



Sustaining the National Spinal Cord Injury Registry of Iran (NSCIR-IR) in a Regional Center: Challenges and Solutions

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Abstract

Background: The National Traumatic Spinal Cord Injury Registry in Iran (NSCIR-IR), was implemented initially in three hospitals as a pilot phase from 11 Oct 2015 to 19 Jun 2016 and has been active in eight centers from 19 Jun 2016. Poursina Hospital, a trauma care referral center in Rasht, Guilan Province of Iran is one of the registry sites, and has been involved in registering eligible patients since 1 Jan 2016. This study aimed to identify the challenges and solutions for sustaining the NSCIR-IR in a regional center.

Methods: This was a mixed-methods study. For the quantitative analysis, a retrospective observational design was used to measure case capture or case identification rate, mapping cases in the registry against those eligible for registry inclusion amongst the register of hospital admissions. For the qualitative component, data was collected using focus group discussions and semi-structured interviews, followed by thematic analysis.

Results: From 19 Jun 2016 to 24 Jan 2018, the proportion of case capture (case identification rate) was 17%. The median time between case identification and data entry to the system was 30.5 d (range: 2 to 193 d). Thematic analysis identified a lack of trained human resources as the most important cause of low case identification rate and delay in data completion.

Conclusion: Recruitment and education to increase trained human resources are needed to improve case capture, the timeliness of data input and registry sustainability in a regional participating site.

Keywords: Trauma; Spinal cord; Disease registries; Iran