

GUEST EDITORIAL

The SwiSCI Cohort Study

The focus of rehabilitation management, health and social policy for people with spinal cord injury (SCI) and, most importantly, of people with SCI themselves, has dramatically shifted in recent years towards the goals of improving functioning and participation in all aspects of community life (1). In part this is a response to increase longevity, at least in high resource countries like Switzerland, owing to improvements in emergency response to injury, clinical care and acute rehabilitation. But it is also because of the widespread recognition that what matters for people living with SCI is optimal functioning, living independently and fully participating in all aspects of community life. The experience of SCI is shaped both by the underlying impairments and by the overall personal and social context in which people live out their lives.

This is implicit in the WHO's *International Classification of Functioning, Disability and Health* (ICF), which conceptualizes functioning and disability as a complex interaction between an individual's health condition and environmental and personal factors (2). It is further reinforced in the political domain by the explicit recognition that people with disabilities enjoy human rights to full inclusion and participation in all areas of life, on an equal basis with others (3).

The need for a new kind of information was the motivation behind the Swiss national community survey on functioning, conducted from September 2011 to March 2013, as an integral part of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) (4). The SwiSCI study offers a unique opportunity for researchers and policy-makers to understand crucial issues of functioning, health maintenance and quality of life for people living with SCI in Switzerland, along the continuum of care, in the community and across the lifespan. Relying on Core Sets developed using the ICF as a reference source for data collection (5, 6), SwiSCI uses distinct research pathways to identify and recruit study participants, in particular, a retrospective study of medical records, the periodic community survey, and an inception cohort study of newly injured persons (7).

The present Special Issue brings together many of the developers and scientific leaders of the SwiSCI study to lay out the foundational elements of the SwiSCI survey, in terms of the basic epidemiological and survey methodology strategies used in the survey, the measurement instruments that provided its empirical and statistical underpinning and, finally, the conceptual groundwork for the basic elements of functioning and disability as well as the determinants of functioning – health conditions, environmental and personal factors – and the important personal perspective on what matters to the lived experience.

In the first set of papers, basic epidemiological, survey issues are discussed. The first paper (pages 120–130) details the SwiSCI community survey protocol, recruitment, and study population, and provides information about response and

non-response and overall data quality. The paper shows why the community survey was effective in recruiting an unbiased sample and provides valuable information to inform social and health policy for the study of functioning, health maintenance and quality of life in community-dwelling people with SCI in Switzerland, setting an example that can be followed elsewhere. The second paper (pages 131–140) generalizes this discussion by reviewing the basic parameters of setting up a cohort study on functioning, in terms of the ICF functioning variables that need to be included (*what needs to be assessed*) as well as identifying which assessment and measurement instruments, linked to the ICF, that can be employed (*how to assess*). The final paper in this part (pages 141–148), reviews the important technical issue of subgroup analysis for epidemiological studies on SCI. The paper reviews the evidence supporting the application of the International Spinal Cord Society recommendations for relevant SCI sub-groups and tests these with SwiSCI data, in terms of distribution, variability and heterogeneity across groups, suggesting recommendations for further research.

The SwiSCI study is based on the insight that in order to respond adequately to the health and health-related needs of persons experiencing SCI, rehabilitation requires an interdisciplinary approach, along the continuum of care from acute to early post-acute and long-term care, including community-based rehabilitation. In order to collect relevant data on all of these aspects of care, and in particular to evaluate the effectiveness of interventions, it is essential to identify, and validate, appropriate measurement instruments.

These days the psychometric evaluation of relevant instruments involves both classical test-theoretical approaches, such as confirmatory factor analyses, and modern test theory approaches, such as the Rasch Measurement Model (8). This measurement model, as often seen in this journal, helps to improve our understanding of the elements of construct validity, some of which are not covered by classical test approaches (9). It also provides interval scale estimates from Patient Reported Outcome Measures so that appropriate statistics can be utilised (10). The papers in the second part of this Special Issue, therefore, rely primarily on Rasch analysis to evaluate the measurement instruments used in the SwiSCI community survey.

The first paper in the second part (pages 149–164) investigates the metric properties of an important tool used in this community survey, namely the Spinal Cord Independence Measure-Self Report version (SCIM-SR). Although SCIM-SR violates certain assumptions of the Rasch measurement model – in particular differential item functioning (DIF) – the researchers found that an intermediate solution was possible to achieve fit in 3 of 4 of the SCI sub-groups. The paper concludes that it remains advisable to use this approach to compute Rasch-transformed SCIM-SR scores. In the second

paper (pages 165–174), a similar statistical approach was used to examine the metric properties the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P). It was determined that the Restrictions and Satisfaction scales of USER-P displayed satisfactory metric properties, while the third scale, Frequency, was less optimal, although it too provides important information concerning the participation of persons with SCI. Lastly, Rasch analysis was used in the third paper of this part (pages 175–188) to evaluate the metric properties of measurement instruments used to measure psychological personal factors of feelings, beliefs, motives, and patterns of experience and behaviour, namely the Positive Affect Negative Affect Scale (PANAS), the Appraisal of Life Events Scale (ALE), the Purpose in Life test – Short Form (PIL-SF), and the Big Five Inventory-K (BFI-K). It was shown that a majority of these measures satisfy the Rasch model assumptions, although invariance across different language versions of these tools remains a challenge.

The last set of papers focus on the crucial notions of functioning and its determinants as tools for achieving a comprehensive understanding of the lived experience of SCI. As cohort studies in general are the most appropriate study design for tracking and monitoring functioning over time in specified populations, the SwiSCI use of the notion is both apt and essential. Yet, functioning is a complex and multidimensional phenomenon, far more intricate and different to measure than mortality or morbidity. Aspects of functioning are not directly observable and need to be operationalized as latent traits along a continuum. Moreover, in order to fully understand functioning as a lived experience, it is essential to account, not only for the major determinants of functioning – namely health conditions, environmental factors and psychological personal factors – but also what matters to the experience from the person's own perspective.

The first paper in the third part (pages 189–196) outlines guiding principles for how to standardize reporting of functioning data from a cohort study, using ICF as a frame of reference and deriving scores that are the most useful for statistical analysis and reporting. The ICF not only facilitates comparability of data and captures the full scope of the SCI experience, it also provides the basis for enriched statistical analysis. The second paper (pages 197–209) uses population-based data from the SwiSCI survey to construct an epidemiology of the health conditions that are experienced by people with SCI by constructing values for prevalence, severity, co-occurrence and treatment patterns. The third paper (pages 210–218) moves on to the important determinant of environment factors, which were measured in SwiSCI using a purpose-designed instrument called the Nottwil Environmental Factors Inventory Short Form (NEFI-SF). This tool provides data on perceived barriers and allows for a comparative analysis across persons, using multivariate regression modelling, with different demographics, lesion characteristics, and degree of physical independence. The next paper (pages 219–234) explored in depth the other major determinant of functioning and disability, namely psychologi-

cal personal factors, assessed by means of a variety of available measurement instruments. The researchers discovered that, although in general study participants were well adjusted to their SCI, those who sustained the injury at an older age, or more recently, reported more negative experiences, making them more at risk for less favourable outcomes of tailored psychological interventions. The final paper in this part (pages 235–243) completes the picture by bringing in the essential, personal perspective on the experience of SCI. Through an innovative post-coding exercise utilising qualitative methodology to analyse quantitative information derived from an open-ended question on the Starter model of the SwiSCI community survey (“What causes you the most problems since your spinal cord injury?”), the researchers were able identify the 10 most cited problems by the participants and 5 most cited problems that are mentioned by participants from each of the relevant sub-groups divided by sex and etiology. The analysis shows the need for a person-centred approach to intervention planning for persons with SCI living in the community.

The papers in this Special Issue not only reflect state-of-the-art applications of statistical and survey-methodological techniques to a community survey of persons with SCI, they also show both the feasibility and immense value of collecting information about the complete lived experience of SCI. Information about people's health conditions, injury-related impairments, and consequential secondary conditions is of course essential information to understand the SCI experience, to plan interventions and to shape health and social policy. But of equal importance and significance is information about the full lived experience, across all domains of day-to-day life, shaped – positively or negatively – by environmental and psychological determinants. It is our hope that the papers in this Special Issue encourage researchers to extend these techniques to cohort studies and community surveys for other health conditions, and to persuade health and social policy makers and other stakeholders to see the value and important of the perspective of functioning.

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Comments from The Editor-in-Chief

It is a great honour for me to thank the guest editors of this special issue, Professors Jerome Bickenbach, Alan Tennant and Gerold Stucki for their excellent proposal to compile this special issue, based on a national survey of Swiss persons' experience of functioning with a spinal cord injury. The data come from the ground-breaking, ICF-based studies recently performed in Switzerland by a large network of researchers, the Swiss Spinal Cord Injury Cohort Study. In this issue, you will find both methodological, epidemiological papers on how to examine functioning in a population and the actual results from the cohort study, regarding health conditions as well as environmental and psychological personal factors in Swiss persons with such injuries. As usual, a large number of external referees and statistical consultants have reviewed the present papers for which I thank them sincerely. I have personally taken all decisions on acceptance of the contributions to this issue.

Malmö, December 22, 2015

Bengt H. Sjölund, Professor, Editor-in-Chief