

Feasibility and Data Quality of the National Spinal Cord Injury Registry of Iran (NSCIR-IR): A Pilot Study

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Abstract

BACKGROUND:

Spinal cord injury (SCI) is one of the most disabling consequences of trauma with unparalleled economic, social, and personal burden. Any attempt aimed at improving quality of care should be based on comprehensive and reliable data. This pilot investigation studied the feasibility of implementing the National Spinal Cord and Column Injury Registry of Iran (NSCIR-IR) and scrutinized the quality of the registered data.

METHODS:

From October ۲۰۱۵ to May ۲۰۱۶, over an ۸-month period, ۶۵ eligible trauma patients who were admitted to hospitals in three academic centers in mainland Iran were included in this pilot study. Certified registered nurses and neurosurgeons were in charge of data collection, quality verification, and registration.

RESULTS:

Sixty-five patients with vertebral column fracture dislocations were registered in the study, of whom ۱۴ (۲۱,۵%) patients had evidence of SCI. Mechanisms of injury included mechanical falls in ۳۰ patients (۴۶,۲%) and motor vehicle accidents in ۲۹ (۴۴,۶%). The case identification rate i.e. clinical and radiographic confirmation of spine and SCI, ranged from ۱۰,۰% to ۸۸,۹% in different registry centers. The completion rate of all data items was ۱۰۰%, except for five data elements in patients who could not provide clinical information because of their medical status. Consistency i.e. identification of the same elements by all the registrars, was ۱۰۰% and accuracy of identification of the same pathology ranged from ۶۶,۶% to ۱۰۰%.

CONCLUSIONS:

Our pilot study showed both the feasibility and acceptable data quality of the NSCIR-IR. However, effective and successful implementation of NSCIR-IR data use requires some modifications such as presence of a dedicated registrar in each center, verification of data by a neurosurgeon, and continuous assessment of patients' neurological status and complications.