Management of Spinal Cord Injury in Tunisia: 2024 landscape and challenges

Prise en charge des blessés médullaires en Tunisie: panorama et défis en 2024

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Abstract

Introduction: Spinal Cord Injury (SCI) is a pressing global health issue, with a notable increase in incidence in Tunisia primarily attributed to traffic accidents. The repercussions of SCI extend beyond physical impairments, significantly affecting patient mental health and quality of life, and pose substantial economic challenges.
Objectives: This study aims to provide an in-depth analysis of the current landscape of SCI management in Tunisia, identifying key challenges faced by patients and healthcare providers while offering actionable recommendations for improvement.
Methods: A comprehensive review of existing literature was conducted to assess the SCI management framework in Tunisia. The study focused on evaluating the rehabilitation system, healthcare provider training, and the implementation of disability rights in the country, while identifying barriers to effective care.
Results: Findings indicate a critical shortage of specialized rehabilitation facilities, with only 13 out of 24 governorates of the country providing adequate services. Additionally, there is a significant lack of trained healthcare professionals and inconsistent application of disability rights. Social stigmas further complicate the situation, hindering access to comprehensive care for SCI patients.
Conclusion: To enhance SCI care in Tunisia, it is essential to expand rehabilitation services, improve healthcare providers training in disability management, and strengthen disability support systems. Implementing policy reforms, increasing data collection efforts, promoting research and peer support programs are vital steps toward addressing the multifaceted challenges of SCI management and improving the quality of life for affected individuals.

Key words: Community Health Services; Developing Countries; Health Policy; Patient Care Management; Rehabilitation Centers

Résumé

Introduction: Les blessures médullaires (BM) constituent un enjeu de santé publique majeur à l'échelle mondiale, avec une incidence croissante en Tunisie, principalement due aux accidents de la circulation. Au-delà des atteintes physiques, ces blessures impactent gravement la santé mentale et la qualité de vie des patients, entraînant des coûts économiques élevés.
Objectifs: Cette étude vise à analyser le paysage actuel de la gestion des BM en Tunisie, en identifiant les défis rencontrés par les patients et les professionnels de santé, tout en proposant des recommandations pour améliorer les soins.
Méthodes: Une revue exhaustive de la littérature a été réalisée pour évaluer le cadre de gestion des BM, en se concentrant sur la rééducation, la formation des professionnels et l'application des droits des personnes handicapées.
Résultats: Les résultats montrent une insuffisance critique de structures de rééducation spécialisées, présentes dans seulement 13 des 24 gouvernorats tunisiens. De plus, il existe un manque significatif de professionnels formés dans ce domaine et une application incohérente des droits des personnes handicapées. Les stigmates sociaux compliquent l'accès aux soins adéquats pour les patients.
Conclusion: Pour améliorer la prise en charge des blessés médullaires en Tunisie, il est essentiel d'élargir les services de rééducation, d'améliorer la formation des prestataires de soins et de renforcer les systèmes de soutien aux personnes handicapées. La mise en œuvre de réformes politiques, l'augmentation des efforts de collecte de données et la promotion de la recherche sont cruciales pour relever les défis liés à la gestion et à l'amélioration de la qualité de vie des blessés médullaires.

Mots clés: Services de santé communautaire ; Politique de santé ; Pays en voie de développement ; Gestion des soins aux patients ; Centres de rééducation

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LA TUNISIE MEDICALE-2025; Vol 103 (04): 408-412 DOI: 10.62438/tunismed.v103i4.5496

Introduction

The management of spinal cord injury (SCI) in Tunisia, as in the developing countries, presents a complex landscape marked by both significant challenges and emerging opportunities (1). Based on the data available in the 2019 Global Burden of Diseases (GBD) study, there is almost 9 million cases of SCI worldwide (2). Published data from low- and middle- income countries (LMICs) are generally scarce (3). From 1990 to 2019, there was a substantial increase in incidence rates of SCI in North Africa and the Middle East (eg; estimated annual percentage change was 2.2) (4). Globally, more than 50% were caused by falls, followed by road injuries and interpersonal violence (4). According to a Tunisian study, traffic road accidents were identified as the primary cause of traumatic SCI (5). Most of injuries in both traumatic and non-traumatic SCI were located at the cervical level (5). In Tunisia, from 1990 to 2019, the global age standardized rates of SCI per 100000 population showed increases in SCI prevalence and incidence by 8.5% and 6.1%, respectively, and a decrease in years lived with disability (YLDs) by -5.6% (6). The burden of SCI extends beyond its physical manifestations (7). Patients with SCI are vulnerable to a range of complications that not only affect their quality of life (QoL), but also pose substantial economic challenges (7). Globally, the financial burden of SCI, with the lifetime cost is estimated at $336,000 per person [4]. This update aimed to provide an overview of the 2024 landscape of SCI management in Tunisia, examining existing literature and identifying key challenges faced by patients and healthcare providers alike.

Challenges and barriers in accessing rehabilitation services for SCI patients in Tunisia

The WHO's International Classification of Functioning, Disability and Health (ICF) emphasizes that effective management of disabilities requires a holistic approach that considers not only medical treatment, but also social integration and community support (8). However, access for specialized rehabilitation for persons with disabilities is not easy especially in LMICs (9). Despite advancements in medical technology and an increasing awareness of disability rights, many Tunisian individuals with SCI face barriers that hinder their access to necessary rehabilitation services. Only three inpatient rehabilitation facilities exist in the country with a rehabilitation bed ratio equal to 0.01 per 1000 Tunisian inhabitants (10). The concluding observations of the United Nations Committee on the Rights of Persons with disabilities in Tunisia highlights significant obstacles to healthcare access (11). These barriers include physical accessibility issues, lack of transportation, and insufficient information about available services (11). Social stigma and discrimination further hinder their integration into society, affecting their access to education and employment opportunities (11).

Inpatient individuals may have better access to coordinated care; however, they may also face limitations in personalized treatment options due to economic constraints and lack of disability cards. In Tunisia, not all patients with disabilities are necessarily in possession of a card (11). This is because some do not consider themselves to have a disability at all, while others simply have not applied for the card (11). Even benefiting from specialized care, the lack of structured communication between healthcare providers, social services, and disability support organizations often leads to fragmented services for individuals with SCI (12). Moreover, follow-up care for SCI patients' remains inadequately addressed (12). Many individuals do not receive the continuous monitoring and support needed to manage secondary health conditions that often arise after an initial injury (12). This gap in care can lead to increased morbidity and diminished QoL for patients (12). The shortage of trained healthcare professionals specializing in the management of persons with disabilities in Tunisia further complicates care for SCI patients (13). In the frame of WHO Rehabilitation 2030 project (14), the Tunisian Society of Physical Medicine and Rehabilitation conducted a comprehensive assessment of the Tunisian rehabilitation system, a prerequisite for preparing a high-quality standardized report that will inform the planning process to facilitate and coordinate the implementation of the national strategic plan for rehabilitation (13). Only 13 governorates out of 24 have specialized rehabilitation facilities in either the public or the private sector, mainly concentrated in urban areas, leaving rural populations underserved (13). The number of physiatrists per 100000 inhabitants vary from 0 in the northern and southern west to 2.1 in the eastern coast of the country (13). Additionally, many healthcare providers may not have the necessary expertise to deliver comprehensive healthcare services for persons with disability (15). A 2020 Tunisian survey has assessed the knowledge and attitudes of general practitioners and family physicians on the management of disability (15). It appears that although the majority of respondents considered that their role is crucial, they stated that they had never received training on disability either during the course of medical studies or as part of their continuous professional development and reported several difficulties in the management of these patients (15).

Advancements and gaps in disability rights and support systems in Tunisia

Tunisia has made notable progress in improving the rights and living conditions of individuals with disabilities (11). The country has adopted the Convention on the Rights of Persons with Disabilities (16), and enshrined protections in its Constitution of 2014, particularly in Article 48, which promotes their full integration into society (17). Increased awareness and advocacy efforts by civil society organizations have further supported disability rights; while initiatives aimed at enhancing employment opportunities and inclusive education have fostered economic independence and social integration

for people with disabilities (11). Additionally, non-governmental organizations have played a crucial role in providing essential services and resources, contributing to better healthcare access and overall support for these individuals (11). While there are ongoing efforts to improve services, the implementation of laws and policies remains inconsistent, highlighting a gap between legislative frameworks and practical support for individuals with disabilities.

Enhancing SCI care in Tunisia: policy recommendations and integrated approaches for long-term management

Policymakers are invited to enhance support systems for SCI management in Tunisia (11). This includes increasing the number of rehabilitation facilities, improving training programs for healthcare workers, ensuring equitable access to care across different regions and adequate resources allocation for long-term care (11). In February 2017, faced with the urgent need to strengthen rehabilitation globally, the WHO launched the Rehabilitation 2030 initiative; a comprehensive approach aiming to optimize functioning and reduce disability for individuals with health conditions worldwide (14). The initiative recommends that rehabilitation be integrated into all levels of healthcare as a fundamental component of universal health coverage (14). It emphasizes the need for timely, high-quality, and accessible rehabilitation services to meet the growing global demand, particularly as populations age and the prevalence of chronic conditions increases (14). The organization calls for enhanced leadership, governance, and financing for rehabilitation services, alongside improved health information systems and workforce development (14). Additionally, the WHO highlights the importance of addressing rehabilitation needs in emergency-situations, ensuring that these services are part of health system preparedness and response plans (14). The European Spinal Cord Injury Federation (ESCIF) advocates for centralized treatment and rehabilitation centers dedicated to SCI care across Europe (18). These centers aim to provide comprehensive services, including peer support and expert counseling, which are crucial for the long-term management of SCI patients (18). After being discharged from inpatient rehabilitation, SCI individuals will mainly rely on ongoing support from the primary care system for health-related questions (19). In Tunisia, general practitioners and family physicians play a crucial role in the ongoing care of these patients (15). They are responsible for monitoring various health aspects, including genitourinary and respiratory systems, skin care, and managing complications (20). They must possess the necessary expertise to provide holistic care for patients with SCI (19). This underscores the critical need for specialized training that addresses the unique challenges faced by SCI patients (19). Such training should be integrated into both graduate medical education and ongoing professional development programs. By equipping Tunisian family physicians with the skills and knowledge to understand the physical, emotional, and social aspects of SCI, we can enhance patient outcomes and improve the overall quality of care. Tunisian Faculties of Medicine and health schools must expand their offerings of specialized programs focused on disability especially SCI care to adequately prepare future healthcare professionals for the unique challenges and needs of this patient population. Follow-up care includes the prevention and management of secondary health conditions that commonly arise after SCI (20). This encompasses monitoring nutritional intake, preventing complications such as autonomic dysfunction, pressure sores, urinary tract infections, spasticity, and contractures and managing pain (20, 21). Continuous psychosocial support is also critical to help patients adjust to their new circumstances and maintain mental well-being (22). Structured follow-up programs specifically designed for SCI patients in Tunisia are needed to assure adequate monitoring and management of long-term complications associated with SCI, ultimately affecting patients' QoL (12). Some countries offer to their SCI patients structured outpatient follow-up care provided by specialists from the SCI rehabilitation center (12). One to four physicians from different disciplines are involved (12). The follow up is either home-based, where the professionals visit the people with SCI at home; or by telemedicine; or by visits of people with SCI to the multidisciplinary team in the rehabilitation center (12). Added to clinic usual care, the effectiveness of interdisciplinary follow-up clinics has been reported (23). The goal of these clinics is to give recommendations regarding the prevention and the control of existing secondary health conditions (23). It is important to mention that in LMICs like Tunisia, where beds are scarce or when patients would not be able to afford to travel, telerehabilitation consultations can be an alternative to provide care for patients and to support health care systems (24). Patients can be screened for complications and referred to local service providers' when necessary (24). The risk is, when implemented in a weak health system, telerehabilitation may fail resolving rehabilitation needs (24). The WHO stated digital interventions should not substitute care but should strengthen health systems (25). Mobile health (mHealth) self-management support tools have significant potential to enhance the care provided to individuals with SCI, particularly in areas such as bowel, bladder, and pain management (26). A 2023 review has highlighted the critical need for these tools to offer more comprehensive coverage of essential self-management components (26). Encouraging further research in this domain is crucial, as it can lead to the development of more holistic mHealth solutions that address not only physical health needs, but also emotional and social aspects of living with SCI and to adopt standardized methods for evaluating their usability and accessibility (26). The ESCIF highlighted the significant benefits that newly injured individuals with SCI gain from connecting with peers who have similar experiences, covering practical and experiential advices, and sensitive topics like sexuality and identity (18). Peer counselors play a vital role by serving as role models facilitating connections and activities that enhance the rehabilitation process and community integration for

individuals with SCI (18). To fully harness this valuable resource, comprehensive peer-counseling and support services must be established in SCI rehabilitation centers, supported by consistent funding from relevant authorities (18). Community-based support services can help mitigate complications associated with SCI (27). While formal follow-up programs may be limited, there is potential for community-based initiatives to provide ongoing support for SCI patients (27). These programs can offer resources for self-management and facilitate access to healthcare services within local communities (27). Current practices emphasize a patient-centered approach, which is essential for effective long-term rehabilitation of individuals with SCI (28). This approach prioritizes the unique needs, preferences, and values of patients, fostering effective communication and collaboration between healthcare providers and patients (28). Recent evidence suggests that when patients are actively engaged in their care decisions, they are more likely to adhere to treatment plans and experience better health outcomes ultimately leading to reduced healthcare costs and improved satisfaction and QoL (28). Moreover, this approach is closely linked to patient education; individuals with SCI must have a solid understanding of their condition to make informed choices about their care (28). Healthcare providers play a vital role in this process by making concerted efforts to educate their patients about their situation, treatment options, and self-management strategies (29). A 2023 systematic review reported that guidance and personalized education provided in rehabilitation programs could positively influence health literacy levels among SCI patients (29).

Strategic recommendations for improving SCI management in Tunisia

To effectively manage SCI patients in Tunisia, it is essential to implement a series of targeted recommendations that address the multifaceted challenges these individuals face in their recovery and long-term care. Table 1 presents the recommendations along with a concise description of the related action steps (30).

Table 1. Key recommendations for enhancing spinal cord injury (SCI) care and support in Tunisia

N°	Recommendation	Description
1	**Enhance data collection**	. Establish comprehensive registries for SCI with uniform and transparent recording practices to allow data collation and comparison, providing reliable epidemiological data for public health policies.
2	**Advocate for policy change**	. Engage with policymakers to create supportive legislation focused on access to rehabilitation services and community resources for SCI patients. . Health care providers play a key role in influencing policymakers to support individuals with SCI by: - Providing valid and reliable data on SCI patient needs. - Emphasizing early intervention to reduce healthcare costs and improve outcomes. - Collaborating with advocacy groups and NGOs. - Communicating constructive ideas to policymakers. - Fostering a sense of ownership over SCI care among decision-makers.
3	**Integrate rehabilitation services**	. Ensure rehabilitation services are part of a coordinated national approach to trauma care, addressing both physical and psychological needs of SCI patients.
4	**Enhance health literacy**	. Develop programs that educate individuals about their health conditions, treatment options, and self-care strategies, empowering them to manage their health effectively.
5	**Utilize mbile health (mHealth) tools**	. Develop and promote mHealth applications for self-management resources tailored to SCI patients, facilitating better health monitoring and communication with healthcare providers.
6	**Promote peer support programs**	. Establish peer support networks that connect individuals with SCI, helping them share experiences, cope with challenges, and foster community integration and emotional support.
7	**Promote research**	. Promote research collaboration between local and international researchers to address knowledge gaps and develop innovative solutions for SCI. . Encourage partnerships between health and higher education ministries to drive research and align educational and healthcare priorities.
8	**Develop targeted prevention programs**	Focus on reducing road traffic accidents through awareness campaigns and improved safety regulations, particularly in regions with high incidence rates of SCI.

Conclusion

In light of these challenges, it is imperative that stakeholders, including healthcare providers, policymakers, and advocacy groups, collaborate to enhance the management of SCI in Tunisia. By focusing on improving rehabilitation services, ensuring equitable access to care across regions and fostering a supportive environment for individuals with disabilities, Tunisia can make significant strides toward better health outcomes for its SCI population. Improved training, community support initiatives, and policy reforms will be essential to enhance the QoL for individuals living with SCI in the country.

ABREVIATIONS
ESCIF: European Spinal Cord Injury Federation
GBD: Global Burden of Diseases
ICF: International Classification of Functioning, Disability and Health
LMICs: low- and middle- income countries
mHealth: Mobile health
QoL: quality of life
SCI: spinal cord injury
YLDs: years lived with disability

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