Swiss Spinal Cord Injury Cohort Study (SwiSCI): Aims, Design and First Results

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Outline of presentation

1. General background
2. Introduction Swiss Spinal Cord Injury (SwiSCI) Cohort Study
3. Medical record study SwiSCI
4. Community survey SwiSCI
5. Key topic Community survey: Labor market participation
6. Concluding remarks
General background
Issues in Spinal Cord Injury (SCI)

• Impaired bladder; bowel; and sexual functions
• Secondary conditions and complications include pressure sores; urinary tract infections; spasticity; chronic pain; osteoporosis; other.
• Difficulties in mobility; self-care; leisure; work; relationships
• Anxiety; depression; suicide; substance use
Difference in life satisfaction between persons with SCI and general population

Deconinck, 2003
Clayton, 1994
Siosteen, 1990
Kemp, 1999
Bach, 1994
Fuhrer, 1992
Moin, 2009
O’Carrol, 2003
Elfström, 2005
Tasiemski, 2005
Hampton, 2001
Kreuter, 1998
Koppenhagen, 2008
Post, 1998
Brown, 1998
Decker, 1985
Schönherr, 2005
Migliorini, 2010
Benony, 2002

Deviation from population

Mean SD = -0.78

Globale Data on Traumatic Spinal Cord Injury (ISCoS Prevention Committee 2010)
Data not available or unreliable in Switzerland

• Basic epidemiological info; e.g. incidence, prevalence
• Basic characteristics of SCI
  – Paraplegia vs. Tetraplegia
  – Etiology
• Long-term outcomes
  – Comorbidities; secondary health conditions
  – Participation: social; labor market
  – Quality of life
  – Survival; life expectancy

Consequence:
Poor basis for planning of prevention measures; rehabilitation and policy programs; and costs.
Introduction
Swiss Spinal Cord Injury Cohort Study
SwiSCI – Mission

To contribute to optimal functioning and quality of life of people living with SCI along the continuum of care and over the life span through comprehensive functioning and rehabilitation research

- To establish an **epidemiological database** for SCI
- To establish a **research platform** for nested and joint projects
- To compare **SCI** with the Swiss General Population
Reference framework of SwiSCI

- Application of the ICF model and classification
- Perspective of the lived experience (Functioning and disability)
- Comprehensive approach (Bio-psycho-social model)
- Ensure comparability across health conditions, settings and countries
SwiSCI Research Objectives

- Empowerment, capacity building and participation
- Social integration and fair opportunities
- Impairment and symptom control
- Health maintenance
- Efficient services, best care provision
- Outcome evaluation
SwiSCI Pathways

**Pathway 1 (comprehensive dataset):**
Medical records study

**Pathway 1 extended (minimal dataset):**
Medical records study

Persons identified in Pathway 1 are invited to participate in Pathway 2

**Pathway 2:**
Community survey
All persons with SCI after first rehabilitation

**Pathway 3:**
Inception cohort
Newly injured persons; recruitment during first rehabilitation

Population-based cohort
Participants from Pathways 2 and 3

Retrospective data collection

2011

2017

Prospective data collection

2022
SwiSCI study population

- Diagnosis of acquired SCI
  - Traumatic or non-traumatic
  - All levels of injury (cervical, thoracic and sacral lesions; incl. cauda equina syndrome)
  - All levels of sensory-motor impairment
  - Excluded: Spina bifida, Multiple sclerosis (MS), Amyotrophic lateral sclerosis (ALS)

- Resident in Switzerland aged over 16 years

- Informed consent for follow-up
Network

Community of people with SCI organized in Swiss Paraplegic Association (SPV)

Four SCI Units: Acute and rehabilitation care of people with SCI

Swiss Paraplegic Association (SPV) organized in 27 local wheelchair clubs about 3000 members with SCI.
Presumed coverage: >60% of SCI population (unique in European countries)
Medical Record Study
Pathway 1: Basic study design

- **Participants:**
  - Pathway 1 extended: new SCI between 1967 and start of Pathway 3
    => Historical cohort

- **Methods:**
  Data extraction from medical records

- **Variables:**
  Socio-demographic characteristics, biomedical data including lesion characteristics, duration of acute care and rehabilitation, discharge destination and planned follow-up

- **Progress with extraction and evaluation of data:***
  PW1: Completed
  PW1 extended: Completion anticipated by September 2013
Pathway 1: Main outcomes

- Annual incidence of SCI
- Etiology of SCI
- Neurological status and morbidity during acute care and first rehabilitation
- All cause mortality and cause-specific mortality during acute care and first rehabilitation
- Duration of first rehabilitation (Length of stay)
- Destination after discharge
Pathway 1: Patient numbers

<table>
<thead>
<tr>
<th>Center</th>
<th>Number of eligible SCI patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>REHAB Basel</td>
<td>141</td>
</tr>
<tr>
<td>Clinique Romande de Réadaptation, Sion</td>
<td>128</td>
</tr>
<tr>
<td>SPZ, Nottwil</td>
<td>497</td>
</tr>
<tr>
<td>University Clinic Balgrist, Zürich</td>
<td>256</td>
</tr>
<tr>
<td>Total (2005-2009)</td>
<td>1022</td>
</tr>
</tbody>
</table>
Pathway 1: Demographics; SCI etiology

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of SCI (Range)</td>
<td>2005-2010</td>
</tr>
<tr>
<td>Number of Patients</td>
<td>1022</td>
</tr>
<tr>
<td>N Male (%)</td>
<td>705 (69%)</td>
</tr>
<tr>
<td>Age (Median, IQR)</td>
<td>55 (38-69)</td>
</tr>
</tbody>
</table>

### Etiology of SCI

<table>
<thead>
<tr>
<th>Etiology of SCI</th>
<th>Number (%)</th>
<th>Context or specification</th>
</tr>
</thead>
</table>
| Traumatic       | 593 (58.1%)| Sports/Leisure: 29%
|                 |            | Fall: 35%
|                 |            | Transportation: 23%
|                 |            | Surgical interventions*: 8%
|                 |            | Other: 5%                                                      |
| Non-traumatic   | 420 (41.1%)| Next slide                                                     |
| Unknown         | 8 (0.8%)   |                                                                |

* mostly related to aorta OP or post-OP bleedings
Pathway 1: Etiology of NTSCI (N = 420)

<table>
<thead>
<tr>
<th>Level 2 Specification</th>
<th>N</th>
<th>%</th>
<th>Level 3 Specification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vertebal column degenerative disorders:</td>
<td>126</td>
<td>30%</td>
<td>Disc prolapse: 39%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Spinal stenosis: 41%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Other: 20%</td>
</tr>
<tr>
<td>Metabolic disorders:</td>
<td>7</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Vascular disorders:</td>
<td>112</td>
<td>26.5%</td>
<td>Hemorrhage: 30%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Vascular malformations: 6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ischemia: 62%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Not further classified: 2%</td>
</tr>
<tr>
<td>Inflammatory and autoimmune diseases:</td>
<td>13</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Radiation related:</td>
<td>0</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Toxic:</td>
<td>0</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Neoplastic:</td>
<td>122</td>
<td>29%</td>
<td>Benign: 34%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Malignant: 64%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Not further classified: 2%</td>
</tr>
<tr>
<td>Infection:</td>
<td>38</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Miscellaneous:</td>
<td>2</td>
<td>0.5%</td>
<td></td>
</tr>
</tbody>
</table>
Annual SCI Incidence rate

<table>
<thead>
<tr>
<th>Etiology group</th>
<th>Crude IR (95% CI) per million population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traumatic and non-traumatic SCI</td>
<td>32.3 (30.4-34.4)</td>
</tr>
<tr>
<td>Traumatic SCI only</td>
<td>18.8 (17.3-20.3)</td>
</tr>
</tbody>
</table>

Crude annual incidence per million population

- Netherlands
- Qatar
- Ireland
- Finland
- Australia
- Poland
- Taiwan
- Switzerland
- France
- Spain
- Sweden
- Norway
- Iceland
- Greece
- Estonia
- Canada
- United States
- China
- Canada
- Estonia
- Greece
- Iceland
- Norway
- Spain
- Sweden
- France
- Switzerland
- Taiwan
- Poland
- Australia
- Finland
- Ireland
- Qatar
- Netherlands

### Pathway 1: Duration of intensive care & 1st rehabilitation

<table>
<thead>
<tr>
<th>SCI Diagnosis</th>
<th>Number (%)</th>
<th>Total Duration (Months; Median)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>ASIA Impairment Scale (AIS)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>350 (34.3%)</td>
<td>9.4</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>574 (56.2%)</td>
<td>6.0</td>
</tr>
<tr>
<td>Cauda equina</td>
<td>93 (9.1%)</td>
<td>3.5</td>
</tr>
<tr>
<td>Unspecified</td>
<td>5 (0.5%)</td>
<td>-</td>
</tr>
</tbody>
</table>
Progress of extended medical record study

- For time period 1967-2012: currently 3429 records extracted.
- Awaiting completion of data collection, particularly before 1990 (REHAB Basel; former SCI Rehabilitation Center HUG, Geneva)
Community Survey
Aims of SwiSCI Pathway 2

- To describe the current SCI community in Switzerland and to collect prevalence data on functioning and disability

- To describe and better understand relevant aspects of life in the Swiss SCI community

- First study with the objective to include all persons aged 16 years or more, living with traumatic or non-traumatic SCI in Switzerland
Measurement in Pathway 2

Challenge

To obtain a comprehensive and detailed picture of the participants' situation while keeping questionnaire length tolerable, to minimize response bias.

What to measure?

(1) ICF categories of the minimal ICF Generic Set
(2) ICF categories of the ICF Core Set for SCI
(3) Relevant personal factors
### Number of ICF codes to be captured

<table>
<thead>
<tr>
<th>ICF Component</th>
<th>Number of ICF categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>12</td>
</tr>
<tr>
<td>Body Structures</td>
<td>4</td>
</tr>
<tr>
<td>Activities and Participation</td>
<td>16</td>
</tr>
<tr>
<td>Environmental Factors</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>40</strong></td>
</tr>
</tbody>
</table>

**Other variables**

- Demographic data and other Personal Factors
- Dates of SCI, admittance, discharge

**Total number of questionnaire items: 610**
Modular structure Pathway 2

1. Starter module
   - ~1 month
2. Basic module
   - ~2 months
   - Psychological Personal Factors and Health Behavior module
   - ~2 months
   - Work Integration module
   - ~2 months
   - Health Services module
Content of shared modules

- **Starter module (19 items)**
  - Basic socio-demographic data
  - Lesion characteristics
  - Care situation and perceived problems

- **Basic Module (155 items)**
  - Socio-demographics
  - Lesion characteristics
  - Health problems (SCI-SCS)
  - Mood (SF36)
  - Quality of life (WHOQoL-BREF)
  - Participation (USER-P)
  - IMPACT-S
  - Health care use
  - Satisfaction with health care
  - Functional independence (SCIM-SR)
Mixed-mode survey

SwiSCI community survey

Contact modes

- Written invitation
  - 1st written reminder
  - 2nd written reminder
  - Telephone reminder

Response modes

- Self-administered
  - Paper-pencil questionnaire

- Telephone interview
  - Web-based questionnaire
## Response to Starter module

### Overall (SPV; Parahelp; SPZ; REHAB; CRR)

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited subjects</td>
<td>3808</td>
<td></td>
</tr>
<tr>
<td>Reminder status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Non-eligible subjects

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>217</td>
<td>34%</td>
</tr>
<tr>
<td>Inclusion criteria not met</td>
<td>286</td>
<td>45%</td>
</tr>
<tr>
<td>Undeliverable (address incorrect)</td>
<td>91</td>
<td>14%</td>
</tr>
<tr>
<td>Contacted by multiple collaborators</td>
<td>42</td>
<td>7%</td>
</tr>
</tbody>
</table>

### Eligible subjects

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent refused</td>
<td>843</td>
<td>27%</td>
</tr>
<tr>
<td>Other reason for non-response</td>
<td>380</td>
<td>12%</td>
</tr>
<tr>
<td>Participation</td>
<td>1949</td>
<td>61%</td>
</tr>
</tbody>
</table>

### Response rate

(= Participation / Eligible subjects)

61%
Characteristics of participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number</td>
<td>1949</td>
</tr>
<tr>
<td>Male (%)</td>
<td>71%</td>
</tr>
<tr>
<td>Age (median; IQR)</td>
<td>52 (42-64)</td>
</tr>
<tr>
<td>Time since SCI (years)</td>
<td>13 (6-24)</td>
</tr>
<tr>
<td>Tetraplegia (%)</td>
<td>31%</td>
</tr>
<tr>
<td>Complete lesion (%)</td>
<td>41%</td>
</tr>
<tr>
<td>Traumatic etiology (%)</td>
<td>77%</td>
</tr>
<tr>
<td>Language (%)</td>
<td></td>
</tr>
<tr>
<td>German</td>
<td>72%</td>
</tr>
<tr>
<td>French</td>
<td>24%</td>
</tr>
<tr>
<td>Italian</td>
<td>4%</td>
</tr>
<tr>
<td>Education (years; median; IQR)</td>
<td>13 (12-15)</td>
</tr>
</tbody>
</table>

- Non-response analysis in preparation
## Response to Basic and further modules

<table>
<thead>
<tr>
<th>Module</th>
<th>N invitations</th>
<th>N positive response</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic</td>
<td>1933</td>
<td>1561</td>
<td>82%</td>
</tr>
<tr>
<td>Health behaviour and Psychological Personal Factors</td>
<td>582</td>
<td>514</td>
<td>89%</td>
</tr>
<tr>
<td>Work integration</td>
<td>384</td>
<td>328</td>
<td>86%</td>
</tr>
<tr>
<td>Health services research</td>
<td>590</td>
<td>494</td>
<td>84%</td>
</tr>
</tbody>
</table>
Key topic Community Survey: Labor Market Participation
Community Survey: Labour market participation (LMP)

Background

- High unemployment rate of persons with disabilities is a key issue in social policy (OECD 2010) ...
- Causing high disability pension expenditure; loss of tax revenue (OECD 2010)
- In SCI, LMP improves self-esteem, health, social integration/participation (Anderson 2007; Lidal 2007).
- In CH, no representative study on LMP in SCI exists; the only study (Marti 2012) suffered poor return rate (24%).
LMP of people with SCI in Switzerland, its determinants, and consequences. Work in progress

**Health-related factors**
- SCI severity
- Co-morbidities
- Complications

**Environmental & personal factors**
- Demographics
- Age, time to injury
- NEFI-scale (Graf 2013)
- Barriers to Work Scale (Krause 2012)

**Labour market participation**
- Percentage
- Time
- Income
- Satisfaction
- Return to previous employer

**Quality of Life; Participation**

**Vocational rehabilitation interventions**
- Counseling
- Vocational re-training
- New education
Employment rate (I): by SCI level

Within Swiss SCI population

In comparison with general population

* Data source: Swiss Federal Statistical Office, 2012, Q3
Employment rate (II): with age

Within Swiss SCI population

Comparison between SCI populations in 4 European countries (Data ILIAS Project)

* Adjusted for: gender; SCI cause; lesion level; lesion type; education; time since SCI; and employment at onset of SCI.
Concluding Remarks
Concluding remarks

1. SwiSCI is a national collaboration

2. Largest SCI study in Europe

3. Secure and sustainable funding for SwiSCI cohort through the Swiss Paraplegic Foundation

4. Research platform for nested and joint research projects

5. SwiSCI may serve as data model for future SCI studies
SwiSCI Pathway 3: Inception cohort

• Started 1\textsuperscript{st} May 2013 in Swiss Paraplegic Center
• ICF-based data set
• Prospective data collection:
  ▪ Standardized across patients
  ▪ Higher data quality
Vision

- Incidence; prevalence
- Morbidity
- Mortality
- Functioning
- Quality of life

Spinal Cord Injury by Country
from traumatic cause
1999–2008

**Incidence per million people**

- 30–45
- 10–25
- Fewer than 10

*Spinal cord incidence data insufficient for inter-country comparison*

<table>
<thead>
<tr>
<th>Aetiology of injury median percentile</th>
<th>Land transport</th>
<th>Falls</th>
<th>Sports/recreation</th>
<th>Violence: assault-victim</th>
<th>Work-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of cases resulting in mortality</td>
<td>up to 1 year from injury</td>
<td>1 – 10 years</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
More information about SwiSCI

www.swisci.ch

Invited Review

Design of the Swiss Spinal Cord Injury Cohort Study

ABSTRACT


The overall goal of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) is to gain a better understanding of how to support functioning, health maintenance, and quality-of-life of persons with spinal cord injury (SCI) along the continuum of care, in the community, and along their life span. The purpose of this study was to present the SwiSCI study design. SwiSCI is composed of three complementary pathways and will include Swiss persons 16 y or older who have diagnosis of traumatic or nontraumatic SCI. Pathway 1 is a retrospective study of medical files of patients admitted to one of the collaborating SCI centers between 2006 and 2008. Pathway 2 is a nationwide survey of persons with chronic SCI. Pathway 3 is an inception cohort study including persons with newly acquired SCI. SwiSCI is conducted in collaboration with the Swiss Paraplegic Association and the major specialized rehabilitation centers in Switzerland. Measurement instruments that are to be used in Pathway 2 and 3 cover body structures and functions, activities, participation, life satisfaction, and personal and environmental factors. SwiSCI is a prospective cohort study that will contribute to a comprehensive understanding of the lived experience of persons with SCI.

Key Words: Spinal Cord Injuries, Cohort Studies, Research Design, ICF, SwiSCI
Thank you!

The SwiSCI Study Center Team:
Teresa Brinkel; Martin Brinkhof; Jonvieve Chamberlain; Sabine de Angulo; Inge Eriks-Hoogland; Veronika Lay; Christine Fekete; Wolfgang Segerer; Christine Thyrian

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