coaching in the area of preventative care.
Methods: In an outpatient setting, four perspectives were assessed: patient, physician, occupational therapist and physiotherapist for a comprehensive bio-psycho-social consideration. All categories were assessed and graphically visualized with the electronic tool, on the basis of the ICF domains: body function, activities/participation and environmental factors.
Results: The assessed data were summarized and graphically represented using three spider charts.
Conclusion: The tool facilitates the patient counselling and the interdisciplinary work in daily clinical practice. Such a visual report helps to recognize predispositions over time. Furthermore, it helps to explain the clinical and patient-related findings accessible to the patients, to involve them as participants in defining the goals and the treatment plan.
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Keywords: spinal cord injury; case management; ICF; ambulatory care; prevention; follow-up care

Introduction

Following the recommendation of Sir Guttmann, regular ambulatory follow-up consultations after the initial inpatient rehabilitation is part of the routine rehabilitation process of patients with spinal cord injury (SCI) in Switzerland.[1] In the first few months after discharge, the aim of these follow-up examinations is to offer specialized medical support during the transition from an inpatient setting (which has often lasted for several months) to an outpatient setting at home; later on, regular examinations every 3–6 months[2] takes place to recognize upcoming problems in time and to continue the rehabilitation process[3] regarding therapies, and the social and professional reintegration of the patient.

Over the long term, a comprehensive check-up is performed every year in the German-speaking Centres for Spinal Cord Injuries in Switzerland, Basel, Nottwil and Zurich, including physical examinations to detect the well-known secondary complications of a SCI, like urological complications, degeneration of the spine with risk for pressure sores, overuse of the shoulders, compression syndromes, secondary syringomyelia and so on. To achieve this, an examination covering the findings of internal medicine, rehabilitation medicine, the neurological status, a spinal and musculoskeletal system examination and a urological examination is performed. Furthermore, the rehabilitation state of the patient, which includes an examination of the psychological and social situation, financial aspects, insurance problems and so on, is assessed. After the check-up, the findings and recommendations are briefly discussed with the patient, to let him/her proceed with formal treatment by their own family doctor, who is given a detailed written report.

After performing these annual check-ups for several years, it was realized that very often when the individual with SCI

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came for the next annual check-up no steps had been taken to address the concerns noticed in the last check-up. When the patients were asked to explain the reason, they often stated that they did not go to the family doctor at all—either because they preferred to wait for the next annual check-up or because they only trust the specialists of a paraplegic centre, or because in the family doctor's practice room no wheelchair was accessible and so on. Hence, many patients did not get the necessary treatment in time.

A similar situation was observed regarding the recommendations about preventive measures that could be taken by the family doctor, such as, cancer screening, treatment of the risk factors of coronary heart disease and so on. It was realized that there is an urgent need to establish a good collaboration between the individual with SCI and a paraplegic centre. Thus, more time needs to be dedicated to patient education and shared decision-making. Furthermore, presenting this information in a written form that can be handed out to the patient at the end of the check-up and includes something like an easily understandable graphic, which can be used as a basis to discuss the findings and the measures, would be very helpful. Such a report would help to involve the individual with SCI fully as a partner, and to serve as a basis for discussions about the patient's priorities, disposition and long-term goals, thus providing an optimized and individual health-coaching session.

Another aspect that was noticed over the years of performing these check-ups was that the comprehensive findings of the medical state of patients (sometimes encompassing more then 30 years) are in fact a treasure trove of knowledge and information.

At about the same time, the ICF—the International Classification of Functioning, Disability and Health of the World Health Organisation (WHO)[4]—was established; almost 1500 categories of ICF offer a differentiated language to describe a patient's health state and disability in his/her specific environment. This was exactly what was needed in order to categorize the comprehensive picture, which was collected from each patient's check-up.

The main advantage of using the ICF is that an international language that allows recording the different aspects of paraplegia in a standardized manner (that is, using a language that is the same for the physician, the physiotherapist (PT), the occupational therapist (OT) and the patient) was adopted. Furthermore, it provides an immediate database for different centres[5] to access to answer upcoming scientific questions regarding long-term follow-up. In addition, it could help to demonstrate the need or effectiveness of interventions and therapies.

With this vision in mind, information technology specialists were asked for help to create a new electronic tool that supports the patients' long-term case management allowing to collect scientific analysable data—based on the terminology of the ICF.

Materials and methods

The development of the electronic tool was planned in a three-step process (Figure 1).

Development of the new tool to support the annual check-up
A study group entitled 'Recording the Long-Term Follow-up using the ICF' was formed in 2005 at one of the regular meetings of experts of the three German-speaking Centres for Spinal Cord Injuries in Switzerland, Basel, Nottwil and Zurich, with the goal of defining such a catalogue of categories. For a comprehensive bio-psycho-social consideration, four perspectives were assessed: patient, physician, OT and PT. The patient answered ICF categories regarding activity and participation.

As described by Stucki *et al.*[6] the ICF categories differ between acute and chronic[7] rehabilitation phases in people with SCI. For this reason, basic rehabilitation items (for example, mobility bowel and bladder function) were defined by additional items describing long-term conditions[8] for example, shoulder pain, fatigue, sleep disorders (Figure 2).

With this objective in mind, a systematic scanning through almost 1500 categories of the ICF catalogue, and extracting and compiling the really essential categories for each module (for example, 78 categories for the 'Basic SCI Catalogue') was carried out. After many discussions and

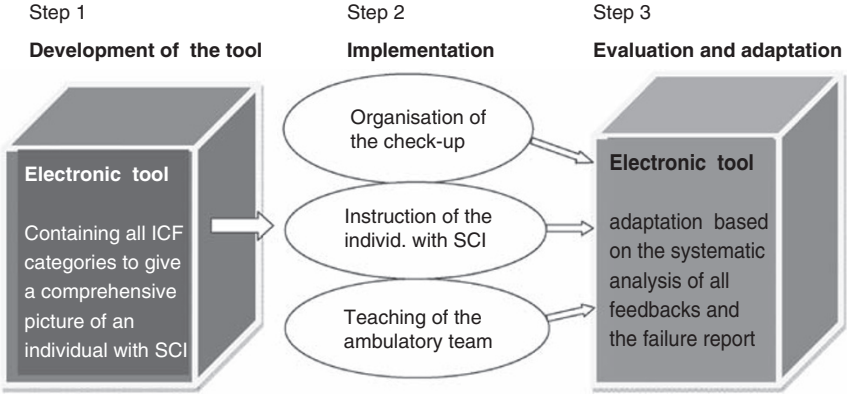


Figure 1 Method to develop the electronic tool to visualize the annual check-up based on ICF.

following additional internal consultations with paraplegia specialists of the Swiss centres, a final collection was assembled comprising 165 ICF categories, which collectively are able to describe the most important aspects affecting medically stable patients with SCI over the long-term course.[9]

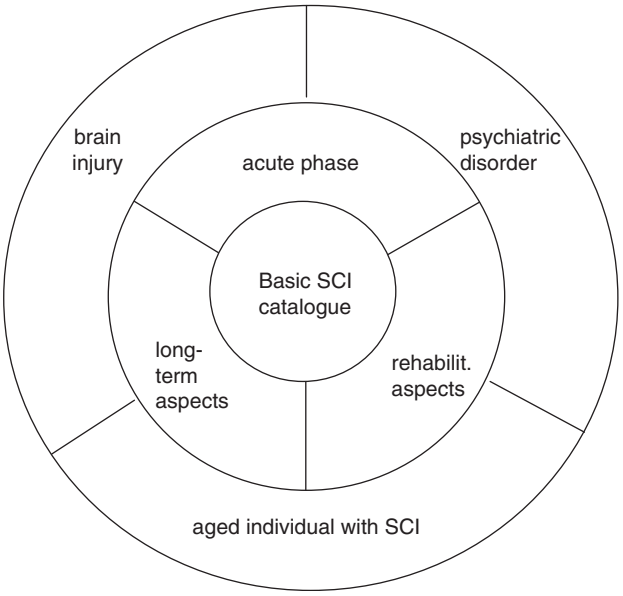


Figure 2 Modular composition of the ICF collection of categories.

Implementation of the electronic tool: organization of the annual check-up

As it was evident that a physician cannot possibly answer all of these 165 categories in a single consultation, it was decided to share this task between all the participants in the process. This implies that the patient would be responsible for answering questions in categories related to activities and participation,[10] the PT for categories regarding the lower limbs, the OT for those of the upper limbs and the physician for all the remaining categories of body function. A questionnaire is sent to the patients 2 weeks before the annual check-up, and the details are explained to him/her by telephone and by a subsequent letter. Included in this concept is an offer to complete the questionnaire together with our nurse if there are any difficulties. The patient's answers are then entered electronically at the beginning of the check-up, so that the information will immediately be available to all participants at the start of the examination.

During the consultation, the physician discusses these answers, performs the physical examination and electronically enters the findings. These findings are then visible for the following examinations by the OT and the PT, who complete their findings regarding the degree of muscle strength, mobility and spasticity of the upper and lower limbs (Figure 3).

Qualifier

According to the recommendations of WHO,[4] information was collected and findings of the four prospective were assessed in ICF categories, and rated with the WHO qualifier in a range between 0 (no problem) and 4 (complete

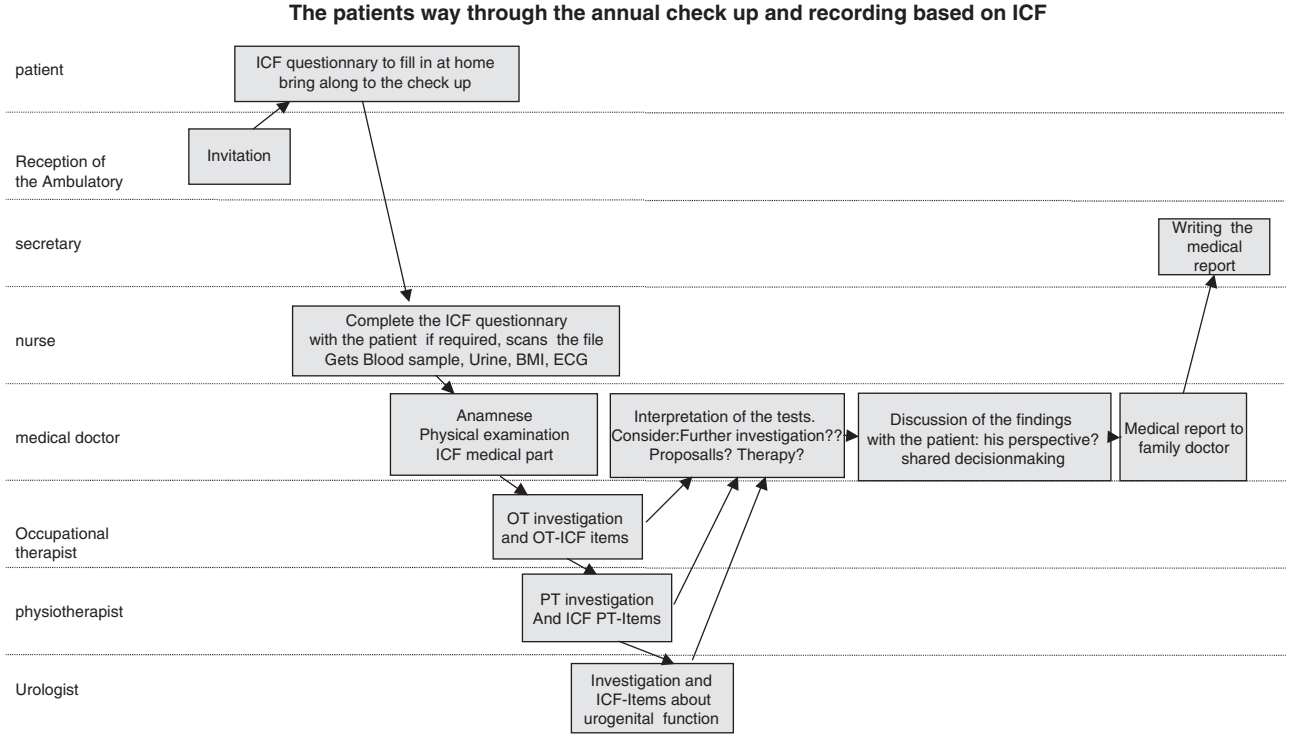


Figure 3 Organisation of the annual check-up: the patient's way.

problem). Such a rating allows to quantify problems in a certain area like, for example, mobility or pain, and enables to observe and compare the evolution over time.[11] This is especially easy to do as the data are in an electronic format, thus the values of every year are stored and can be chosen to display as a comparative diagram. This results in a graphical representation of the patient's current state that includes three spider charts based on the following ICF domains: body function, activities/participation and environmental factors.

The spider charts allow to recognize immediately in which areas the main impairments lie and whether the course is stable over the years, whether improvements have occurred or whether there have been any deteriorations. It also becomes visually apparent in which areas there is still a need for further action: a therapy, an investigation or a support. The physician comments on this for every single aspect, and the printout of this chart including the medical notes becomes the base for the final discussion with the patient at the end of the annual follow-up meeting.

Health coaching

In the final meeting, the patient is shown the graphic and the findings are pointed out, explaining their interpretation and meaning in detail, answering any questions and stating proposals for upcoming care. During the talk, the patient's perspective is heard, and then common goals are agreed on and necessary measures for going forward, including the timing are taken. At the end, a handout of the graphic representation of his/her health and rehabilitation state is printed out, including comments and recommendations, as well as the targets and measures jointly agreed upon (Figure 4).

Evaluation of the tool and adaptations

When the new tool and procedure was introduced in August 2008, a structured feedback and failure report was installed with the idea that any small or big problems, or comments from participants could be collected, to optimize the tool in time. A systematic evaluation was conducted 6 months after the initial installation.

Results

The findings show that this new electronic tool works surprisingly well, with a good face validity.

The features of the tool were very well accepted by the team, and the individuals with SCI were mostly open to the new organization and the questionnaire. The main problem for both groups of participants was the extra time required to answer the ICF categories. However, this extra time decreased for the health professionals with routine practice, and this disadvantage for the patient was often counteracted by the benefit of a very comprehensive check-up.

The content of this tool (that is, the number and the selection of ICF categories to describe an individual with SCI) is astonishingly good—as it was realized that there is a significant overlap between the tool and the ICF core set for SCI published in January 2010 by Stucki and colleagues.[7] However, a limitation of the described tool might be the fact that the WHO qualifiers has not yet been validated and there is no generally accepted, psychometrically sound measure of participation.[12]

During the systematic evaluation, which was undertaken 6 months after introduction of this tool, 98 different inputs and feedbacks of patients and team were analysed and the required adaptations were transferred.

With the PTs' and the OTs' rating,[13] and consideration of muscle function of the patients, spasticity and mobility were defined.

The experience of the proceeding physicians was that the patients mostly expressed satisfaction and could see the benefit of the new procedure, which leads to the graphic representation and extra time taken for a detailed counselling.

Comments from physicians indicated that they hoped that the graphic representation of the annual check-up, together with the comments of the physician themselves, would permit a distinctly better and longer-lasting informative experience for the patient. This means that the patient can go over the findings and targets again at home, where he has more time and tranquillity, and can consider the physician's recommendations and the jointly agreed targets at leisure. The reaction to the questionnaire of 57 consecutive patients in the first half-year was analysed: 44% came to the annual check-up with a completely filled-out questionnaire; 49% had problems and brought it partially answered and 7% had not completed the form. The feedback about the questionnaire was positive in 43 patients, negative in 3 and neutral in 11 patients.

Discussion

The new electronic tool with its graphical representation and the common discussion about aims and measures allows the patient to become a partner, thus enabling the patient to take more responsibility for his/her own health.

Furthermore the new procedure is enriched by the important aspect of medical prevention measures.

Prevention as a new part of the annual check-up

A discussion about the preventative measures recommended for patients of a certain age and after a certain amount of years with SCI is now included in the final meeting. As mentioned in the introduction, it was decided to undertake this additional responsibility as otherwise patients would usually miss them.

Knowing from the SCI literature that the patients have an increased risk in some specific aspects, for instance osteoporosis[14–16] or coronary heart disease,[17] it was decided to adapt the usual up-to-date medical recommendations for prevention to the special situation needed for individuals with SCI.

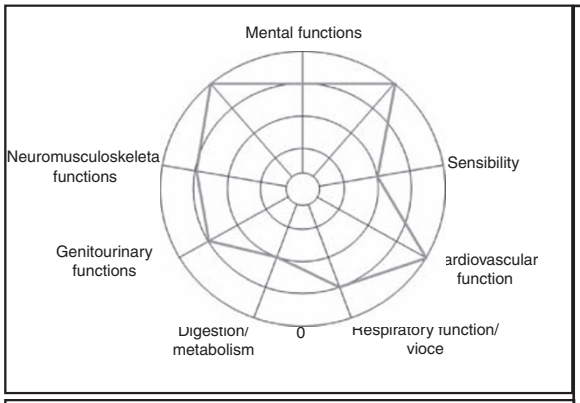
On the basis of the current guidelines of internal medicine, the important differences regarding SCI patients were worked out. Up-to-date SCI literature was reviewed, as well

Patient **X, Y**
03/06/1953

Evaluation of the paraplegiological assessment of April 1, 2008

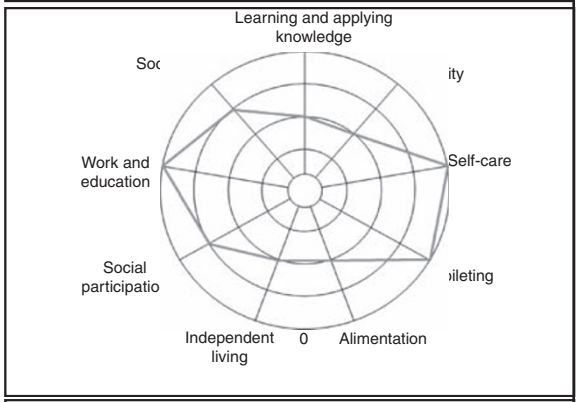
REHAB

April 1, 2008



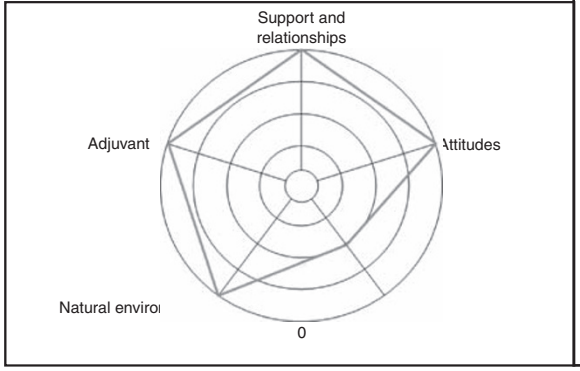
Restrictions of sensibility and paralysis are stable. No actions required.

Bladder: Recurrent urinary infections and slight urinary incontinence



Restricted mobility due to the general weakness; moving inside the apartment supported by a walking frame, moving around outside only possible with a wheelchair.

Due to restricted mobility participation in social life is limited. Living independently is not possible actually; supporting services are required



Problems with a health professional

Aims	Until date
Optimise mobility	1 June, 2008
Support for living independently is required further.	
Diagnostic evaluation of etiology of the current urinary infections.	

Measures
Support with an electric wheelchair is required; XY will apply at the insurance.
Medical confirmation for a housekeeper 4h/week.
Urodynamic investigation and consultation of the neuro-urologist.

Figure 4 Net-graph representing the health and rehabilitation state of an individual with SCI.

as the guidelines of American Spinal Injury Association and Spinal Cord Injury Rehabilitation Evidence, listing all the hints for earlier or aggravated problems caused by SCI (for example, earlier hypercholesterinaemia or diabetes),[18] and then got adapted into the general guidelines to the special needs of spinal-cord-injured patients. A table was arranged in which the examining physician could find a patient's medical and rehabilitation needs years after injury, categorized in defined age groups and structured regarding the needs to define preventive measures like blood check, colonoscopy or cardiological investigation.

The tool may also help to hold on to a certain level of quality and it encourages collaboration within the interdisciplinary team. Furthermore, the systematic collection of findings covering the long-term evolution of patients provides the medical and rehabilitation team with vital information that will allow to improve the quality of inpatient rehabilitation and after-care strategies—to maintain a good, healthy condition in SCI patients for as long as possible.

Conclusion

The tool and its graphic representation of the long-term development is helpful to support the follow-up care process in people with SCI in daily practice. As the ICF categories have to be rated, it is a data source that can be analysed systematically to obtain more knowledge of the long-term course of paraplegia,[19] where so much is still unknown, in particular, regarding the aspects of aging in SCI patients.

This tool also allows to visualize the effect of measures or to justify a treatment not only for the individual with SCI, but also for the insurance company that provides the financial part.

Conflict of interest

The authors declare no conflict of interest.

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