Journal of Health and Rehabilitation Research 2791-156X JHRR

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Original Article

Challenges Faced by Family Caregivers of Patients with Spinal Cord Injury

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Conflict of Interest: None.

Karim S., et al. (2024). 4(1): DOI: https://doi.org/10.61919/jhrr.v4i1.467

ABSTRACT

Background: Spinal Cord Injury (SCI) presents significant challenges not only to the individuals directly affected but also to their family caregivers. The sudden onset of SCI demands immediate adaptation to new caregiving roles, inducing physical, financial, emotional, and psychological strains on caregivers. Understanding these dynamics is crucial for developing supportive interventions that can alleviate the burdens faced by caregivers and improve the quality of care for SCI individuals.

Objective: This study aimed to explore the experiences of family caregivers of individuals with SCI, focusing on the challenges they face, the roles they assume, the strains encountered, and the coping strategies they employ.

Methods: A qualitative exploratory study was conducted among family caregivers of individuals with SCI at the Punjab Institute of Neurosciences, Lahore. Purposive sampling was used to select participants who were engaged in caregiving for at least 10 hours per week. Data were collected through semi-structured interviews, utilizing a specifically designed interview question grid. Demographic data were analyzed using SPSS software, while thematic analysis of interview data was conducted using NVivo 12 software. The study adhered to ethical standards, including obtaining informed consent from all participants.

Results: The study comprised an equal distribution of male and female participants, with a majority engaged in caregiving for nine to twelve hours per week. Four main themes emerged: the initial challenge of becoming a caregiver, the multifaceted roles of caregiving, the strains of caregiving, and the coping strategies adopted. Caregivers reported significant physical strain, financial burdens, emotional and psychological stress, and relied on a combination of spiritual beliefs, optimism, and social support to navigate their caregiving responsibilities. The study also highlighted the importance of psychotherapy and comprehensive caregiving training sessions for caregivers.

Conclusion: Family caregivers of individuals with SCI face substantial challenges that impact their physical, financial, emotional, and psychological well-being. Supportive interventions, including psychotherapy, comprehensive training, and the establishment of support groups, are essential to aid caregivers in managing the complexities of their roles effectively. Further research is needed to quantify these challenges and evaluate the effectiveness of proposed interventions.

Keywords: Spinal Cord Injury, Family Caregivers, Challenges, Coping Strategies, Qualitative Study, Psychotherapy, Caregiving Training.

INTRODUCTION

Spinal Cord Injury (SCI) is a significant global health concern, resulting from trauma, disease, or degeneration, such as cancer, and affects between 250,000 and 500,000 individuals annually worldwide (1). The majority of these injuries are attributable to road traffic accidents and violence, with reports indicating that in the United States alone, approximately 250,000 people have sustained an SCI, with the distribution nearly evenly split between paraplegics (52%) and quadriplegics (47%) (2, 3). In China, the incidence of spinal cord injuries ranges from 23.7 to 60.6 per million people each year (4). However, in countries like Pakistan, where resources are limited and no national registry for spinal injuries exists, the exact prevalence remains unknown. Estimates suggest that 90% of SCI individuals in Pakistan are paraplegics and the majority are male (5), highlighting an alarming prevalence in low-income countries, affecting around 207.9 million individuals (6).

The long-term impact of SCI extends beyond the individuals to their family caregivers, introducing profound changes in their lives. Often, the responsibility of care falls on a single family member, encompassing physical, mental, and emotional challenges that complicate management at home and work (7-10). This dynamic can lead caregivers to neglect their own health needs (11, 12). People with SCI rely on their families for nutrition and routine care, which significantly improves their quality of life and ability to engage in society (13). Yet, the social and financial burdens placed on families are immense, with healthcare and daily living costs potentially reaching US$185,000 annually, surpassing the expenses associated with diseases like Alzheimer's, multiple sclerosis, and cerebral palsy (14). This financial strain, coupled with potential loss of income from the injured individual, can severely affect the entire family's well-being (15).

The role of caregivers, often taken by partners or other family members, is critical yet fraught with challenges. The shift in relationships between the person with SCI and their caregiver can introduce physical, psychological, and social difficulties, straining the caregiving relationship and necessitating significant lifestyle adjustments (16). Notably, the majority of new SCI cases involve young males (80%), with over half being unmarried at the time of injury, and married individuals facing higher divorce rates post-injury (17). This demographic trend underscores the need for focused support and resources for caregivers.

Recent research has broadened to encompass the diverse aspects of caregiver burden, satisfaction, and well-being, recognizing the evolving interests, understanding, and needs of those who provide long-term, intensive care for SCI individuals (18-20). While caregiving is associated with numerous adverse outcomes, including decreased physical and mental health, financial hardship, and reduced quality of life (21), studies have also identified positive aspects of caregiving, such as increased resilience, support from social networks, and personal growth (20).

The challenges faced by family caregivers of SCI patients are multifaceted, impacting their physical and mental health, financial stability, and overall quality of life. Medical professionals and support organizations play a crucial role in providing training, awareness, and counseling to help caregivers and their families adapt to life after an SCI (14). Enhancing caregiver resilience through recognition of stressors and the promotion of strengths can mitigate the negative consequences of caregiving. Importantly, the care provided by family members is often on par with, if not superior to, institutional care, emphasizing the need for strategies to reduce caregiving hours and improve independence in daily activities for SCI individuals (18-20, 22). Addressing these challenges requires a holistic approach that considers the physical, emotional, and financial well-being of both the individuals with SCI and their caregivers.

MATERIAL AND METHODS

A qualitative exploratory study was conducted to delve into the experiences of family caregivers of paraplegic individuals, focusing on their challenges, coping strategies, and the perceived positive aspects of their caregiving roles. The research targeted caregivers of patients with spinal cord injuries (SCI) classified under the American Spinal Injury Association (ASIA) Impairment Scale categories B, C, and D, who were actively engaged in caregiving for at least 10 hours per week. Caregivers of individuals categorized as ASIA A and E were not included in this study. Recruitment was facilitated through purposive sampling techniques, ensuring a focus on caregivers who could provide rich, relevant, and diverse insights into the caregiving experience for individuals with SCI-induced paraplegia.

The study was conducted after obtaining the necessary permissions for data collection from the Medical Superintendent and the Department of Neurosurgery at the Punjab Institute of Neurosciences (PINS), Lahore. Participants were approached and briefed about the study's objectives and procedures. A semi-structured Interview Question Grid was developed and refined with input from expert researchers in the field, designed to elicit comprehensive information on the caregivers' experiences, challenges, and coping mechanisms. Informed consent was obtained from all participants in writing before the commencement of the interviews, ensuring adherence to ethical standards and respect for participants' autonomy, confidentiality, and welfare, in line with the Declaration of Helsinki.

Data collection was carried out through semi-structured interviews, utilizing the Interview Question Grid, which comprised questions and probes designed to explore the depth and breadth of the caregiving experience. The demographic data collected in Part I of the question grid were analyzed using SPSS software, while the qualitative data from Part II of the interview questions were analyzed using NVivo 12 software. This approach facilitated a thorough examination of the themes and patterns emerging from the caregivers' narratives (6, 14).

The thematic analysis of the interview data provided insights into the complex dynamics of caregiving for family members with SCI-induced paraplegia, including the emotional, physical, and social challenges faced by caregivers. The study also explored the support systems available to caregivers, their coping strategies, changes in their lives and relationships following their assumption of the caregiving role, and their perspectives on the future (1, 23). Through this comprehensive analysis, the study aimed to contribute valuable knowledge to the field of medical research on caregiving for individuals with spinal cord injuries, highlighting the need for targeted support and interventions to enhance the well-being of both caregivers and care recipients (13, 24).

RESULTS

Table 1 Demographic Data of Participants

Variables	Frequency (n)	Percent (%)
Age (years)		
18-29	3	30%
30-45	6	60%
46-65	1	10%
Gender		
Male	5	50%
Female	5	50%
Caregiving hours/week		
1-8	0	0%
9-12	8	80%
13-15	2	20%
Relationship with Care Recipient		
Spouse	4	40%
Sibling	3	30%
Parent	0	0%
Off-spring	3	30%
Caregiving period		
< 6 Months	0	0%
> 6 Months	10	100%

Table 2 Generating Themes and Sub-Themes from Interviews

MAJOR THEMES	SUB-THEMES
Becoming A Caregiver	- General Problems
	- Social Problems
Caregiving Roles	- Activities of Daily Living
	- Instrumental Activities Of Daily Living
Caregiving Strain	- Physical Strain
	- Financial Strain
	- Emotional Strain
	- Psychological Strain
Coping Strategies	- Source of Strength
	- Religious Practices
	- Social Support

In this study, the participants comprised an equal distribution of males and females. Thirty percent were aged between eighteen to twenty-nine years, sixty percent fell within the thirty to forty-five years age group, and ten percent were between forty-six to sixty-five years old. The majority, eighty percent, provided care for nine to twelve hours per week, while twenty percent dedicated thirteen to fifteen hours per week to caregiving. Forty percent of the participants were spouses, and thirty percent were equally divided between siblings and offspring. All participants had been caregivers for individuals with paraplegia for more than six months.

The first major theme identified was Becoming a Caregiver, which underscores the challenges faced by family caregivers as they navigate the unanticipated and sudden nature of spinal cord injuries (SCI). This theme is divided into two subthemes: general problems and social problems.

General Problems: This subtheme highlights the initial shock and adjustment period following the unexpected onset of SCI. The narratives reveal the immediate and profound impact of the injury, often resulting from a road traffic accident or a fall, leading to urgent medical interventions and a long journey of caregiving. For example, one participant recounted the sudden injury their brother sustained from falling from a tree, leading to an L1 fracture and emergency surgery (P2). Another shared the story of their husband, a sugar cane laborer, who suffered a severe lower limb injury, resulting in three years of bed rest and complete dependency (P1). The caregivers expressed a sense of moral and Islamic duty to care for their loved ones, despite the shock and the challenges it brings (P5). The experience of becoming a caregiver was described as a "mixed experience" by one participant, indicating the emotional and physical ups and downs associated with the caregiving role (P4).

Social Problems: Participants also discussed how their roles as caregivers have altered their social lives, consuming their time and limiting their ability to engage with friends and family. One caregiver lamented the loss of the ability to enjoy outings and vacations due to the demands of caring for their father in the hospital (P9). However, some also noted positive aspects, such as the strengthening of family bonds and the opportunity to connect with others going through similar experiences (P10).

These findings illuminate the complex and multifaceted experiences of caregivers for individuals with SCI, encompassing both the immediate challenges of adapting to a caregiving role and the ongoing adjustments to their social lives and personal identities.

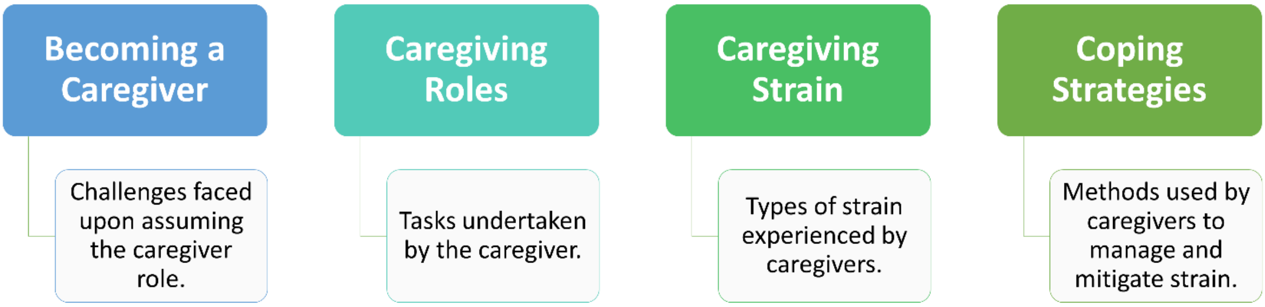

Figure 1 Thematic Schema

The theme of Caregiving Roles highlights the transition of family members into their newfound responsibilities and the deepening of bonds and compassion towards their loved ones with spinal cord injuries (SCI). This theme also explores how individuals with SCI increase their efforts towards recovery, necessitating caregivers to adapt and acquire new skills essential for providing comprehensive care.

The caregiving roles theme encompasses two critical sub-themes: Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), reflecting the learning curve caregivers must navigate to effectively support their care recipients.

Activities of Daily Living (ADLs) encompass essential self-care tasks such as bathing, eating, grooming, toileting, showering, and mobility, including the use of a wheelchair. These activities are crucial for the day-to-day well-being of individuals with SCI, who often require assistance due to their physical limitations. For instance, one participant underscored the importance of ensuring that dependent patients have easy access to daily necessities, emergency items, and meals, highlighting the specialized care needs of those with paralysis or diabetes (P5). Another caregiver discussed the significant responsibility of managing toileting needs, suggesting the delegation or hiring of help if necessary (P5). The physical challenges of caregiving were poignantly illustrated by a caregiver who described the difficulty and emotional pain of transferring the patient using a stretcher with the help of four others (P3).

Instrumental Activities of Daily Living (IADLs) include tasks that extend beyond personal care, such as transportation, cooking, managing finances, and housekeeping for the person with SCI. Caregivers shared their adaptive strategies and the skills they developed to enhance the recovery process. For example, one caregiver detailed a comprehensive treatment plan that included olive oil massages, Methalcobalamine tablets for nerve health, and the use of herbal remedies and sheep's coverings for warmth (P1). The importance of maintaining a straight posture, engaging in regular exercise, and adhering to a structured physiotherapy regimen was also emphasized (P1). Another caregiver highlighted the necessity of acquiring physiotherapy skills from registered professionals to provide effective care, particularly for dependent and paralyzed patients (P5).

In managing the extended care needs of individuals with SCI, caregivers play a pivotal role in their rehabilitation, incorporating exercises and nursing care as integral components. The dedication to daily routines, such as cooking, feeding, changing positions, and bedsore prevention, reflects the comprehensive and adaptive nature of caregiving. The innovative use of remedies, including honey for wound healing, showcases the caregivers' commitment to finding solutions to enhance the recovery and comfort of their loved ones (P3).

These findings illuminate the multifaceted and dynamic roles of caregivers in supporting individuals with SCI, highlighting the physical, emotional, and skill-based challenges they face, as well as the strategies they employ to navigate these challenges effectively.

The theme of Caregiving Strains delves into the multifaceted challenges faced by caregivers of individuals with spinal cord injuries (SCI), underscoring the profound impact such injuries have not only on the patients but also on their families, communities, and society at large. SCI transforms into a social dilemma, characterized by the loss of intellectual function and physical mobility, rendering the affected individuals heavily reliant on their families and, by extension, society.

Physical Strain emerges as a critical aspect of caregiving, with tasks such as lifting, transferring patients, assisting with bathing and grooming, and managing mobility aids, exerting considerable physical demands on caregivers. The participants' narratives reveal the extensive physical toll, including body pain, sleep deprivation, exhaustion, and illness, attributed to the relentless nature of their caregiving duties. For instance, one caregiver recounted the exhaustive challenge of staying awake throughout the night to attend to the patient, only to proceed to their day job thereafter, highlighting the immense personal sacrifice involved in caregiving (P4). Another caregiver detailed the strenuous tasks of applying diapers, changing Foley’s catheter, and assisting with posture changes, necessitating the help of additional persons due to the patient's inability to move independently (P2).

Financial Strain is another significant concern, with the cost of medical treatments, assistive devices, and home modifications posing substantial financial challenges for families. The narrative from one participant illustrates the reliance on parental support during the illness period of their spouse, reflecting the economic hardships and the collective family effort required to navigate such trying times (P1).

Emotional Strain is evident as caregivers grapple with the prolonged dependency of the SCI patient, which can strain the caregiver-patient relationship. The emotional burden and vulnerability to stress can threaten the durability and quality of this relationship, as exhaustion becomes a mutual experience for both caregiver and patient (P5).

Psychological Strain, highlighted by the challenges of managing a busy schedule and prioritizing tasks, can lead to mental distractions and overload, potentially escalating to psychiatric issues if not addressed. Effective time management is crucial for caregivers to navigate their responsibilities without succumbing to mental fatigue (P5).

Coping Stratagems encompass the efforts employed by caregivers to manage, tolerate, reduce, or minimize the stress associated with caregiving. This theme is underpinned by sources of strength, optimism, religious practices, and social support as essential subthemes. Caregivers describe various strategies to cope with the caregiving situation, including scheduling personal time and accepting caregiving as a part of their normal life.

Sources of Strength for caregivers include the support from friends, neighbors, and relatives, which serves as a crucial pillar during challenging times. One participant emphasized the moral and generational legacy of caregiving, underscoring the importance of passing on the values of love and support (P5). Another found solace and strength in their faith, trusting in divine guidance to navigate the caregiving journey (P1).

Religious Practices play a pivotal role in providing solace and strength, with continuous prayers and hope in a higher power offering a sense of perseverance and gratitude for the progress made (P1).

Social Support is highlighted as an indispensable component of the caregiving experience, with support groups, family, in-laws, and neighbors providing emotional, financial, spiritual, and practical support. This multifaceted support system proves vital in balancing the well-being of both the caregiver and the dependent, emphasizing the collective responsibility to nurture, protect, and support one another (P5). The gratitude expressed towards those who offered assistance during hardships reflects the deep appreciation for the communal and familial bonds that sustain caregivers through their journey (P1).

DISCUSSION

In this qualitative exploratory study, the demographic variables assessed included Participant ID, age, gender, relationship with the care recipient, the type of spinal cord injury (SCI), caregiving period, and caregiving hours per week. The analysis conducted using SPSS software revealed an equal distribution of male and female participants. Among them, forty percent were spouses, thirty percent were siblings, and thirty percent were off-springs, predominantly providing care for nine to twelve hours per week. A minority of participants engaged in caregiving for thirteen to fifteen hours weekly.

The study elucidated four principal themes: the initial challenge of becoming a caregiver, the multifaceted roles assumed during caregiving, the strains associated with caregiving, and the coping strategies developed to mitigate these strains. Initially, participants expressed significant concern regarding the sudden onset of their caregiving responsibilities, exacerbated by a lack of familiarity with medical settings and the unexpected nature of the SCI. This abrupt transition into caregiving roles brought about considerable social and routine life adjustments, underscoring the profound impact of caregiving on their lives.

Psychotherapy was suggested as a beneficial intervention to help family caregivers manage depressive symptoms, stemming from the exhaustive demands of caregiving. The study's findings resonated with those of (23), highlighting the mental and physical repercussions of caregiving for individuals with SCI. Participants reported physical strain manifesting as body pain, sleeplessness, and exhaustion, aligning with previous research that caregiving is an unanticipated role requiring significant physical and emotional investment (24).

The financial implications of caregiving, as reported by participants, align with the findings of Boschen, Tonack, and Gargaro and Rodakowski et al., emphasizing the economic pressures family caregivers face (24). The study revealed that caregivers are forced into financial strain, often resorting to loans to cover medical expenses and caregiving costs, corroborating earlier studies that highlight the fiscal challenges associated with long-term care.

Regarding coping mechanisms, caregivers drew strength from their spiritual beliefs, optimism, and the support of relatives and friends. This reliance on spiritual practices and social support networks was found to be crucial in sustaining caregivers through the challenges they faced, findings that are consistent with those of (25) and supported by the research of Charlifue et al. (20). The study further underscores the importance of comprehensive caregiving training and the establishment of support groups to bolster caregivers' resilience and capacity to manage caregiving responsibilities effectively (8, 18, 21).

The study's strengths lie in its detailed exploration of the caregiving experience, laying a foundational basis for further quantitative and qualitative research into effective strategies for managing the challenges faced by family caregivers of SCI individuals. However, the study's limitations include a relatively small sample size, which restricts the generalizability of the findings. Additionally, the reliance on participants' recollections may introduce bias, particularly given the potential for gender differences in emotional response to caregiving roles. The time-consuming and resource-intensive nature of in-depth qualitative research also presents challenges (1, 4, 14).

CONCLUSION

In conclusion, the study highlights the critical need for healthcare facilities to develop tailored support mechanisms that address the unique challenges faced by family caregivers of individuals with SCI. By fostering a comprehensive understanding of the caregiving experience and implementing targeted interventions, it is possible to enhance the well-being of both caregivers and care recipients alike.

REFERENCES

1. Hardy TA. Spinal cord anatomy and localization. CONTINUUM: Lifelong Learning in Neurology. 2021;27(1):12-29.
2. Almuneef M, Saleheen H, Albuhairan F, Al-Eissa M, Al Muntaser M, Al Alem H, et al. Child mortality in Saudi Arabia: Time for action at all levels. International journal of pediatrics and adolescent medicine. 2021;8(3):165-71.
3. Kuris EO, Alsoof D, Osorio C, Daniels AH. Bowel and Bladder Care in Patients With Spinal Cord Injury. JAAOS-Journal of the American Academy of Orthopaedic Surgeons. 2021:10.5435.
4. Yuan S, Shi Z, Cao F, Li J, Feng S. Epidemiological features of spinal cord injury in China: a systematic review. Frontiers in neurology. 2018;9:683.
5. Darain H, Ilyas SM, Zeb A, Ullah I, Muhammad D. Epidemiology of spinal cord injury in Pakistan: a retrospective study. Physikalische Medizin, Rehabilitationsmedizin, Kurortmedizin. 2017;27(02):106-9.
6. Khanzada FJ, Che AZCCD, Masuri MG, Rahim MZA, Poot EFM, Ranabhat MK. Participation in Daily Activities and Quality of Life among Individuals with Paraplegic Spinal Cord Injury in Pakistan. Environment-Behaviour Proceedings Journal. 2023;8(25):115-22.
7. Budd MA, Gater Jr DR, Channell I. Psychosocial consequences of spinal cord injury: a narrative review. Journal of personalized medicine. 2022;12(7):1178.
8. 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.
9. 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.
10. 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.

11. 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.

12. 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.

13. 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.

14. 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.

15. Song Z, Zubizarreta JR, Giuriato M, Paulos E, Koh KA. Changes in health care spending, use, and clinical outcomes after nonfatal firearm injuries among survivors and family members: a cohort study. Annals of internal medicine. 2022.

16. 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.

17. 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.

18. 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.

19. 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.

20. 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.

21. 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.

22. 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.

23. Glover CD. Impact of Resilience on Quality of Life in Spinal Cord Injured Clients: Walden University; 2023.

24. 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.

25. 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.