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Spinal Cord Injury and Psychosocial Burden of Survivors: Lived Psychosocial Realities and the Scope of Social Work Intervention

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ABSTRACT

Spinal cord injury (SCI) is a life-altering condition with far-reaching physical, psychological, social, and economic consequences. In India, the impact of SCI is intensified by inadequate rehabilitation services, limited psychosocial support, and persistent social stigma surrounding disability. While medical literature has extensively documented the clinical aspects of SCI, comparatively less attention has been given to the lived psychosocial realities of individuals navigating long-term disability within constrained social systems. This paper examines spinal cord injury as a multidimensional social issue, drawing upon existing literature and field-based insights derived from lived experiences of the survivors. The paper explores the psychosocial burden associated with SCI, including emotional distress, family caregiving dynamics, economic vulnerability, and social exclusion. It further highlights the scope of social work intervention across individual, family, community, and policy levels. The paper argues for a holistic, rights-based, and psychosocially informed social work intervention to spinal cord injury rehabilitation in India.

Keywords: Spinal Cord Injury, Psychosocial Burden, Disability, Social Work Intervention

INTRODUCTION

Spinal cord injury (SCI) refers to damage to the spinal cord resulting in partial or complete loss of motor, sensory, and autonomic functions below the level of injury. Globally, SCI is recognised as a major public health concern due to its long-term impact on individuals, families, and healthcare systems (World Health Organization [WHO], 2023). In India, spinal cord injuries are commonly caused by road traffic accidents, falls from height, and occupational hazards, particularly affecting young adults in their productive years (Neomotion, 2025).

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The consequences of SCI extend far beyond physical impairment. Therefore it becomes important to capture the lived realities of the survivors. In this context the important aspects are related to individual and care givers experiences, profound disruptions in emotional wellbeing, social relationships, education, employment, and participation in community life. Families are burdened with immediate, short term and long-term caregiving responsibilities, which directly and indirectly leads to financial strain and emotional exhaustion. Moreover, in a context where disability continues to be associated with stigma and dependency, people with SCI frequently face marginalisation and social exclusion in multiple levels. " *In 2017, WHO launched Rehabilitation 2030, emphasizing health system strengthening and calling for stakeholders worldwide to: improve leadership and governance; develop a strong multidisciplinary rehabilitation workforce; expand financing for rehabilitation; and improve data collection and research on rehabilitation*". In view of this social work practice, with its emphasis on person-in-environment and a call for social justice, offers a critical lens for understanding and responding to the psychosocial dimensions of spinal cord injury. This paper seeks to situate SCI within a broader psychosocial and structural framework, examining the burden on family and individuals associated with SCI, the lived realities of survivors, and the scope of social work intervention in the Indian context.

REVIEW OF LITERATURE

Spinal Cord Injury and Health Outcomes

The World Health Organization (WHO), stated that globally over 15 million people living with SCI (WHO 2024). In 2023 WHO, estimated that between 250,000 and 500,000 people worldwide sustain spinal cord injuries each year. It is a leading cause of permanent and long term disability, especially among males of productive age group. It is adding social, economic, and psychosocial burden on individuals and families. The WHO sets agenda for 2030 to work for rehabilitation of survivors with appropriate intervention with relevant stakeholders. The burden of SCI in India is difficult to estimate with accurate data set, the absence of a national spinal injury registry limits accurate prevalence data; however, available estimates indicate a substantial and growing burden (Neomotion, 2025). From a bio medical perspective the Individuals with SCI are at increased risk of secondary complications such as pressure sores, urinary tract infections, bowel dysfunction, chronic pain, and respiratory problems, all of which significantly affect quality of life (Bennett, 2024).

Psychological and Emotional Impact

Research consistently highlights high rates of depression, anxiety, and psychological distress among individuals with spinal cord injury (van Leeuwen et al., 2010). The sudden loss of bodily function, uncertainty regarding recovery, and dependence on others contribute to emotional vulnerability. In low-resource settings, limited access to mental health professionals within rehabilitation services further compounds psychological distress. Women with spinal cord injuries often face additional emotional burdens due to gendered expectations related to caregiving, marriage, and sexuality. Disability, when combined with patriarchal social norms, can intensify stigma and social isolation (Ghai, 2015).

Family, Caregiving, and Social Support

Families play a central role in long-term SCI care, particularly in countries where formal caregiving services are limited. Caregiver burden has been linked to emotional strain, reduced social participation, and financial hardship (Pinquart & Sörensen, 2007). Despite these challenges, family support remains a key protective factor in adjustment and rehabilitation.

Social Participation and Economic Exclusion

People with spinal cord injuries frequently encounter barriers to education, employment, and community participation due to inaccessible infrastructure and discriminatory attitudes (García-Rudolph et al., 2024). Although legislative frameworks such as the Rights of Persons with Disabilities Act (2016) promote inclusion, gaps in implementation continue to limit opportunities for economic independence.

METHODOLOGY

The paper adopted a qualitative, exploratory approach based on sustained field engagement and critical review of existing literature. Insights are drawn from lived experiences of individuals with spinal cord injury and limitations encountered in healthcare and community support contexts. The analysis synthesises recurring psychosocial patterns across individual and their care givers experiences. Based on individual narratives their lived experiences are captured to analyse the situation at individual, familial and caregiver's point of view. In total 15 in-depth interviews are undertaken with the consent of survivors, family and hospital based caregivers (doctors and support staffs). As far as data analysis is concerned an inductive thematic approach was used to identify key dimensions of psychosocial burden, including emotional adjustment, healthcare access, family caregiving, social participation, and economic challenges (Braun & Clarke, 2006). Ethical considerations such as confidentiality, anonymity, and sensitivity to vulnerability were maintained throughout. The methodology allows for contextual understanding while remaining suitable for future doctoral research. The collected data is presented under different themes to highlight the psychosocial and care giving burden and areas of intervention.

Locating Spinal Cord Injury and Psychosocial Burden

The area of spinal cord injury and it's impact on individuals demands multidimensional critical understanding. In order to develop a comprehensive understanding about this area within the social work practice required locating the lived experiences. This section is highlighting the important aspects under various themes through the lens of lived experiences of the SCI survivors.

Healthcare Access and Rehabilitation Challenges

Field-based insights reveal fragmented healthcare pathways for individuals with SCI. Initial trauma care is often followed by inconsistent rehabilitation services, particularly within public health settings. Limited guidance on long-term self-management contributes to preventable health complications and prolonged dependence.

Emotional Distress and Identity Adjustment

Psychological distress emerges as a recurring concern, particularly during transitions from hospital to home. Feelings of grief, fear, and uncertainty are common, especially in the absence of structured psychosocial support. Adjustment is an ongoing process, influenced by health setbacks, social interactions, and economic pressures.

Stigma, Relationships, and Social Isolation

Social withdrawal is frequently reported following spinal cord injury. Negative societal attitudes, inaccessible public spaces, and discomfort around disability restrict social participation. Women with SCI face heightened stigma related to marriage and femininity, reinforcing isolation and emotional distress.

Economic Vulnerability and Employment Barriers

Loss of livelihood significantly affects independence and dignity. Disability pensions and welfare schemes are often inadequate to meet medical and daily living costs. Despite educational qualifications, individuals encounter discrimination in the labour market due to reluctance to provide reasonable accommodations.

Family Support and Care Dynamics

Family members provide essential physical, emotional, and financial support. While this support enables survival and adjustment, it also places significant strain on caregivers. The lack of formal caregiving services shifts responsibility almost entirely onto families, particularly women.

Resilience and Agency

Despite systemic barriers, individuals with SCI demonstrate resilience through education, skill development, advocacy, and creative pursuits. These efforts challenge deficit-based perceptions of disability and highlight the importance of enabling environments.

Social Work Intervention Scope

Social work intervention in spinal cord injury must be multidimensional and rights based.

At the individual level, social workers can provide psychosocial counselling to support emotional adjustment, trauma processing, self-esteem, and future planning. Addressing issues related to sexuality, identity, and mental health is essential for holistic rehabilitation. The future stability and financial independence emerged as one important area.

At the family level, social workers can facilitate services to caregivers through counselling, psychoeducation, and linkage to various services and welfare schemes. Family-focused caregiving trainin, stress and burnout knowledge and remedies, timely consultations and support group based interventions can reduce caregiver burden and improve coping and communication.

At the community level, social workers can facilitate the awareness and educational programmes, peer support groups, promote community-based rehabilitation, and advocacy for stigma free support systems. Community engagement are important to enhance social inclusion and collective resilience.

At the policy and advocacy level, social workers play a critical role action and advocacy for ensuring access to disability entitlements, welfare schemes and programmes, timely medical, and rehabilitation services, assistive aids, appliances and devices. The inclusive economic assistance and employment opportunity for survivors is the need of the hour. Advocacy efforts are essential to bridge gaps between policy, legislation, and welfare schemes to create inclusive environment for positive intervention and outcomes.

CONCLUSION

Spinal cord injury is not merely a medical condition but a complex psychosocial experience shaped by response of various stakeholders involved in services. The need is to focus on healthcare systems, family structures, economic conditions, and societal attitudes. Field- insights gathered through lived experiences reveal persistent psychosocial burdens, including emotional distress, social exclusion, and economic vulnerability. While individuals demonstrate resilience and agency, systemic barriers continue to limit wellbeing and participation. A holistic social work approach that integrates psychosocial support, family engagement, community inclusion, and policy advocacy is essential for meaningful rehabilitation. Strengthening social work involvement within spinal cord injury care can contribute significantly to dignity, autonomy, and social justice for persons living with SCI in India.

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