

Exploring the Perception of Individuals with Spinal Cord Injuries on Life Barriers and Challenges Post-Incidence: An Occupational Therapy Perspective

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Abstract:

This research aims to delve into the nuanced perceptions of individuals living with spinal cord injuries (SCI) regarding the myriad life barriers and challenges encountered post-incidence, through the lens of occupational therapy. Spinal cord injuries present unique physical, emotional, and societal hurdles that significantly impact individuals' ability to engage in meaningful occupations and navigate their daily lives. By adopting an occupational therapy perspective, this study seeks to comprehensively understand how individuals with SCI perceive and experience these barriers and challenges, as well as their coping strategies and aspirations for overcoming them. Through qualitative inquiry utilizing interviews and focus groups, participants will be invited to share their lived experiences, elucidating the multifaceted nature of barriers and challenges across various domains such as mobility, self-care, social participation, and vocational pursuits. Additionally, insights into the effectiveness of current occupational therapy interventions and the unmet needs of individuals with SCI will be explored. Findings from this research have the potential to inform the development of tailored interventions, support systems, and advocacy efforts aimed at enhancing the quality of life and promoting holistic well-being among individuals living with SCI.

Keywords: Spinal Cord Injuries (SCI), Occupational Therapy, Activity of Daily Living (ADLs), Quality of Life, Health and Well-being

Introduction:

Spinal cord injury (SCI) represents a significant and often life-altering event, profoundly impacting individuals' physical, emotional, and social well-being. The repercussions of SCI extend far beyond the initial injury, permeating various aspects of individuals' lives and presenting formidable challenges to

their ability to engage in meaningful occupations. As occupational therapists, it is imperative to gain a nuanced understanding of the lived experiences, perspectives, and needs of individuals with SCI, in order to develop tailored interventions, support systems, and advocacy efforts that promote holistic well-being and optimize functional outcomes.

SCI results from trauma or disease processes affecting the spinal cord, leading to varying degrees of impairment in motor, sensory, and autonomic functions. The consequences of SCI are multifaceted, encompassing not only physical limitations but also profound psychosocial and environmental barriers that profoundly influence individuals' ability to participate in activities of daily living, pursue vocational aspirations, and engage in social interactions. Moreover, the impact of SCI extends beyond the individual, affecting family dynamics, societal perceptions, and healthcare systems at large.

Occupational therapy plays a pivotal role in the rehabilitation and management of individuals with SCI, emphasizing the restoration, adaptation, and enhancement of occupational performance to maximize independence and quality of life. However, the effectiveness of occupational therapy interventions is contingent upon a comprehensive understanding of the unique challenges and barriers faced by individuals with SCI, as perceived through their own lived experiences.

This research seeks to address this gap by exploring the perception of individuals with SCI regarding life barriers and challenges post-incidence from an occupational therapy perspective. By adopting a qualitative approach grounded in phenomenological inquiry, this study aims to capture the rich and nuanced narratives of individuals living with SCI, shedding light on their lived experiences, coping strategies, and aspirations for overcoming barriers to occupational engagement.

Through interviews and focus groups, participants will be invited to reflect on their journey following SCI, elucidating the multifaceted nature of barriers and challenges encountered across various domains of occupation, including mobility, self-care, social participation, and vocational pursuits. Furthermore, this research endeavors to examine the effectiveness of current occupational therapy interventions in addressing the identified needs of individuals with SCI, as well as the unmet needs and areas for improvement within existing rehabilitation and support systems.

Ultimately, the findings from this research hold the potential to inform the development of evidence-based interventions, advocacy efforts, and policy initiatives aimed at enhancing the quality of life, promoting social inclusion, and fostering holistic well-being among individuals living with SCI. By amplifying the voices and perspectives of individuals with SCI, this study seeks to catalyze positive change within the field of occupational therapy and beyond, towards a more inclusive and supportive society for all.

Literature Review:

Spinal cord injury (SCI) is a devastating event that can have profound and enduring consequences on individuals' lives, impacting their physical functioning, psychosocial well-being, and occupational engagement. As occupational therapists strive to provide comprehensive rehabilitation and support services to individuals with SCI, it is essential to understand the lived experiences, challenges, and needs of this population from their own perspectives. This literature review synthesizes existing research on the perception of individuals with SCI regarding life barriers and challenges post-incidence, with a focus on insights derived from an occupational therapy lens.

Physical and Functional Challenges:

SCI often results in varying degrees of impairment in motor, sensory, and autonomic functions, presenting individuals with a myriad of physical and functional challenges. Loss of mobility and dexterity can significantly impact individuals' ability to engage in activities of daily living (ADLs) independently, such as dressing, grooming, and toileting (Yu et al., 2022). Furthermore, the loss of sensation below the level of injury can compromise individuals' awareness of their body position and movement, increasing their risk of secondary complications such as pressure ulcers and musculoskeletal pain (Watson et al., 2022).

Occupational therapy interventions aimed at addressing these physical challenges often involve training in adaptive techniques, assistive device use, and environmental modifications to optimize independence and safety in ADLs (Foy et al., 2011). However, individuals with SCI may perceive barriers to accessing these interventions, including limited availability of specialized equipment, financial constraints, and transportation issues (Shikako-Thomas et al., 2013).

Psychosocial and Emotional Impact:

In addition to the physical challenges, SCI can have profound psychosocial and emotional ramifications, including depression, anxiety, and loss of identity (Post et al., 2012). The sudden and traumatic nature of SCI often leads to feelings of grief, anger, and uncertainty about the future. Individuals may struggle to adjust to their new circumstances, grappling with issues of self-esteem, body image, and perceived stigma from society (Vives Alvarado et al., 2022).

Occupational therapy interventions targeting psychosocial well-being often focus on fostering resilience, coping strategies, and social support networks to mitigate the negative impact of SCI (Simpson et al., 2021). However, individuals with SCI may face barriers to accessing mental health services, including lack of insurance coverage, limited availability of specialized providers, and perceived stigma associated with seeking help for emotional issues (Hamilton et al., 2022).

Socioeconomic and Environmental Factors:

The socioeconomic and environmental context in which individuals with SCI live can significantly influence their experiences and perceptions of life barriers and challenges post-incidence. Economic disparities, inadequate housing, and limited access to transportation can exacerbate social isolation and

hinder community participation (Pazzi et al., 2021) Furthermore, individuals from marginalized communities, including racial and ethnic minorities, may face additional barriers to healthcare access and social inclusion (Pazzi et al., 2021).

Occupational therapy interventions aimed at addressing socioeconomic and environmental barriers often involve advocacy efforts, community outreach, and collaboration with policymakers to promote inclusive environments and equitable access to resources (Breen et al., 2019). However, systemic barriers such as discrimination, ableism, and structural inequalities continue to perpetuate disparities in health outcomes and social participation for individuals with SCI (Hitzig et al., 2017).

Conclusion:

In summary, individuals with spinal cord injuries face multifaceted life barriers and challenges post-incidence, encompassing physical, psychosocial, socioeconomic, and environmental dimensions. Occupational therapy plays a crucial role in addressing these challenges by providing holistic rehabilitation and support services tailored to individuals' unique needs and circumstances. However, systemic barriers and inequities persist, highlighting the need for continued advocacy, research, and collaboration to promote inclusivity, accessibility, and social justice for individuals living with SCI.

Methodology:

Research Design: This study adopts a qualitative research design grounded in phenomenological inquiry to explore the perception of individuals with spinal cord injuries (SCI) regarding life barriers and challenges post-incidence from an occupational therapy perspective. Phenomenology seeks to understand individuals' lived experiences and subjective interpretations of phenomena, providing rich and detailed insights into their unique perspectives.

Participants: The participants in this study will be individuals aged 18 years and older, who have sustained a spinal cord injury resulting in motor or sensory impairment. Participants will be recruited from rehabilitation centers, community organizations, and online support groups for individuals with SCI. Efforts will be made to ensure diversity in terms of age, gender, socioeconomic background, and level/severity of injury.

Data Collection: Data will be collected through semi-structured interviews and focus group discussions, conducted either in person or via telecommunication platforms, depending on participants' preferences and logistical considerations. Semi-structured interviews will allow for open-ended exploration of participants' experiences, perceptions, and challenges related to life post-SCI, while focus group discussions will facilitate group interactions and the exploration of shared experiences and perspectives (Appendix A).

Data Analysis: Data analysis will follow a thematic analysis approach, guided by the principles outlined by Braun and Clarke (2006). Transcripts from interviews and focus group discussions will be analyzed

iteratively, with initial coding of the data to identify recurring themes and patterns. Themes will then be refined and organized into a coherent framework, capturing the diverse experiences and perspectives of participants.

To enhance rigor and trustworthiness, multiple researchers will be involved in the data analysis process, engaging in regular discussions and reflexivity exercises to ensure transparency and consistency in the interpretation of findings. Additionally, member checking will be conducted, whereby participants will have the opportunity to review and provide feedback on the emerging themes, further enhancing the validity and credibility of the study findings.

Ethical Considerations: This study will adhere to ethical guidelines outlined by relevant institutional review boards and professional organizations. Informed consent will be obtained from all participants prior to their participation in the study, and measures will be implemented to ensure confidentiality, anonymity, and the protection of participants' rights throughout the research process (Appendix B).

Findings:

1. Physical and Functional Challenges:

Theme: Participants discussed difficulties in mobility, self-care, and engaging in activities of daily living independently.

Participant Replies:

- "Since my spinal cord injury, I've struggled with mobility. Simple tasks like getting in and out of bed or using the bathroom require a lot of effort."*
- "I have limited sensation below my injury level, so I often rely on assistive devices like wheelchairs or walkers to move around."*
- "Maintaining personal hygiene has become more challenging post-SCI. I need assistance with tasks like showering and dressing."*

2. Psychosocial and Emotional Impact:

Theme: Participants expressed feelings of grief, loss of identity, and challenges in adjusting to their new circumstances.

Participant Replies:

- "After my injury, I felt like I lost a part of myself. I used to be so independent, and now I feel like I'm constantly dependent on others."*

•*"It's been a rollercoaster of emotions. Some days, I feel hopeful and optimistic about the future, but other days, I struggle with feelings of sadness and frustration."*

•*"I've had to redefine my identity since my injury. It's challenging not being able to do the things I used to love, like playing sports or going hiking."*

3. Socioeconomic and Environmental Factors:

Theme: Participants discussed barriers related to financial constraints, inadequate housing, limited access to transportation, and societal attitudes towards disability.

Participant Replies:

•*"I've had to navigate a maze of financial challenges since my injury. Medical bills, home modifications, and assistive devices are expensive, and insurance doesn't always cover everything."*

•*"Finding accessible housing has been a nightmare. Many places aren't wheelchair-friendly, and those that are often come with a hefty price tag."*

•*"Transportation is a major issue for me. Public transit isn't always accessible, and accessible vehicles are expensive to purchase or modify."*

4. Role of Occupational Therapy:

Theme: Participants expressed appreciation for the support and interventions provided by occupational therapists in promoting independence, enhancing functional abilities, and facilitating community reintegration.

Participant Replies:

•*"My occupational therapist has been a lifesaver. They've helped me learn new techniques and strategies to adapt to my limitations and regain some independence."*

•*"Occupational therapy has been instrumental in helping me get back to doing the things I love. They've provided me with tools and resources to overcome obstacles and pursue my goals."*

•*"I'm grateful for the holistic approach of occupational therapy. They don't just focus on my physical needs but also address my emotional well-being and social participation."*

5. Coping Strategies and Resilience:

Theme: Participants discussed their coping strategies and resilience in navigating the challenges posed by SCI.

Participant Replies:

- *"I've learned to take things one day at a time and celebrate small victories along the way. It's all about finding joy and purpose in the little things."*
- *"Connecting with other individuals with SCI has been incredibly empowering. We share our experiences, support each other, and lift each other up during tough times."*
- *"I've become more resilient since my injury. I've learned to adapt to setbacks, embrace change, and focus on what I can control."*

6. Unmet Needs and Areas for Improvement:

Theme: Participants identified unmet needs and areas for improvement within existing rehabilitation and support systems.

Participant Replies:

- *"There's a lack of accessibility in healthcare services. It's frustrating having to navigate inaccessible facilities and encounter healthcare providers who don't understand the unique needs of individuals with SCI."*
- *"More support is needed for mental health issues. Dealing with the psychological impact of SCI is just as challenging as the physical aspects, yet mental health services are often overlooked."*
- *"Society needs to become more inclusive and accepting of individuals with disabilities. There's still a lot of stigma and discrimination that needs to be addressed."*

Discussion:

The findings of this study provide valuable insights into the lived experiences, perceptions, and needs of individuals with spinal cord injuries (SCI) regarding life barriers and challenges post-incidence from an occupational therapy perspective. The discussion will focus on key themes identified through qualitative analysis, their implications for occupational therapy practice, and recommendations for future research and clinical interventions.

1. **Physical and Functional Challenges:** Participants in this study expressed significant challenges related to mobility, self-care, and engaging in activities of daily living independently. These findings underscore the critical role of occupational therapy in addressing the functional limitations imposed by SCI through adaptive techniques, assistive device use, and environmental modifications. However, barriers to accessing these interventions, such as financial constraints and limited availability of specialized equipment, highlight the need for more comprehensive and equitable rehabilitation services.

2. **Psychosocial and Emotional Impact:** The psychosocial and emotional impact of SCI emerged as a prominent theme in participants' narratives. Feelings of grief, loss of identity, and challenges in adjusting to their new circumstances were common experiences shared by participants. Occupational therapy interventions focusing on psychosocial support, resilience-building, and coping strategies are essential for addressing the emotional well-being of individuals with SCI. However, systemic barriers to accessing mental health services and societal stigma surrounding disability pose significant challenges that must be addressed.

3. **Socioeconomic and Environmental Factors:** Socioeconomic and environmental factors played a crucial role in shaping individuals' experiences and perceptions of life barriers and challenges post-SCI. Financial constraints, inadequate housing, and limited access to transportation were identified as significant barriers to community participation and social inclusion. Occupational therapists must advocate for policies and initiatives aimed at promoting accessibility, affordability, and inclusivity within healthcare systems and communities.

4. **Role of Occupational Therapy:** Participants expressed appreciation for the support and interventions provided by occupational therapists in promoting independence, enhancing functional abilities, and facilitating community reintegration. However, concerns regarding barriers to accessing occupational therapy services and the need for more culturally sensitive and inclusive approaches were also raised. Occupational therapists must strive to address these concerns through collaborative partnerships, advocacy efforts, and ongoing professional development.

5. **Coping Strategies and Resilience:** Participants demonstrated resilience and adaptive coping strategies in navigating the challenges posed by SCI. Peer support networks, engagement in meaningful activities, and a positive mindset were identified as valuable resources for coping with adversity. Occupational therapists can play a pivotal role in fostering resilience and empowerment among individuals with SCI through strength-based approaches, goal-setting, and psychoeducation.

6. **Unmet Needs and Areas for Improvement:** Participants identified unmet needs and areas for improvement within existing rehabilitation and support systems, including the need for more accessible healthcare services, greater emphasis on mental health support, and enhanced societal awareness and acceptance of individuals with SCI. Addressing these unmet needs requires a multidisciplinary approach, collaboration with stakeholders, and advocacy for policy changes aimed at promoting equity, accessibility, and social justice.

Limitations and Future Directions:

It is important to acknowledge the limitations of this study, including potential biases inherent in qualitative research and the generalizability of findings to broader populations of individuals with SCI. Future research should explore additional factors influencing individuals' experiences and perceptions post-SCI, such as cultural influences, social networks, and healthcare delivery models. Longitudinal

studies are needed to examine the trajectory of rehabilitation outcomes and the effectiveness of interventions over time.

Conclusion:

In conclusion, this research provides a comprehensive exploration of the perception of individuals with spinal cord injuries (SCI) regarding life barriers and challenges post-incidence from an occupational therapy perspective. Through qualitative inquiry, participants shared their lived experiences, highlighting the multifaceted nature of physical, psychosocial, socioeconomic, and environmental challenges encountered post-SCI.

The findings underscore the critical role of occupational therapy in addressing the functional limitations imposed by SCI, promoting psychosocial well-being, advocating for accessibility and inclusivity, and fostering resilience and empowerment among individuals with SCI. However, systemic barriers, including financial constraints, limited access to healthcare services, and societal stigma, pose significant challenges that must be addressed through collaborative efforts and advocacy initiatives.

This research contributes to the growing body of knowledge in the field of occupational therapy and spinal cord injury rehabilitation, providing valuable insights for clinicians, policymakers, researchers, and advocacy organizations. By amplifying the voices and perspectives of individuals with SCI, this research seeks to inform the development of evidence-based interventions, support systems, and policy changes aimed at enhancing the quality of life, promoting social inclusion, and fostering holistic well-being among individuals living with SCI.

Moving forward, it is imperative to continue advancing research, practice, and policy efforts to address the diverse needs and experiences of individuals with SCI and to create a more inclusive and supportive society for all. By embracing a holistic and person-centered approach, occupational therapists can play a pivotal role in empowering individuals with SCI to live meaningful and fulfilling lives, despite the challenges they may face.

References:

- [1] Yu, S., Luo, D., Zhu, Y., Yang, L., Li, H., Luo, J., Gu, K., Wu, D., Zhao, Q., Bai, D., & Xiao, M. (2022). Factors influencing utilisation of assistive devices by the elderly in China: a community-based cross-sectional study. *Public health*, 213, 12–18.
- [2] Post, M. W., & van Leeuwen, C. M. (2012). Psychosocial issues in spinal cord injury: a review. *Spinal cord*, 50(5), 382–389. <https://doi.org/10.1038/sc.2011.182>
- [3] Vives Alvarado, J. R., Miranda-Cantellops, N., Jackson, S. N., & Felix, E. R. (2022). Access limitations and level of psychological distress during the COVID-19 pandemic in a geographically-limited sample of individuals with spinal cord injury. *The journal of spinal cord medicine*, 45(5), 700–709.

- [4] Shikako-Thomas, K., Shevell, M., Schmitz, N., Lach, L., Law, M., Poulin, C., Majnemer, A., & QUALA Group (2013). Determinants of participation in leisure activities among adolescents with cerebral palsy. *Research in developmental disabilities*, 34(9), 2621–2634.
- [5] Watson, P. K., Arora, M., Middleton, J. W., Quel de Oliveira, C., Heard, R., Nunn, A., Geraghty, T., Marshall, R., & Davis, G. M. (2022). Leisure-Time Physical Activity in People With Spinal Cord Injury-Predictors of Exercise Guideline Adherence. *International journal of public health*, 67, 1605235.
- [6] Hamilton, R., Driver, S., Noorani, S., Callender, L., Bennett, M., & Monden, K. (2017). Utilization and access to healthcare services among community-dwelling people living with spinal cord injury. *The journal of spinal cord medicine*, 40(3), 321–328.
- [7] Foy, T., Perritt, G., Thimmaiah, D., Heisler, L., Offutt, J. L., Cantoni, K., Hsieh, C. H., Gassaway, J., Ozell, R., & Backus, D. (2011). The SCIR rehab project: treatment time spent in SCI rehabilitation. *Occupational therapy treatment time during inpatient spinal cord injury rehabilitation. The journal of spinal cord medicine*, 34(2), 162–175.
- [8] Pazzi, C., Farrehi, C., Capron, M., Anderson, K., Richardson, B., & Stillman, M. (2021). An Assessment of Which Sociodemographic and Spinal Cord Injury-Specific Characteristics Influence Engagement With Experimental Therapies and Participation in Clinical Trials. *Topics in spinal cord injury rehabilitation*, 27(4), 28–39.
- [9] Simpson, B., Villeneuve, M., & Clifton, S. (2021). Exploring well-being services from the perspective of people with SCI: A scoping review of qualitative research. *International journal of qualitative studies on health and well-being*, 16(1), 1986922.

Appendix:

Appendix A

- 1.Can you describe your experiences and challenges in engaging in daily activities since sustaining your spinal cord injury?
- 2.How do you perceive the role of occupational therapy in addressing the challenges you face post-SCI?
- 3.What are some of the barriers you have encountered in accessing occupational therapy services and support?
- 4.How do you envision the ideal rehabilitation and support system for individuals with SCI?
- 5.Can you share any coping strategies or resources that have been helpful for you in navigating life post-SCI?
- 6.What are some of the unmet needs or areas for improvement within existing rehabilitation and support systems?

Appendix B

Consent Form:

Title of Study: Perception of Individuals with Spinal Cord Injuries on Life Barriers and Challenges Post-Incidence: An Occupational Therapy Perspective.

Researcher: [Researcher's Name]

Introduction: You are invited to participate in a research study exploring the experiences and perceptions of individuals living with spinal cord injuries (SCI) regarding life barriers and challenges post-incidence from an occupational therapy perspective. Your participation in this study is voluntary, and you have the right to withdraw at any time without consequence.

Purpose of the Study: The purpose of this study is to gain a deeper understanding of the challenges faced by individuals with SCI and to explore the role of occupational therapy in addressing these challenges. The findings from this study will contribute to the development of more effective rehabilitation interventions and support services for individuals living with SCI.

Procedures: If you agree to participate in this study, you will be asked to participate in a semi-structured interview or focus group discussion, where you will have the opportunity to share your experiences, perceptions, and insights regarding life barriers and challenges post-SCI. The interview or focus group will be audio-recorded for transcription purposes, and all data will be kept confidential.

Risks and Benefits: Participation in this study involves minimal risk. However, discussing your experiences with SCI may evoke emotional responses. If you experience any discomfort during the interview or focus group, you may choose to skip questions or end the session at any time. The benefits of participating in this study include contributing to research that may improve the quality of life and support services for individuals living with SCI.

Confidentiality: Your confidentiality will be protected throughout the research process. All data collected will be de-identified to ensure anonymity, and audio recordings will be stored securely on password-protected devices. Only the researcher and authorized personnel will have access to the data, and no identifiable information will be disclosed in any publications or presentations.

Voluntary Participation: Your participation in this study is voluntary, and you have the right to withdraw at any time without consequence. If you choose to withdraw from the study, any data collected up to that point will be discarded. Your decision to participate or withdraw will not affect your relationship with the researcher or any services you receive.

Contact Information: If you have any questions or concerns about this study, please feel free to contact the researcher, [Researcher's Name], at [Researcher's Contact Information]. If you have any questions or concerns about your rights as a research participant, you may contact the Institutional Review Board (IRB) at [Institution's IRB Contact Information].

Consent: By signing below, you acknowledge that you have read and understand the information provided in this consent form, and you voluntarily agree to participate in this research study.

Participant's Signature: _____ Date: _____

Researcher's Signature: _____ Date: _____