Oral Communication
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Cohort Profile of the Second International Spinal Cord Injury (InSCI) Community Survey

Topic: Rehabilitation Across the Continuum of Care

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BACKGROUND

Spinal cord injury/disease (SCI/D) contributes significantly to the global burden of disease, with increased mortality and long-term disability. This highlights the need for systematic epidemiological data and a better understanding of the lived experiences of people with SCI/D. The international spinal cord injury (InSCI) community survey aims to address these needs by identifying the factors influencing the functioning and well-being of people with SCI/D across countries, considering health systems, policies, services, and personal characteristics. The survey examines health dimensions such as secondary conditions, functional independence, participation in life domains, mental health, health services use, and quality of life. The present study aims to describe the participating countries in the second InSCI survey, focusing on recruitment processes, outcomes, and participant characteristics.

METHODS

The InSCI community survey is a cross-sectional, multi-national, and cross-cultural study conducted every five years across all WHO regions. The second InSCI community survey was conducted between May 2022 and October 2024. In brief, participants eligible for this study included individuals aged 18 years or older with either traumatic or non-traumatic SCI, living in the community and able to complete a self-report questionnaire.

RESULTS

Thirty-one countries (African region, n = 1; Americas region, n = 4; Eastern Mediterranean region, n = 4; European region, n = 13; Southeast Asia region, n = 5; Western Pacific region, n = 4) participated in the second InSCI community survey, providing datasets from 15,051 persons with SCI/D (response rate: 24.5%). A total of 209 recruitment centers sampled participants for the survey, mainly from general hospitals (41.1%), specialized SCI facilities (36.4%) and patient organizations (12.9%). Compared to European countries, more participants from the WHO Southeast Asia region participated in the survey (median: n = 589; range: 206 - 789). The survey was completed by countries with a median duration of 12 months. Most of the study participants were male (70%), with a median age of 43 years, slightly more than half lived in urban areas, and were married (49.4%). The majority had traumatic SCI (86.7%), were incompletely injured (53.8%), and had paraplegia (68.5%). Participants had a mean of 5.1 (range 1-10) on the subjective social standing scale.

CONCLUSION

The continued rise in SCI incidence worldwide necessitates ongoing efforts to tailor healthcare, rehabilitation, and support systems to meet the needs of this growing population. Data from the second InSCI survey will be instrumental in identifying gaps in healthcare provision, informing targeted interventions, and optimizing resource allocation.

Statement of Disclosures

None

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