

Establishing the Israeli Spinal Cord Rehabilitation Registry: From Acute Care to Rehabilitation

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Abstract

Background: Given the severe consequences of spinal cord injuries (SCI), it is important to store high-quality medical and functional data. Until recently, there was no SCI rehabilitation registry in Israel.

Objectives: To describe the process of initiating a rehabilitation registry for individuals with SCI in Israel and to provide a descriptive analysis of data from a single rehabilitation centre.

Setting: The department of neurological rehabilitation and Spinal Cord Rehabilitation Unit at Sheba Medical Centre, Israel; The Israel National Trauma Registry (INTR) at the Gertner Institute.

Methods: Individuals with traumatic and non-traumatic SCI admitted to the Spinal Cord Rehabilitation Unit at Sheba between January 2012 and December 2017 were included. Data collection was designed in accordance with the International Classification of Functioning, Disability and Health (ICF) and based on International SCI Data Sets. Data from the INTR and rehabilitation settings were matched.

Results: The first phase of the Israeli Spinal Cord Rehabilitation Registry (ISCIR) was completed at Sheba. Retrospective data from 408 individuals with SCI were analyzed. Among the 160 individuals with an acute traumatic SCI, traffic accidents were the leading cause of injury, followed by falls. 47% had tetraplegia and the average length of stay was 148 days. 144 individuals had a non-traumatic SCI, mostly due to degenerative disease, with an average length of stay of 71 days. The remaining 104 individuals hospitalized during that period had chronic SCI.

Conclusion: The current work demonstrated the feasibility of creating a SCI rehabilitation registry in Israel. In the near future, the data set will be extended and additional rehabilitation centres will join the registry.

Keywords: Spinal cord injury; Rehabilitation; Registry; Israel; Trauma system; Data linkage

Introduction

A Spinal Cord Injury (SCI) frequently causes severe, life-long disability, with affected individuals requiring assistance with mobility and activities of daily living. Individuals with SCI experience a variety of medical conditions related to their injuries, such as pressure injuries, neurogenic bladder and bowel, pain and spasticity, among others. Thus, long-term care for people with SCI is associated with significant health-care costs [1].

Due to the severe consequences of SCI, it is important to collect and store diverse, high-quality data, including medical, functional, and social aspects. In the United States (US), the National SCI Database began data collection in 1973 at a total of 28 centres. With 14 centres presently involved, the database captures data from an estimated 6% of new traumatic SCI cases each year [1]. The database enables examination of the longitudinal course of SCI, with the longest patient follow-up exceeding 40 years. Operating all over Europe, the European Multicentre Study about Spinal Cord Injury (EMSCI) collects data from 19 European centres (www.emsci.org). Meanwhile, new registries are being developed in countries across the world including Canada, Australia, Austria and other countries [2-4].

These registries usually contain data from the acute phase immediately following injury and from the rehabilitation period. Some also conduct long-term follow-up of patients. Combining data from the

acute and rehabilitation phases provides important insights regarding trauma and rehabilitation care as well as functional outcomes and community reintegration.

SCI rehabilitation in Israel

Today, there are two designated SCI rehabilitation units in Israel, at the Sheba Medical Centre and Loewenstein Hospital. Persons with SCI who do not reach these facilities receive care at general rehabilitation units across Israel. People with chronic SCI are also admitted to these units, usually due to various medical complications such as hard to heal pressure injuries, infections, fractures and general deterioration [5].

Currently, Israel does not have a national SCI registry and no reliable data regarding SCI rehabilitation are available. Several papers have been

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published sporadically regarding epidemiology and survival following SCI in Israel [6-10]. The Israel National Trauma Registry contains data pertaining to persons with traumatic spine injuries.

Merging trauma and rehabilitation registries

Following the establishment of trauma systems and trauma registries, several studies have shown a significant reduction in mortality both worldwide and in Israel [11,12]. Further studies demonstrate that the reduction in mortality and morbidity rates slows down as trauma systems mature [13]. Therefore, when assessing injury outcomes, greater focus is currently placed on non-mortality outcomes and long-term community-based outcomes than on solely hospital-based outcomes [13].

The Model Trauma System Planning and Evaluation document, which was released by the Health Resources and Service Administration in 2006, recognizes the role of trauma systems not only in reducing mortality but also in the successful integration of trauma survivors back into society through Rehabilitation Medicine [14]. Due to the continuity of the data, links between the emergency department, trauma centres, and rehabilitation centres enable the creation of an all-inclusive registry and support more extensive research. A recent paper, for example, reported on the identification of early predictors of functional outcome based on trauma and rehabilitation registry data [15].

Established in 1995, the Israel National Trauma Registry (INTR) at the Gertner Institute encompasses all six Level-I trauma centres in Israel as well as 13 additional regional trauma centres. Currently, there are over 600,000 records in the database, all associated with injuries classified as ICD-9-CM with diagnosis codes 800-959.9. Medical registrars collect the data in each hospital and enter the data into the central database. Individuals who experienced traumatic SCI are also included in the INTR, but their record only includes the acute hospitalization period. The new Israeli Spinal Cord Rehabilitation Registry (ISCIR) is stepping in to fill this gap, starting with the collection of data from the rehabilitation phase and continuing with long-term follow-up after discharge. The merging of these registries will facilitate the evaluation of relationships between trauma variables and medical and functional outcomes. The ISCIR will provide a platform for research and development in the rehabilitation settings and facilitate studies of the longitudinal course of SCI in Israel.

Methods

The ISCIR includes persons with traumatic and non-traumatic SCI. In the first phase of its establishment, retrospective data collected at the Sheba Medical Centre between January 2012 and December 2017 were reviewed and inserted into the database. After insights from this preliminary registry are processed and data collection is refined in accordance, the second phase will begin. This phase, starting in 2018 with prospective data collection, will cover a larger number of data elements and include more Israeli rehabilitation facilities.

Data collection for the ISCIR

The dataset was designed in accordance with the International

Classification of Functioning, Disability and Health (ICF) [16]. The ICF is an internationally accepted framework for the classification and description of functioning, disability, and health in persons with various types of diseases and conditions, including SCI. Disability and functioning are conceived as products of a dynamic interaction between health conditions and personal and environmental factors.

Data were acquired from both the acute-care and the rehabilitation settings. The majority of data collected were based on the International SCI Data Sets, most notably, the core dataset [17]. This path was chosen in order to standardize data collection and enable future collaboration with other international registries.

Inclusion criteria: adults (≥ 18 years) with traumatic or non-traumatic SCI, including conus medullaris and cauda equina injuries, admitted to the SCI rehabilitation program. Individuals with chronic SCI that were re-admitted during this period were also included. Exclusion criteria: spinal column injury without a cord injury, radiculopathy without a cord injury, any severe and concomitant acquired brain injury.

Data collected for each individual included personal demographic data, etiology and characteristics of injury including neurological (e.g., severity and level of injury) and functional data (e.g., Spinal Cord Independence Measure [SCIM]) [18].

The Sheba Medical Centre was set as the coordinating centre for the ISCIR. The rehabilitation data are manually extracted from the Electronic Medical Record (EMR) at each local site and stored at the local ISCIR database. A data check is performed to ensure completeness of details and to verify that included cases meet the eligibility criteria. The data are then transferred in a secure manner and stored on protected data servers at the hosting centre, the INTR unit at the Gertner institute. Subsequently, the data are matched with data from the trauma registry, duplicates are removed and consistency of medical records is verified. Personal data extracted from the medical records are stored separately from the research data using a unique identifier. Acute-care and rehabilitation data are then stored at the hosting centre and data analysis is performed. Refer to Figure 1 for the complete flow of data.

Use of data collected in the registry requires a submission of a research proposal. If approved, access is governed by the data manager. Patient records are de-identified to ensure patients privacy.

Results

Data were collected on all persons with an acute or chronic SCI that were hospitalized at the Spinal Cord Rehabilitation Unit at Sheba between 2012 and 2017. A total of 160 individuals with traumatic SCI were admitted to the rehabilitation unit. Characteristics are presented (Table 1). Of these individuals, 144 were identified in the trauma registry.

In addition, 144 individuals with non-traumatic SCI were admitted to the rehabilitation unit. Characteristics are presented (Table 2).

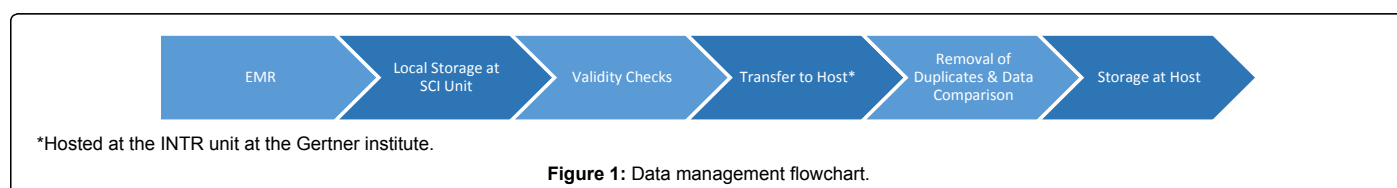


Figure 1: Data management flowchart.

| Characteristics | Traumatic SCI (n=160) |
|--|-----------------------|
| Age at admission, mean ± SD | 40.2 ± 17 |
| Male sex (%) | 133 (83%) |
| Cause of injury (%) | |
| Motor vehicle accident | 71 (44%) |
| Falls | 59 (37%) |
| Other | 30 (19%) |
| Severity of injury (%) | |
| Tetraplegia, complete motor* | 30 (19%) |
| Tetraplegia, incomplete | 45 (28%) |
| Paraplegia, complete motor* | 53 (33%) |
| Paraplegia, incomplete | 32 (20%) |
| Length of stay in acute care, mean ± SD | 44 ± 46 |
| Length of stay in rehabilitation, mean ± SD | 148 ± 104 |
| SCIM upon admission, mean ± SD | 24 ± 21 |
| SCIM upon discharge, mean ± SD | 56 ± 25 |
| SCIM – Spinal Cord Independence Measure *Complete motor injury – ASIA Impairment Scale (AIS) A or B | |

Table 1: Characteristics of individuals with traumatic SCI admitted to the Spinal Cord Rehabilitation Unit at Sheba, 2012-2017.

| Characteristics | Non-traumatic SCI (n=144) |
|---|---------------------------|
| Age at admission, mean ± SD | 52.5 ± 14 |
| Male sex (%) | 95 (66%) |
| Cause of injury (%) | |
| Degenerative | 78 (54%) |
| Neoplasm | 42 (29%) |
| Other | 24 (17%) |
| Severity of injury (%) | |
| Tetraplegia, complete motor** | 3 (2%) |
| Tetraplegia, incomplete | 53 (37%) |
| Paraplegia, complete motor** | 10 (7%) |
| Paraplegia, incomplete | 74 (51%) |
| Length of stay in rehabilitation, mean ± SD | 71 ± 63 |
| SCIM upon admission, mean ± SD | 48 ± 22 |
| SCIM upon discharge, mean ± SD | 74 ± 19 |
| SCIM – Spinal Cord Independence Measure *Severity of injury for 3% of individuals with non-traumatic SCI was not available **Complete motor injury – ASIA Impairment Scale (AIS) A or B | |

Table 2: Characteristics of individuals with non-traumatic SCI admitted to the Spinal Cord Rehabilitation Unit at Sheba, 2012-2017.

104 individuals with chronic SCI were admitted during the specified period (some more than once). The most common reasons for admission were general deterioration and infections (pulmonary and urinary), which accounted for 41% of admissions. Pressure injuries accounted for 28% and procedures (e.g., intrathecal Baclofen trials, colonoscopy) accounted for 18%. Average length of stay in rehabilitation was 58 days.

Discussion

This manuscript describes the main steps that have been taken toward the implementation of the first SCI rehabilitation registry in Israel. A patient registry is the basic infrastructure required to address research aims, such as identification of the different factors that influence prognosis and quality of life. It provides a mechanism for observing the course of disease and comparing different interventions, and thereby contributes to the improvement of patient care and outcomes. It also establishes a platform for future clinical trials.

Given that there have been recent advances in spinal cord medicine, the establishment and maintenance of such registry is more important than ever, as there appears to be significant progress in treatment and possibly improved prognosis for people with SCI [19].

A main strength of the Israeli registry is the continuity of data, which begins with early data from the trauma registry, continues with data from the rehabilitation registry, and will continue further with long-term follow-up data from standardized assessment tools described below. The trauma and rehabilitation registries were merged by matching the two data files for each participant. The majority of individuals were easily matched. Several individuals, mainly those that were injured abroad and underwent rehabilitation in Israel, were listed in the rehabilitation registry but did not appear in the Israeli trauma registry.

An additional strength of the registry arises from the inclusion of persons with non-traumatic SCI, a population that many other registries lack. An increasing number of individuals with degenerative spine conditions undergo surgical interventions [20]. Individuals with non-traumatic SCI comprise a large subgroup within people with SCI, and share many characteristics with individuals with traumatic SCI. In Israel, individuals with both traumatic and non-traumatic SCI participate in the same rehabilitation programs and in the same rehabilitation units. Several other SCI registries, as noted as a limitation in the papers that describe them, do not include non-traumatic SCI. This is partially due to the fact that acute care and rehabilitation for individuals with non-traumatic SCI are conducted in a variety of different settings, and overall care tends to be poorly integrated [2-4]. Due to the nature of non-traumatic SCI, early data from the trauma registry are not available for these individuals.

In terms of limitations, similar to most SCI registries in the world, the ISCIR is not a population-based registry and in its first phase, it includes only individuals with traumatic or non-traumatic SCI treated at the Spinal Cord Rehabilitation Unit at Sheba [1-4]. The average number of persons with traumatic SCI admitted to the centre per year was 26.6. This accounts for at least 6% of all individuals admitted to a rehabilitation department in Israel to treat a new traumatic SCI. These numbers are estimates, as the data currently available on SCI in Israel are limited. As mentioned previously, the National SCI database in the U.S. encompasses 6% of all new traumatic injuries, which is comparable to the early-stage ISCIR data [1].

It is important to note that many persons with SCI, especially those with ASIA Impairment Scale (AIS)-D grade injuries, are not admitted to inpatient rehabilitation centres and instead undergo rehabilitation in community settings. Therefore, these individuals are not included in the rehabilitation registry, although they do appear in the trauma registry.

An additional limitation in the rehabilitation registry results from missing data in the medical record, a common issue with retrospective data collection. This issue will be resolved in future phases by modifying the design of the EMR to include all relevant data in structured forms and by introducing automated data extraction directly from patient charts into the registry.

We encountered a minor challenge during linkage with the trauma registry data. On at least one occasion, the same abbreviation was used in both registries, but with a different meaning. Specifically, in the trauma field, AIS stands for the Abbreviated Injury Scale, a global severity scoring system that classifies each injury by body region [21]. In spinal cord medicine, AIS stands for ASIA Impairment Scale, a scale used to classify the severity (completeness) of injury in individuals with SCI. All persons involved in the study should be made aware of these differences to avoid future mistakes.

Preliminary analysis of data from the first phase shows that traffic accidents were the leading cause of traumatic SCI, followed by falls. Due to aging of the population, the percentage of falls is gradually increasing and represents now the leading cause of SCI in many countries worldwide [22-25]. In the US, similarly to our results, traffic accidents are still the most common etiology for SCI [1].

Due to differences between the health systems, the length of stay in acute care and rehabilitation facilities in Israel is considerably longer than in the US but similar to Europe [26]. In the US, length of stay in rehabilitation for individuals with traumatic SCI decreased from 98 days in the 1970s to 34 days in 2018 [1]. A similar trend has been reported in Israel. A cohort from the years 1962-2000 indicated that the average length of stay was 239 days for individuals with traumatic SCI and 106 days for non-traumatic SCI [27]. In our data, the average length of stay was 148 days and 71 days for traumatic and non-traumatic SCI, respectively.

In Europe, the percentage of cervical injuries among cases of traumatic SCI ranges from 40% to 60%. In the US, this percentage is 55.7% [28]. In line with these numbers, 47% of individuals with a traumatic SCI had tetraplegia in our cohort.

Following completion of the retrospective first phase of the registry, new SCI data will be prospectively collected at Sheba and additional rehabilitation hospitals in Israel. Further data will be collected to complete the ICF frame dataset, including personal factors such as marital and employment status, environmental factors such as insurer, and impairments such as sexual dysfunction and bladder function. Activity and participation will be assessed in a long-term follow-up by using either the WHO DAS II or the PROMIS-10 [29,30]. Ongoing analysis of retrospective data is currently underway, including the correlation of trauma and rehabilitation variables and the identification of predictors of functional outcome, as are additional prospective studies.

Conclusion

The current work demonstrated the feasibility of creating a SCI rehabilitation registry in Israel. In the near future, the dataset will be extended and additional rehabilitation centres will join the registry.

Funding

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Conflicts of Interest

The authors report no conflicts of interest.

Statement of Ethics

The study was approved by the Sheba Medical Centre IRB/Ethics Committee.

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