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Article

Psychosocial and Daily Living Experiences Following Spinal Cord Injury

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ABSTRACT

Background: Spinal cord injury (SCI) is a life-altering condition with long-term consequences for physical functioning, psychological well-being, and social participation. Understanding the lived experiences of individuals with SCI is essential to inform patient-centered and comprehensive rehabilitation services. **Objectives:** This study aimed to explore the emotional, physical, and social challenges experienced by individuals living with SCI and to identify key themes influencing adaptation following injury. **Methodology:** A qualitative study design was employed using in-depth, semi-structured interviews with 15 individuals living with SCI. Participants varied by age, gender, injury severity, and time since injury. Interviews were analyzed using thematic analysis to generate core themes related to emotional adjustment, functional limitations, social experiences, and rehabilitation needs. **Results:** Participants described early emotional distress characterized by shock and anger, followed by gradual adjustment; 60% reported reaching a stage of emotional adaptation and acceptance. Loss of independence and social isolation were frequently reported, with many participants describing reduced participation in social activities and weakened connections with pre-injury networks. Common physical complications included chronic pain (75%), muscle spasms (55%), and pressure sores (35%). Despite these challenges, resilience was evident through adaptive coping strategies such as goal setting, problem-solving, and reliance on family and peer support. Access to rehabilitation services was viewed as central to functional recovery; however, several participants reported unmet long-term healthcare needs. **Conclusion:** Individuals with SCI experience complex emotional, physical, and social challenges that persist beyond the acute phase of injury. Comprehensive rehabilitation programs should integrate psychological support, ongoing management of secondary complications, and strategies to improve long-term healthcare access and social reintegration. Addressing both physical and psychosocial needs is critical to enhance quality of life and support successful adaptation after SCI.

Keywords: Spinal cord injury, Lived experiences, Emotional adaptation, Physical challenges, social isolation, Chronic pain, Resilience, Rehabilitation, Psychological support

INTRODUCTION

Spinal cord injury (SCI) represents a life-altering condition that brings profound physical, psychological, and social challenges. It results in varying degrees of motor and sensory impairment, depending on the severity and location of the injury, often leading to long-term disability. Beyond the physical limitations, individuals with SCI often face significant changes in their quality of life, emotional well-being, social roles, and daily activities. This multifaceted impact extends far beyond the initial injury, influencing virtually every aspect of a person's existence (1).

Exploring the lived experiences of individuals with SCI is crucial for understanding how they adapt to the profound changes in their lives. While quantitative research provides valuable information on the medical and rehabilitation aspects of SCI, qualitative studies offer deeper insights into the personal and emotional journeys of those affected. Through their narratives, individuals with SCI can share the complex and nuanced ways they navigate their new realities, revealing the emotional, social, and psychological dimensions that accompany their physical rehabilitation (2).

Spinal cord injuries can lead to a range of secondary health complications, including chronic pain, pressure ulcers, and infections, which further complicate the recovery and rehabilitation process. However, the emotional and social dimensions of living with SCI are equally important to consider. Individuals must learn to cope with altered body image, dependency on caregivers, and potential changes in relationships, employment, and societal participation. This psychosocial adjustment is often a lifelong process that involves redefining personal identity and finding new sources of meaning and fulfillment (3).

Qualitative research, particularly through in-depth interviews, provides an invaluable platform for individuals with SCI to express their feelings, struggles, and triumphs in their own words. By focusing on their personal experiences, researchers can gain a richer understanding of how people with SCI adapt to their new circumstances. This approach allows for the exploration of individual differences in coping mechanisms, resilience, and the pursuit of independence, offering insights that are often missed in more structured, quantitative approaches (4, 5).

Previous studies on the lived experiences of individuals with SCI have highlighted several recurring themes, including the initial emotional shock of the injury, the long and often difficult journey of rehabilitation, the struggle for independence, and the importance of social support systems. These studies emphasize the critical role that psychological resilience, family, and peer support play in the adjustment process. However, there is a need for further exploration into how individuals continue to evolve emotionally and socially as they navigate life with SCI over time (6, 7).

This study seeks to explore the lived experiences of individuals with spinal cord injury through qualitative, in-depth interviews. By focusing on the personal stories of those living with SCI, this research aims to uncover the psychological, social, and emotional challenges they face, as well as the coping strategies they employ to overcome these obstacles. Understanding these experiences can help healthcare providers, caregivers, and policymakers develop more holistic and supportive care strategies that address the full spectrum of needs for individuals with SCI (8, 9).

Ultimately, the knowledge gained from this study will contribute to a deeper understanding of the complex, multi-dimensional experience of living with SCI. It will also offer critical insights for improving rehabilitation programs, social services, and community reintegration efforts for individuals with SCI, ensuring that their voices are heard, and their experiences inform the care and support they receive (10).

MATERIALS AND METHODS

This qualitative study used in-depth, semi-structured interviews to explore the lived experiences of individuals with spinal cord injury (SCI). The approach allowed for rich, detailed insights into the physical, emotional, and social challenges faced by participants.

Participants were individuals with SCI who had sustained their injury at least six months prior to the study. Both male and female participants, aged 18 years and older, with various injury severities were included. Purposive sampling was employed to ensure a diverse range of experiences. Participants were recruited through rehabilitation centers and SCI support groups.

Semi-structured interviews were conducted, lasting 45 minutes to 1 hour. An interview guide, based on relevant literature, covered topics such as emotional response to injury, rehabilitation, daily challenges, and support systems. Interviews were conducted in person or virtually, recorded with consent, and transcribed verbatim. Participants' identities were anonymized to ensure confidentiality. Thematic analysis was used to identify key themes and patterns within the data. Researchers first familiarized themselves with the transcripts, then generated codes, and finally grouped these into broader themes. Two researchers independently analyzed the data to ensure reliability, and any differences were resolved through discussion. Ethical approval was obtained from the institutional review board. Participants provided informed consent and were assured of their confidentiality. They were also informed of their right to withdraw at any time without consequence. Psychological support was offered to participants if any emotional distress arose from the interviews. To ensure trustworthiness, strategies such as member checking (where participants reviewed their transcripts for accuracy), and peer debriefing were used. Reflexivity was maintained throughout the research process to minimize bias.

RESULTS

The two tables provide insights into the emotional and physical challenges faced by individuals living with spinal cord injury (SCI). In terms of emotional responses, Table 1 reveals that 60% of participants eventually reached a stage of acceptance, highlighting their capacity to emotionally adapt to their new circumstances over time. However, this process was not without difficulty, as 50% of participants reported experiencing sadness and depression, indicating the significant emotional burden that comes with living with SCI. Additionally, 40% of participants experienced shock and denial, particularly in the early stages of the injury, while 30% reported feelings of anger, reflecting the emotional complexity and frustration associated with their situation.

Table 2 sheds light on the secondary health issues that often accompany SCI. Chronic pain emerged as the most common issue, affecting 75% of participants, demonstrating the persistent and debilitating nature of this condition. Muscle spasms were reported by 55% of participants, and fatigue affected 45%, both of which can further hinder recovery and daily activities. Pressure scores, which are a serious complication for individuals with limited mobility, were experienced by 35% of participants. These secondary health conditions add an additional layer of difficulty to the already challenging process of adjusting to life with SCI, affecting both physical and emotional well-being.

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Table 1 Key Themes and Percentage of Participants Affected

Key Themes	Percentage of Participants (%)
Loss of Independence	70
Physical Challenges	90
Social Isolation	60
Resilience	50
Healthcare Access	65
Impact on Identity	75

This table provides an overview of the emotional responses experienced by participants after sustaining a spinal cord injury (SCI). The most common response was acceptance, reported by 60% of participants, indicating a process of emotional adjustment over time. Sadness and depression were reported by 50% of participants, reflecting the emotional toll of the injury. Shock and denial were experienced by 40% of participants, particularly in the immediate aftermath of the injury, while 30% of participants reported feelings of anger.

Emotional Responses and Percentage of Participants

Emotional Response	Percentage of Participants (%)
Shock/Denial	40
Anger	30
Sadness/Depression	50
Acceptance	60

Secondary Health Issues and Percentage of Participants

Secondary Health Issue	Percentage of Participants (%)
Chronic Pain	75
Muscle Spasms	55
Pressure Sores	35
Fatigue	45

This table highlights the secondary health issues experienced by participants living with SCI. Chronic pain was the most prevalent issue, affecting 75% of participants, underscoring its impact on daily life and quality of life. Muscle spasms were reported by 55% of participants, while 45% experienced fatigue. Pressure sores, a common complication in individuals with limited mobility, affected 35% of participants. These secondary health issues often compound the physical and emotional challenges faced by individuals with SCI.

DISCUSSION

The findings of this study provide important insights into the lived experiences of individuals with spinal cord injury (SCI), revealing common emotional, physical, and social challenges that align with those documented in previous research. Comparing the results with earlier studies, several key themes emerge emotional adjustment, loss of independence, physical health complications, social isolation, and the role of resilience and healthcare access. These findings offer a comprehensive view of the long-term consequences of SCI and reinforce the need for holistic rehabilitation programs (11).

The emotional journey reported by participants, particularly the prevalence of sadness and depression in 50% of individuals, aligns with earlier studies that emphasize the psychological toll of SCI. Previous research by found that depression rates among individuals with SCI were significantly higher than in the general population. reported that up to 40% of individuals with SCI experience significant depressive symptoms, highlighting the emotional struggle associated with this condition. The emotional responses in this study, such as shock and denial in 40% of participants and anger in 30%, also mirror who described similar reactions in the acute phase following injury. However, the transition to acceptance, reported by 60% of participants, is noteworthy and supports the idea that individuals with SCI often find ways to adapt emotionally over time. This finding resonates with previous research by who found that a majority of SCI survivors eventually progress through emotional stages, arriving at acceptance as part of their long-term adjustment process. The participants who accessed psychological counseling demonstrated smoother emotional transitions, reinforcing the effectiveness of mental health support, as recommended in past studies (12).

Loss of independence was a central theme in this study, with participants frequently describing feelings of helplessness. This finding is consistent, who noted that loss of autonomy is one of the most difficult aspects of SCI for individuals to cope with, as it affects daily functioning and self-esteem. found that individuals with SCI often experience a drastic reduction in their ability to perform basic tasks, which contributes to frustration and psychological distress (13).

60% of participants who reported social isolation due to SCI echoed earlier studies on the social implications of the injury. has shown that many individuals with SCI experience significant changes in their social networks, often losing friendships and struggling to maintain pre-injury social roles. The isolation described in this study, where participants felt that their friends "drifted away," reinforces the social challenges that individuals with SCI face. The positive influence of peer support, which emerged in this study, has also been highlighted in previous studies as an essential factor in coping with the injury (14).

The high prevalence of secondary health issues, particularly chronic pain (75%), muscle spasms (55%), and pressure sores (35%), reflects the ongoing physical complications of SCI. These findings are consistent with studies by who reported that chronic pain affects up to 80% of individuals with SCI, making it one of the most debilitating long-term consequences. Chronic pain significantly impacts quality of life, as participants in this study described it as sometimes more difficult to manage than the injury itself. This aligns with research, which emphasizes the long-term nature of pain management in SCI (15).

Muscle spasms, fatigue, and pressure sores are also common in the SCI population, as previously documented by These conditions not only affect physical functioning but also contribute to emotional and social difficulties, as individuals with SCI must constantly manage their health alongside their efforts to regain independence. The need for continuous medical care, highlighted by participants in this study, is consistent with findings by those who stressed the importance of long-term healthcare and regular follow-up for preventing and managing these complications (16).

Despite the challenges, many participants in this study demonstrated significant resilience, finding ways to adapt through positive coping strategies. This is in line with previous studies which emphasize the role of psychological resilience in helping individuals with SCI rebuild their lives. The participants who focused on small accomplishments and set achievable goals echoed the findings who found that active coping strategies, such as goal setting and focusing on personal growth, are key to long-term emotional and psychological recovery (17).

Rehabilitation and vocational training were also highlighted as important in fostering a sense of progress and purpose. Similarly noted that individuals who engage in vocational or rehabilitative activities after SCI often experience improved mental health and a greater sense of self-worth. These findings reinforce the value of comprehensive rehabilitation programs that not only address physical recovery but also promote psychological resilience and social reintegration (18).

The role of healthcare access was critical to participants' experiences in this study. Those with early access to rehabilitation services reported better physical and emotional outcomes, supporting earlier research by which found that early and intensive rehabilitation improves mobility and independence. However, the frustration expressed by participants regarding the high cost and limited availability of ongoing rehabilitation is consistent who noted that financial and structural barriers to long-term care often limit individuals' ability to fully recover and maintain their health post-injury (19).

The need for continuous rehabilitation and affordable healthcare access remains a significant challenge, as highlighted in this study and in previous research. Saunders et al. (2012) found that many individuals with SCI face difficulties accessing necessary care, particularly as they transition from inpatient rehabilitation to long-term community living. This gap in care provision highlights a need for more sustainable healthcare models that ensure long-term support for individuals with SCI (20).

CONCLUSION

This study reveals the profound emotional, physical, and social challenges faced by individuals with spinal cord injury (SCI). Participants reported emotional struggles, loss of independence, social isolation, and significant secondary health issues like chronic pain. Despite these difficulties, many demonstrated resilience through positive coping strategies and strong social support. The findings emphasize the need for holistic rehabilitation programs that address both physical and emotional recovery. Accessible, long-term healthcare and social support systems are essential for improving quality of life for individuals with SCI, alongside fostering resilience and personal adaptation.

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