

# EXPLORING THE QUALITY OF LIFE OF WOMEN WITH SPINAL CORD INJURY: A COMPREHENSIVE REVIEW AND PATHWAYS TO EMPOWERMENT

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**Abstract:** Women with spinal cord injuries (SCI) face unique challenges affecting their quality of life, including limited healthcare access, societal stigma, and psychological strain. This paper explores these issues through a review of existing literature and in-depth case studies, emphasizing the underrepresentation of women in SCI research. It identifies barriers such as family dynamics, societal expectations, and infrastructural limitations. The study offers recommendations for improving support systems, focusing on financial independence, education, and self-empowerment to enhance the quality of life for women with SCI.

**IndexTerms - Women with Spinal Cord Injury, SCI, Gendered Disability, Disability, Rehabilitation, Barriers**

## I. INTRODUCTION

Spinal cord injury (SCI) is a significant health concern in India, where over 300,000 individuals live with this disability, making it the second largest population of spinal cord injury sufferers globally. (Foundation, n.d.) The causes of SCI in India are multifaceted, including traumatic events such as falls and road traffic accidents, as well as non-traumatic factors like tumours, infections, and degenerative conditions. The impact of SCI extends beyond physical impairment, often resulting in long-term disability that affects an individual's ability to perform daily activities and can lead to premature mortality. (Fernandes & Nakray, 2024)

Notably, women with SCI in India encounter unique barriers compared to their male counterparts, often facing intensified discrimination and social exclusion rooted in gender norms. (Chhabra, Sharma, & Arora, 2018) These barriers include limited access to healthcare services, financial dependence, and societal stigma, which collectively hinder their rehabilitation and reintegration into society. (Lu, et al., 2024) Research highlights the importance of addressing not just physical rehabilitation but also the psychological, social, and sexual health needs of women to enhance their overall well-being. (Isaksson & Hellman, 2012) Controversies surrounding the management of SCI in India also highlight significant disparities in care, particularly in rural areas where resources are scarce, further complicating recovery efforts for women with SCI. (Lucke, Coccia, Goode, & Lucke, 2004) Advocacy for improved policies and comprehensive support systems is crucial for addressing these inequities and ensuring that women with SCI receive the holistic care they deserve. (Divyalasya T. V., Kumar, Bhat, Lakhan, & Agrawal, 2021)

## II. AIM

The aim of this research is to explore the quality of life of women with spinal cord injuries (SCI) by examining the socioeconomic, psychological, and physical challenges they face, while identifying pathways to their empowerment.

## III. RESEARCH OBJECTIVES

The objectives of the study are to:

- Explore the socioeconomic, psychological, and physical challenges faced by women with spinal cord injuries (SCI).
- Examine the role of family, caregivers, and societal expectations in shaping the experiences and well-being of women with SCI.
- Identify pathways to empowerment through education, financial independence, and self-advocacy, and recommend gender-sensitive policies and support systems.

## IV. REVIEW OF LITERATURE

The epidemiology of traumatic SCI in developing countries, including India, shows a troubling trend. Systematic reviews indicate that incidence rates are rising, necessitating urgent attention to prevention and treatment strategies. (Lu, et al., 2024) Effective rehabilitation is crucial for improving the quality of life of women with SCI in India. Research emphasizes the importance of personalized rehabilitation programs that not only address physical recovery but also consider psychological, social, and sexual health aspects. (Isaksson & Hellman, 2012) Despite the significant need for tailored rehabilitation services, there remain substantial gaps in support, particularly regarding the sexual health needs of women with SCI. (Sharma, 2022)

Given the complexities surrounding rehabilitation and care, understanding these dimensions is crucial for improving the overall well-being of this population. The primary physical, social, and economic barriers that prevent women with spinal cord injuries (SCI) in India from accessing available support systems and resources are multifaceted and deeply entrenched.

Cultural attitudes and beliefs in India have a profound impact on the quality of life for women suffering from spinal cord injuries (SCI). One of the primary cultural issues is the pervasive discrimination faced by women with disabilities, which often exacerbates

the challenges they encounter. In Indian society, women with disabilities, including those with SCI, face a "triple handicap" due to their gender, disability, and the societal stigma associated with both. This triple burden significantly affects their social and psychological well-being. For instance, they are frequently subjected to violence, ranging from neglect to more severe forms of abuse, which further diminishes their quality of life. (Dawn, 2013)

In India, spinal cord injury (SCI) patients face significant challenges in their recovery and rehabilitation. Supportive therapies play a crucial role in the treatment process, with assistive devices, adaptive equipment, and psychological support being integral components. Devices such as wheelchairs, braces, and orthotics aid mobility and promote independence, while adaptive equipment assists individuals in performing daily activities like dressing, bathing, and eating. Psychological support, including counselling and support groups, addresses the emotional and psychological impacts of SCI, equipping individuals with necessary coping tools. (Magazine, n.d.)

The management of SCI in India presents numerous challenges, particularly in terms of comprehensive care and rehabilitation. These challenges include inadequate rehabilitation services, poor access to healthcare facilities, and a lack of trained professionals, which collectively hinder the recovery and quality of life for individuals with SCI. (Chhabra, Sharma, & Arora, 2018) Additionally, social attitudes toward disability can exacerbate these challenges.

## V. RESEARCH METHODOLOGY

For fulfilling the aim and objectives of the study, the researcher has opted for case study method to get into the depth of the problem. The researcher has conducted in-depth interviews with four women having spinal cord injuries residing in Delhi to capture their lived experiences. Each case study has been conducted using a semi-structured questionnaire having open-ended questions covering each of the dimension. Interviews have been conducted in-person and virtually as per the availability of the person, and comfort of participants. The researcher has employed Thematic analysis to analyse the interview transcripts and past researches.

## VI. DATA INTERPRETATION AND ANALYSIS

### 6.1 Case Study 1: Ridhi's Journey with Spinal Cord Injury

Ridhi (name changed), from Bihar, suffered a life-changing spinal cord injury in 2019 at the age of 17, just after completing her 12th board exams. She fell from the terrace of her home and was found by neighbors who rushed her back to her family. Although she was fully conscious and aware that she couldn't feel anything below her waist, those around her dismissed the severity of the injury because there was no external damage. She was unable to stand, despite encouragement from those around her. At the time, Ridhi's father, a civil engineer, was in Delhi. Upon hearing about her condition, he consulted a doctor in Delhi, who advised an MRI scan. The MRI revealed that Ridhi had a spinal cord injury at L1 and L2, and surgery was needed immediately. Ridhi's family spent all their savings to transfer her to Delhi, where she underwent surgery on 8th July 2019. Despite the operation, she lost control over her legs, as well as her bowel and bladder functions.

In the hospital, Ridhi struggled with accepting her condition. Initially during rehabilitation, she resisted to purchase wheelchair, believing it was only necessary during her stay at ISIC. Her mental state was fragile, and she refused to speak with a counselor. However, her turning point came when Dr. Chhabra encouraged her to focus on her future rather than her limitations. She learned to manage her daily tasks, including transferring herself from her bed to a wheelchair, and gradually regained her independence. Returning home to Bihar after two months in the hospital, Ridhi faced emotional challenges, especially from visitors who pitied her. She found their comments demotivating and once asked her father to take her to an NGO or somewhere away from the negativity. Over time, she realized the sacrifices her parents made for her recovery and decided to pursue her studies. Ridhi prepared for the NEET exam, using online resources during the COVID-19 lockdown, and passed in 2021. She is now in her third year of MBBS at IPGME&R and SSKM Hospital in Kolkata. Ridhi manages her daily tasks independently, and her mother stays with her in the hostel to provide emotional support. While she is focused on her studies, she is open to finding a long-term relationship in the future.

### 6.2 Case Study 2: Karuna's Journey with Spinal Cord Injury

Karuna (name changed) was only 1.5 years old when she and her family were involved in a car accident in 2005, which left her with a C7-D1 nerve compression injury. Despite receiving physiotherapy in Agra and Bulandshahar, her condition did not improve, and her family had to accept that Karuna would be permanently paralyzed. Her father became her primary caretaker, ensuring she continued her education. Thanks to the support of her friends and adjustments made at school, Karuna completed her studies.

Physiotherapy remains central to Karuna's life, helping her maintain her physical and mental well-being. She underwent stem cell therapy early in her recovery, which initially improved her bowel and bladder control, but subsequent treatments were less effective, leaving her family feeling disappointed. Financially, Karuna's family faced a heavy burden. They filed a lawsuit against the truck company responsible for the accident, but it took many years to receive an insurance payout in 2022. During that time, her family used their savings to cover her treatment costs, with no assistance from the government. Karuna's parents remain protective, particularly regarding her future, and have not encouraged her to think about marriage, fearing the challenges it could bring. Although she occasionally struggles with the emotional toll of her condition, she remains hopeful about finding a life partner who will understand and support her. Her story underscores the emotional, financial, and social challenges of living with a spinal cord injury in India, as well as the importance of family support.

### 6.3 Case Study 3: Navigating Life with D12 Spinal Cord Injury (Anonymous)

In February 2002, a 19-year-old woman from Delhi experienced a serious injury when she fell from the second floor of her under-construction home. Her father took her to a nearby nursing home, and later to a private hospital in Delhi. The doctors there informed her family that surgery was necessary, but the family couldn't afford the Rs 1,00,000 required. They sought treatment at Safdarjung Hospital, where the doctors initially recommended bed rest, believing the bones would heal over time. However, her condition worsened, and she was eventually readmitted for surgery. She spent months bedridden, relying on a urine bag and receiving only basic guidance in managing her condition. Despite the challenges, two years after the injury, she resumed her education through an open education program at Indira Gandhi National Open University (IGNOU), where she earned her degree. Financial instability was a constant problem, as she relied on a disability pension and some online part-time work.

The injury led to social isolation as well. Superstitions about disabilities distanced her from relatives, and societal stigma restricted her social interactions. Her brother helped with her mobility, as public spaces were not accessible. While she remains open to the idea of marriage, her family has never discussed it seriously.

### 6.4 Case Study 4: A Journey from Trauma to Advocacy (Anonymous)

At the age of 25, the fourth respondent's life changed dramatically after a pool accident at a party. A misjudged dive resulted in a C5 spinal cord injury that left her wheelchair-bound. Before the injury, she was an accomplished Kathak dancer and national-level swimmer. She was rushed to a nearby hospital and then transferred to the Indian Spinal Injuries Centre in Delhi, where she underwent surgery. After regaining consciousness two days later, she realized she had lost all sensation below her waist, including bowel and bladder control.

Her mother, already caring for her older sister who has cerebral palsy, became her primary emotional and physical support. During her stay at the hospital, she sought emotional guidance from a psychologist, which helped her deal with the trauma. Despite these efforts, she faced a social fallout—many friends drifted away after the accident, and her romantic relationship ended soon after. While this was painful, it allowed her to focus on her recovery and personal growth.

Once discharged, she found solace in spirituality and set new life goals. She decided to channel her energy into becoming a motivational speaker, aiming to inspire others with disabilities. She also developed aspirations of becoming a para-swimmer and a TED Talk speaker, using her story to advocate for better accessibility and support for people with disabilities in India.

Financially, her family's stability helped her access proper medical equipment and caregiving services, but she became acutely aware of the challenges that people from less privileged backgrounds face. Her experience applying for a disability certificate was particularly frustrating. A doctor questioned her condition, despite clear MRI evidence of her injury. This incident, along with the lack of accessible infrastructure in India, motivated her to become an advocate for disability rights.

## VII. THEMATIC ANALYSIS

The experiences of these four women reveal several key themes regarding the challenges and resilience of women with spinal cord injuries in India.

### 7.1 Healthcare Accessibility and Rehabilitation

Each of the women faced challenges in accessing adequate healthcare and rehabilitation services. Ridhi and the third respondent encountered delays in receiving proper care due to initial misdiagnoses, while Karuna's family had to navigate expensive and often ineffective treatments like stem cell therapy. Rehabilitation, particularly mental health support, was insufficient in all cases, with many women struggling emotionally after their injuries.

### 7.2 Financial Independence and Employment Challenges

Financial instability was a common issue for all four women. Ridhi's family spent all their savings on her treatment, while Karuna's family endured years of financial strain before receiving compensation. The fourth respondents, though from relatively stable financial backgrounds, faced employment discrimination, with their employers hesitant to provide the necessary accommodations for their disabilities.

### 7.3 Social Isolation and Relationship Changes

All four women experienced social isolation after their injuries. Ridhi lost friends, including a boy she had been close to before her injury, while the other respondents also saw friendships fade as people distanced themselves. Romantic relationships were similarly affected, with one respondent losing a relationship shortly after her injury.

### 7.4 Family Support and Caregiving

Family support played a crucial role in each woman's journey to recovery. While family support is essential, it often comes with emotional and financial burdens. Many families are left to manage the long-term care of their loved ones without adequate government support or access to professional caregiving services.

### 7.5 Resilience and Aspirations

Despite the immense challenges they faced, each woman displayed remarkable resilience. Ridhi's determination to pursue her dream of becoming a doctor, Karuna's focus on completing her education, and the fourth respondent's aspirations of becoming a motivational speaker and para-swimmer are examples of how these women have found strength through adversity.

## VIII. CONCLUSION

The case studies presented of the four women highlight the immense challenges faced by women with spinal cord injuries in India, ranging from inadequate healthcare and financial hardships to social isolation and emotional struggles. However, their resilience and determination also show that with the right support, these women can overcome barriers and pursue fulfilling lives. By addressing the systemic barriers, they face—such as inadequate healthcare, financial instability, and a lack of accessible infrastructure—India can create an environment in which women with spinal cord injuries can thrive. With improved rehabilitation services, financial assistance, inclusive employment opportunities, and enhanced social and caregiving support, these women can lead empowered lives and contribute to society as equals. Their stories remind us that disability does not diminish potential and that every woman deserves the opportunity to pursue her dreams and live a life of dignity and independence.

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