INSIGHTS-JOURNAL OF

LIFE AND SOCIAL SCIENCES

INSIGHTS-JLSS
Insights-Journal of Life and
Social Sciences

EXPLORING THE COPING STRATEGIES ADOPTED BY FAMILY CAREGIVERS OF PATIENTS WITH SPINAL CORD INJURY

Original Article

Shazia Karim[1]*, Sarfraz Masih[2], Hajira Sarwer[3]
[1]MS Nursing Graduate, University of Lahore, Pakistan.
[2]Principal & Associate Professor, LSN, University of Lahore, Pakistan.
[3]Assistant Professor, University of Lahore, Pakistan.
Corresponding Author: Shazia Karim, MS Nursing Graduate, University of Lahore, Pakistan. shaziakarim7799@gmail.com

Conflict of Interest: None
Grant Support & Financial Support: None

ABSTRACT

Background: Spinal cord injury (SCI) is a debilitating condition and a global health concern caused by trauma or disease, significantly impacting individuals and their families. Caring for individuals with SCI at home often becomes the responsibility of family caregivers, who face substantial physical, emotional, and social challenges. These challenges necessitate effective coping mechanisms to ensure the well-being of both caregivers and patients, making the exploration of these strategies critical to improving caregiving practices and outcomes.

Objective: The objective of this study was to explore the coping strategies adopted by family caregivers of patients with incomplete spinal cord injuries.

Methods: A qualitative exploratory study design was employed. Patients with incomplete SCI were enrolled from the Punjab Institute of Neurosciences (PINS), Lahore, and their family caregivers were selected through purposive sampling. A total of ten caregivers, providing home care for more than six months and caregiving for at least 10 hours per week, were recruited until data saturation was achieved. Face-to-face semi-structured interviews were conducted using a validated interview grid consisting of two parts: demographic data and questions exploring coping mechanisms. Demographic data were analyzed using SPSS, while qualitative responses were analyzed using NVivo software. Ethical approval and informed consent were obtained before data collection.

Results: The study included 50% male and 50% female caregivers, with 40% being spouses, 30% siblings, and 30% offspring. Most caregivers (80%) provided care for 9–12 hours per week, while 20% dedicated 13–15 hours per week. Caregivers relied on three main coping strategies: sources of strength, religious practices, and social support. Spirituality was a key mechanism, with caregivers expressing reliance on prayer and faith to endure challenges. Social support from relatives, neighbors, and friends also played a critical role in alleviating caregiving burdens.

Conclusion: Family caregivers of SCI patients face significant physical and emotional challenges during caregiving. To address these, they utilize coping strategies, including drawing strength from personal resilience, seeking religious and spiritual solace, and leveraging social support networks. These findings underscore the need for structured training programs and support groups to equip caregivers with effective strategies to manage caregiving demands.

Keywords: Adaptation, Psychological; Caregivers; Coping Mechanisms; Family; Spinal Cord Injuries; Social Support; Spirituality.

INTRODUCTION

Spinal cord injury (SCI) refers to damage to the vertebral column caused by trauma, such as road traffic accidents, or by illness and degenerative conditions like cancer (1). SCI represents a profound life-altering event, not only for the affected individuals but also for their family caregivers, who often assume the bulk of responsibilities associated with providing care (2). This role places significant physical, mental, and emotional demands on caregivers, complicating their ability to balance care responsibilities with their own health, household duties, and work obligations (3, 4). Caregivers frequently neglect their own well-being, leading to deteriorated health, fatigue, and increased susceptibility to mental health challenges, including depression (5).

Caregivers play a critical role in supporting patients with SCI, often managing a wide range of essential tasks such as nutrition, respiratory care, physical maintenance, bowel and urinary regulation, mobility, and activities of daily living (6). These caregivers, often unpaid family members or close friends, bear the burden of responsibility in a home setting, where the absence of sufficient training or support exacerbates stress and burnout (7). The transformation of familial roles, such as a spouse becoming a caregiver, can introduce additional physical, psychological, and social challenges, further straining relationships (8). Long-term caregiving frequently necessitates significant lifestyle adjustments and carries the potential for personal sacrifices that affect the caregiver's quality of life (9).

The challenges faced by caregivers are compounded by demographic factors, including the predominance of young males in SCI cases, limited access to social support, and inadequate caregiver training (10, 11). These stressors highlight the need for effective coping strategies, which involve both cognitive and behavioral efforts to manage the psychological and physical toll of caregiving. Coping mechanisms are influenced by factors such as education, prior life experiences, personality traits, and social networks, suggesting a critical role for healthcare professionals in guiding caregivers toward effective strategies (12).

Social support, encompassing interactions with family, friends, and peer groups, has been shown to mitigate caregiver stress and enhance well-being (13). Maintaining such connections is associated with reduced mortality and improved quality of life for caregivers, reinforcing the protective value of these relationships (14). Furthermore, the concept of rehabilitation, often misunderstood as limited to physiotherapy, requires a multidisciplinary approach to adequately address the diverse needs of SCI patients and their caregivers (15, 16). Effective rehabilitation not only benefits the patient but also alleviates the caregiver's burden by promoting independence in daily activities (14, 21).

Research into caregiver experiences underscores the duality of caregiving, with evidence highlighting not only the distress but also the potential benefits, such as improved self-efficacy, personal growth, and strengthened relationships (18, 19). These positive outcomes are influenced by how caregivers perceive and approach their roles, emphasizing the importance of fostering resilience and providing targeted support to optimize their experience (18).

Professional support, including counseling, training, and awareness initiatives, plays a pivotal role in equipping caregivers to manage their responsibilities effectively. Caregivers frequently cite faith, social networks, and professional guidance as critical sources of strength in coping with stress and challenges (20). Structured interventions aimed at reducing emotional turmoil and enhancing caregiving capacity are essential for improving outcomes for both patients and caregivers (18, 21). The objective of this study is to examine the coping strategies adopted by family caregivers of patients with spinal cord injury, addressing the multifaceted challenges they encounter and identifying pathways to support them in delivering effective care.

METHODS

The study utilized a qualitative exploratory research design to examine the coping strategies adopted by family caregivers of individuals with spinal cord injuries (SCI), specifically paraplegics. Participants were recruited from the Punjab Institute of Neurosciences (PINS) in Lahore. Family caregivers were identified through purposive sampling, focusing on those providing care for SCI patients classified under ASIA categories B, C, or D, and who had been engaged in caregiving for at least 10 hours per week. Caregivers of patients in ASIA scale categories A and E were excluded from the study to maintain a consistent focus on paraplegic caregiving experiences. The recruitment process ensured the inclusion of participants who had caregiving responsibilities for more than six months, guaranteeing relevant insights into long-term caregiving challenges.

Semi-structured face-to-face interviews were conducted with participants to gather detailed qualitative data. An interview question grid was developed and revised with input from expert researchers to ensure its relevance and validity. The grid consisted of two parts:

demographic information in the first section and open-ended interview questions in the second. Data collection was initiated after obtaining written informed consent from each participant, adhering to established ethical standards and ensuring confidentiality.

Demographic data collected in Part I of the question grid were analyzed using SPSS software, facilitating a quantitative overview of the sample characteristics. In contrast, qualitative data from Part II, which included the transcribed verbatim responses to the semi-structured interviews, were analyzed using NVivo software to identify themes and subthemes related to coping strategies. The demographic results indicated an equal distribution of male and female participants, with 30% aged 18–29 years, 60% aged 30–45 years, and 10% aged 46–65 years. The majority of caregivers (80%) reported providing care for 9–12 hours per week, while 20% provided care for 13–15 hours per week. Spouses represented 40% of the sample, siblings 30%, and offspring 30%, with no parents included in the study.

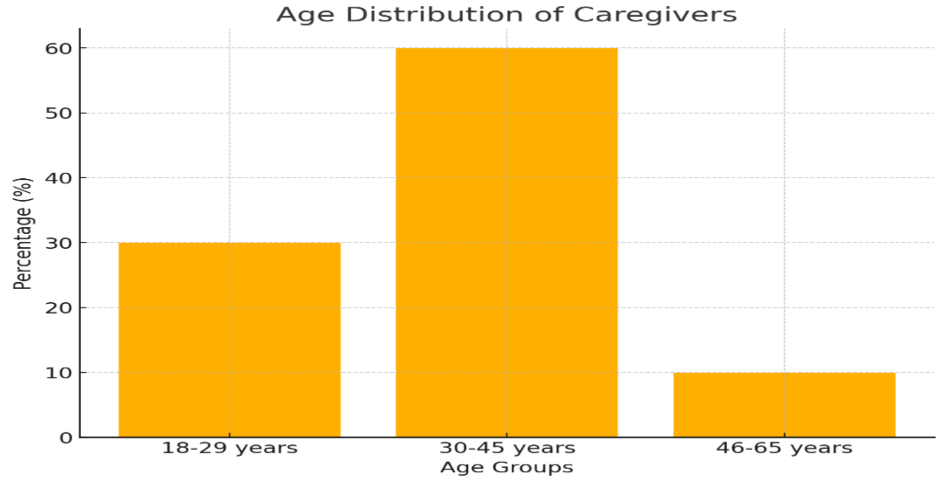
The exclusion of caregivers involved in short-term care (less than six months) ensured the data represented the experiences of those engaged in sustained caregiving. While the demographic data provided a quantitative overview, the interviews illuminated the nuanced coping strategies employed by caregivers, including their reliance on social, emotional, and spiritual resources. This multifaceted methodology, combining statistical analysis of demographic data and qualitative exploration of interview responses, allowed for a comprehensive understanding of the challenges and adaptive strategies employed by caregivers.

RESULTS

The study included an equal distribution of male and female caregivers, with each group representing 50% of the sample. Regarding age distribution, 30% of participants were aged 18–29 years, 60% were between 30–45 years, and 10% were 46–65 years old. Most caregivers (80%) reported providing care for 9–12 hours per week, while a smaller group (20%) dedicated 13–15 hours weekly to caregiving activities. The relational dynamics of caregiving showed that spouses made up 40% of caregivers, while siblings and offspring each contributed 30%. Notably, all participants had provided caregiving services for over six months, indicating a consistent level of long-term caregiving experience across the sample.

Qualitative analysis of semi-structured interviews revealed the multifaceted coping strategies employed by caregivers, emphasizing social, emotional, and spiritual dimensions. Participants consistently highlighted the significance of time management, social support from friends and relatives, and reliance on faith as key mechanisms to cope with the psychological and physical demands of caregiving. The narratives reflected a shared sense of responsibility and moral commitment to caregiving, with some caregivers describing it as a generational legacy of love and support. Caregivers also underscored the necessity of balancing their personal needs with caregiving responsibilities, as this contributed to their resilience and ability to manage challenges effectively.

One notable limitation in the findings is the absence of data on caregivers' socioeconomic status, which could provide further insight into their access to resources and support systems. Additionally, the exclusion of caregivers involved in short-term care limits the exploration of early-stage coping strategies. Despite these gaps, the study successfully identifies the critical role of spiritual and social support networks and highlights the significant time investment required by caregivers. These findings underscore the need for targeted interventions to support caregivers, particularly in enhancing their time management skills and fostering robust social support systems.



The bar chart illustrates the age distribution of caregivers, showing that the majority, 60%, fall within the 30–45 age group. Caregivers aged 18–29 years account for 30%, while those aged 46–65 years make up the remaining 10%. This distribution highlights that caregiving responsibilities are predominantly managed by middle-aged individuals.

Figure 1 Age Distribution of Caregivers

Table.1 Demographic Data

Variables	**Frequency (n)**	**Percent (%)**
Gender		
Male	5	50%
Female	5	50%
Caregiving Hrs./week		
9-12 hrs	8	80%
13-15 hrs	2	20%
Relationship with Care Recipient		
Spouses	4	40%
Siblings	3	30%
Parent	0	0%
Offspring	3	30%
Caregiving period		
< 6 Months	0	0%
> 6 Months	10	100%

The demographic data indicate an equal distribution of male and female caregivers, with each group representing 50% of the total sample. Most caregivers (80%) provided care for 9–12 hours per week, while 20% dedicated 13–15 hours weekly. In terms of their relationship with the care recipients, 40% were spouses, 30% were siblings, and another 30% were offspring, with no parents included in the caregiver group. All participants had caregiving periods exceeding six months, accounting for 100% of the sample, reflecting their substantial long-term involvement in caregiving.

Part-II includes Interview questions, Semi- Structured Interviews conducted; verbatim transcribed. Quotes were interpreted.

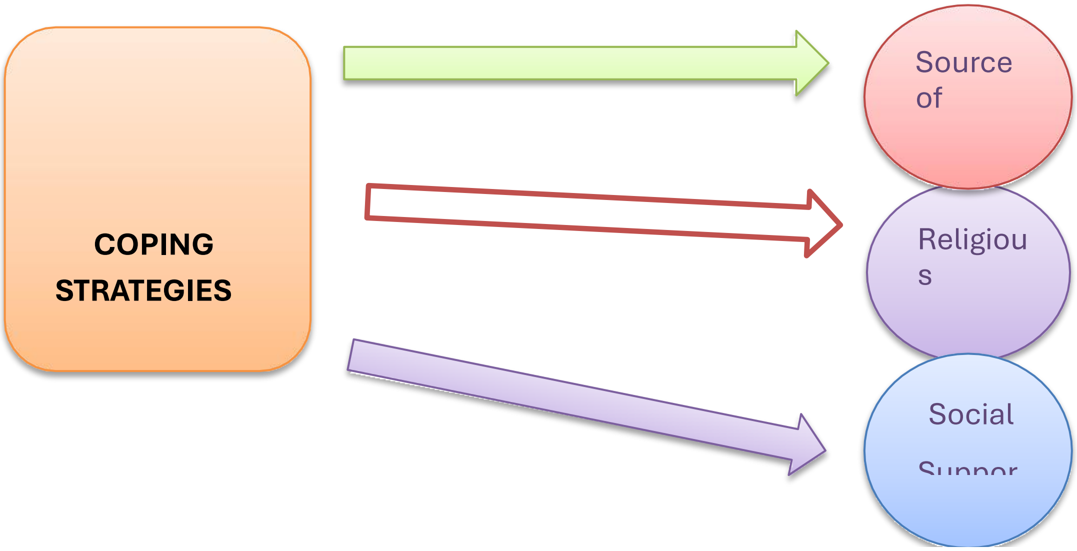


Figure 2 Coping Strategies for Caregivers

The diagram highlights the three major coping strategies adopted by caregivers of spinal cord injury patients, which include sources of strength, religious practices, and social support. Sources of strength were mentioned by the majority of caregivers (80%) as essential in maintaining resilience, while religious practices were cited by 70% as a vital element for emotional and spiritual well-being. Additionally, social support from family, neighbors, and friends, acknowledged by 90% of participants, played a crucial role in alleviating caregiving burdens and enhancing their capacity to manage caregiving challenges effectively.

DISCUSSION

The study explored the demographic variables and coping strategies of family caregivers of individuals with spinal cord injuries (SCI), revealing several critical findings that align with previous research. Demographic analysis showed an equal distribution of male and female caregivers, with the majority being spouses (40%), followed by siblings (30%) and offspring (30%). Most caregivers provided care for 9–12 hours per week (80%), while a smaller proportion dedicated 13–15 hours weekly (20%). These findings indicate a significant time commitment from family members, reflecting the intensity of caregiving for SCI patients who often require long-term support.

Participants highlighted the profound challenges faced upon assuming caregiving roles, including emotional, physical, and social stress. Caregivers frequently reported feelings of exhaustion and physical discomfort, consistent with the high demands of assisting individuals who are often entirely dependent on their families for daily activities. Caregivers disclosed that their responsibilities extended to ensuring proper rehabilitation, nutrition, and physical maintenance, often leading to burnout. This aligns with earlier findings that caregiving imposes substantial physical and emotional strain, requiring comprehensive support systems to sustain caregivers' well-being.

The role of social and spiritual support emerged as a cornerstone of coping mechanisms. Participants emphasized the assistance of in-laws, neighbors, and friends as pivotal in alleviating caregiving burdens. Acts of kindness, such as the provision of meals and emotional encouragement, were described as vital to maintaining the caregivers' ability to cope. Spirituality played a significant role, with many caregivers relying on prayer and faith in divine guidance to endure the challenges. This reflects findings from prior studies that identify spirituality as a critical coping mechanism for family caregivers, especially those caring for individuals with chronic conditions like SCI (Charlifue et al.; Chan, Lee, & Lieh-Mak). Belief in recovery and divine will provided caregivers with hope and resilience, enabling them to navigate financial and emotional hardships while maintaining their caregiving roles.

The study's strength lies in its qualitative exploration of caregivers' lived experiences, providing rich insights into the multifaceted challenges and coping strategies involved in SCI caregiving. However, certain limitations must be acknowledged. The exclusion of socioeconomic data restricts a deeper understanding of how financial factors influence caregiving capacity and outcomes. Additionally, the study's focus on long-term caregivers excludes insights from those newly transitioning into caregiving roles, potentially limiting the exploration of early-stage coping mechanisms. Despite these limitations, the findings underscore the need for targeted interventions, such as psychotherapy and structured social support, to address the physical and emotional toll on caregivers. These interventions should aim to enhance caregivers' resilience and ensure sustainable caregiving practices, ultimately improving outcomes for both caregivers and SCI patients.

CONCLUSION

The findings of the study highlighted that both male and female caregivers of individuals with spinal cord injuries rely heavily on family support, assistance from neighbors and relatives, religious practices, and social networks as key coping mechanisms. These strategies play a vital role in helping caregivers manage the significant physical, emotional, and social challenges of their roles. The study emphasizes the importance of developing comprehensive caregiving training programs and support groups to equip family caregivers with the skills and resources needed to enhance their well-being and caregiving effectiveness.

AUTHOR CONTRIBUTIONS

Author	Contribution
Shazia Karim	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Sarfraz Masih	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published
Hajira Sarwer	Substantial Contribution to acquisition and interpretation of Data Has given Final Approval of the version to be published

REFERENCES

1. Hardy TA. Spinal cord anatomy and localization. CONTINUUM: Lifelong Learning in Neurology. 2021;27(1):12-29.

2. Budd MA, Gater Jr DR, Channell I. Psychosocial consequences of spinal cord injury: a narrative review. Journal of personalized medicine. 2022;12(7):1178.

3. Hall SA, Rossetti Z. The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. Journal of Applied Research in Intellectual Disabilities. 2018;31(3):423-34.

4. Pope ND, Baldwin PK, Gibson A, Smith K. Becoming a Caregiver: Experiences of Young Adults Moving into Family Caregiving Roles. Journal of Adult Development. 2022:1-12.

5. Kum C, Miller EL, Jones H, Kean EB, Kreitzer N, Bakas T. Theoretically based factors affecting stroke family caregiver health: An integrative review. Western Journal of Nursing Research. 2022;44(3):338-51.

6. Zanini C, Amann J, Brach M, Gemperli A, Rubinelli S. The challenges characterizing the lived experience of caregiving. A qualitative study in the field of spinal cord injury. Spinal cord. 2021;59(5):493-503.

7. Shekhani SS. Daughters and daughters-in- law providing elderly care: a qualitative study from Karachi, Pakistan. BMC geriatrics. 2024;24(1):785.

8. Jeyathevan G, Cameron JI, Craven BC, Munce SE, Jaglal SB. Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. BMC neurology. 2019;19(1):1-13.

9. McCoy AD. An exploration of the lived experiences of the caregiving role and life satisfaction in caregivers following traumatic spinal cord injury: University of Nevada, Reno; 2016.

10. Pallerla S, Krishnareddy SR, Parthasarathy NB, Navaneetham J, Gupta A. Rehabilitation Professionals' Perspectives on Psychosocial Needs of Family Caregivers of Persons with Spinal Cord Injury: A Qualitative Study from India. Korean Journal of Family Medicine. 2023;44(3):168.

11. Edelman C, Kudzma EC. Health promotion throughout the life span-e-book: Elsevier Health Sciences; 2021.

12. Machado BM, Dahdah DF, Kebbe LM. Caregivers of family members with chronic diseases: coping strategies used in everyday life. Cadernos Brasileiros de Terapia Ocupacional. 2018;26:299-313.

13. Vang C, Sieng M, Thao A. Coping at the Margins. 2024.

14. Jeyathevan G, Catharine Craven B, Cameron JI, Jaglal SB. Facilitators and barriers to supporting individuals with spinal cord injury in the community: experiences of family caregivers and care recipients. Disability and rehabilitation. 2020;42(13):1844-54.

15. Huang J, Li P, Wang H, Lv C, Han J, Lu X. Exploring elderly patients' experiences and concerns about early mobilization implemented in postoperative care following lumbar spinal surgery: a qualitative study. BMC nursing. 2023;22(1):355.

16. Islam J. Impact of physiotherapy intervention to increase spinal cord independence measure on SCI patients: Bangladesh Health Professions Institute, Faculty of Medicine, the University …; 2022.

17. Scott RK, Nadorff DK, Barnett M, Yancura L. Respect Your Elders: Generativity and Life Satisfaction in Caregiving Grandparents. The International Journal of Aging and Human Development. 2022:00914150221092128.

18. Charlifue S, Botticello A, Kolakowsky- Hayner S, Richards J, Tulsky D. Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits. Spinal cord. 2016;54(9):732-6.

19. Smith L, Morton D, van Rooyen D. Family dynamics in dementia care: A phenomenological exploration of the experiences of family caregivers of relatives with dementia. Journal of Psychiatric and Mental Health Nursing. 2022.

20. Lynch J, Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. Spinal cord. 2017;55(11):964-78.

21. Smith E, Boucher N, Miller W. Caregiving services in spinal cord injury: a systematic review of the literature. Spinal cord. 2016;54(8):562-9.

22. Mohammed RS, Boateng EA, Amponsah AK, Kyei-Dompim J, Laari TT. Experiences of family caregivers of people with spinal cord injury at the neurosurgical units of the Komfo Anokye Teaching Hospital, Ghana. Plos one. 2023;18(4):e0284436.

23. Graf NM. Family adaptation across cultures toward a loved one who is disabled. The Psychological and Social Impact of Illness and Disability:. 2017:201-22.