https://doi.org/10.36570/jduhs.2020.1.900

JDUHS

ORIGINAL ARTICLE

The Impact of Psychosocial Burden of Spinal Cord Injury Survivors on the Family Caregivers

Hamida Begum,[1] Sardar Ali,[2] Dildar Muhammad,[2] Asghar Khan[3]

1. College of Nursing Bannu, Pakistan.
2. Khyber Medical University, Peshawar, Pakistan.
3. Pak-Swiss Nursing College, Swat, Pakistan.

Correspondence to: Asghar Khan, Email: asghar802@gmail.com, ORCID: 0000-0003-1351-2833

ABSTRACT

Objective: To evaluate the psychosocial burden among family caregivers of spinal cord injury survivors, attending Paraplegic Center Hayatabad, Peshawar, Pakistan

Methods: An analytical cross-sectional study was conducted from May 2018 to August 2019 in Paraplegic Center Hayat Abad Peshawar, Pakistan. Data were collected from family caregivers by using Zarit Burden Interview version-22. The psychosocial burden has been categorized in questionnaire as 0-20 "no burden", 21-40 "mild", 41-60 "moderate" and 61-80 "severe burden". The burden was assessed in the form of feeling strained and stressed, embarrassed, angry, privacy deprivation, insufficient friends, financial constraints, loss of control over life and failure in providing care.

Results: Of 105 individuals, 39 (37.14%) individuals had mild, 58 (55.23%) had moderate and 8 (7.62%) had severe psychosocial burden. Moderate psychosocial burden was found to be higher in females (23/33, 69.6%), individuals with ≤matric educational status (36/59, 61%), unemployed individuals (48/80, 60%), married (38/67, 56.7%), and having duration of care >2 months (22/35, 62.9%). In total, 66 (62.85%) individuals had moderate and severe psychosocial burden. A significant association of psychosocial burden (moderate and severe) was observed with gender (p-value 0.022) and employment (p-value 0.025).

Conclusion: The findings concluded that caregivers of patients with spinal cord injury were impacted by psychosocial burden as no participant was found without psychosocial burden. Based on these evidences, there is a need for the appropriate interventions and policies to minimize the psychosocial burden on family members which will lead to improved health outcomes for patients.

Keywords: Spinal cord injury, Spinal cord injury survivors, Psychosocial burden, Family caregivers, Zarit burden interview

INTRODUCTION

Spinal Cord Injury is widely considered transformative, complex and turning point both for patients and their families. Multiple factors contribute to maintain healthy life of the patient which may include patient's physical health, the level of psychological effects on the patient and the contribution of family and friends.[1] Consequently, every chronic disorder impact the lifestyle of an individual as well as the whole family. Additionally, the spinal cord injury is an event that impairs the physical mobility of the patients. Moreover, the patients incline to depend on others, especially their immediate family members.[2] The dependency may be merely limited to physical mobility or may lead to the influential activity of daily living like household finances and shopping.[3]

Generally, when spinal cord injury occurs, one member of the family takes up the responsibility of patient's care which ultimately lead to the harmful repercussions on the physical, emotional and psychological well-being.[4,5] Further studies suggest that the myriad of problems arises from the inability to balance the responsibility of care with other tasks such as activities of job and household.[6] As a result of this imbalance, they begin to ignore their health and ultimately lead to miserable condition of the patients' health.[7] The problem confronted with the caregivers is attracting a substantial attention among the researchers in the present time.[8] Presently, the patients with spinal cord injury enjoy productive lives as compared to past in high income countries.[9] Comparatively, the situation is still worse and patients and their families are still suffering in middle and low income countries.[10] Accordingly, the availability of quality helping maneuvers such as wheel chairs, medical and restoration services are excessively inadequate in these countries. Consequently, the activities of patients and their families especially the caregivers are limited to participate in the public and private lives.[11] There is a huge number of morbidities and mortalities on account of spinal cord injuries and the survivors mostly had to live with lifetime dependency. Worldwide 90 million people are living with spinal cord injury and the incidence ranges between 1 to 5 persons per 100,000 in the middle and low income countries.[12] Mortality among high income countries ranges from 3.1% to 22.2%, while in middle and low income countries it varies from 1.4% to 20.0%.[13]

In Pakistan, there is lack of proper reporting of incidence mainly due to the scarce resources and limited research. Therefore, the researchers had suggested a dire need for spinal cord registry in Pakistan.[14] The findings of the study may provide credible evidence for the policy makers, hospital management and healthcare workers to plan appropriate interventions for the patients suffering from spinal cord injuries and their families thereafter.

METHODS

An analytical cross-sectional study was conducted at Paraplegic Center Hayatabad Peshawar Pakistan from May 2018 to August 2019.

Research board (ASRB) of Khyber Medical University had approved the study formally (DIR/KMU-AS&RB/PB/000926). Moreover, signed informed consent was also obtained from all study participants prior to inclusion in the study.

All the caregivers of eighteen years and above and accompanying the patients during data collection time, were included in the study by using the census method. The participants suffering from chronic illnesses and with history of psychiatric disorders were excluded. The total sample in the study consisted of 105 participants, with 100% response rate.

An adapted self-administered questionnaire was used for data collection.[15] The questionnaire of Zerit Burden Interview (ZBI-22) consisted of 22 questions regarding psychosocial burden of caregivers. The questionnaire tool assesses the psychosocial burden in the form of feeling strained and stressful, embarrassed, angry, privacy deprivation, inadequate friends, financial constraints, loss of control over life and being unsuccessful in providing care to the patient. Each question had 5 options of likert scale. The internal consistency (Cronbach's alpha) of the questionnaire has been reported to be 0.92.[1] The grading marks on ZBI ranges from 0 to 88. On the scale from 0 to 20 is considered no impact, 21 to 40 mild, 41 to 60 moderate and 60 to 88 is severe impact on the caregivers. Data were collected in the Paraplegic Center Peshawar from the caregivers of patients by the principal investigator, using Urdu version of the questionnaire.

SPSS 22 version was used for the purpose of data analysis. Mean and standard deviation was calculated for age, whereas frequencies and percentages were calculated for the categorical variables like gender, employment, education and the responses of the participants. Chi-squared test was applied to see association between the demographic characteristics and the psychosocial burden. P-value <0.05 taken as significant.

RESULTS

The sample consisted of 105 participants, majority 72 (68.57%) were males and 33 (31.43%) were females. Most of the individuals had less than or equal to matric educational status 59 (56.19%), followed by intermediate or greater in 29 (27.61%) and illiterate were 17 (16.19%). There were 80 (76.19%) who were unemployed, 67 (63.81%) married, whereas only 35 (33.33%) individuals were caring patients for more than 2 months. (Table 1)

The relationship of the caregivers with the patients showed that majority of the caregivers had no first blood relationship 80 (76.19%), 9 (8.57%) were mothers, 8 (7.62%) were fathers, 7 (6.67%) were children, while only 1 (0.95%) was spouse.

The psychosocial burden showed that 39 (37.14%) individuals had mild, 58 (55.23%) had moderate and 8 (7.62%) had severe psychosocial burden. The comparison of psychosocial burden with respect to general characteristics showed that moderate psychosocial burden was found to be higher in females (23/33, 69.6%), individuals with ≤matric educational status (36/59, 61%), unemployed individuals (48/80, 60%), married (38/67, 56.7%), and having duration of care >2 months (22/35, 62.9%). (Table 2)

To see the association of psychosocial burden with general characteristics, moderate and severe psychosocial burden were merged in order to minimize differences in extreme responses because there were only 8 participants with severe psychosocial burden. In total, 66 (62.85%) individuals had moderate and severe psychosocial burden. A significant association of psychosocial burden was observed with gender (p-value 0.022) and employment (p-value 0.025). (Table 3)

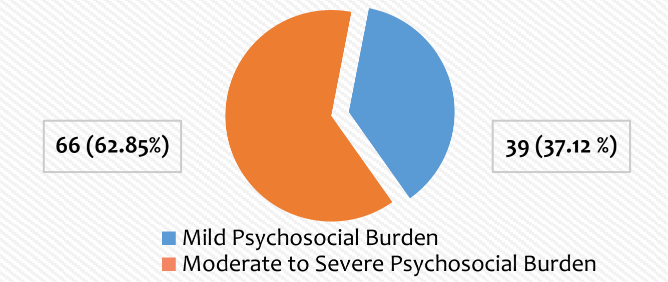

Figure 1: Severity of psychosocial burden (n=105)

Table 1: Demographic characteristics of the patients (n=105)

Variables	n	%
Gender		
Male	72	68.57
Female	33	31.43
Education		
Illiterate	17	16.19
≤matric	59	56.19
≥Intermediate	29	27.62
Employment		
Employed	25	23.81
Unemployed	80	76.19
Residence		
Urban	23	21.90
Rural	82	78.09
Marital Status		
Single	38	36.19
Married	67	63.81
Care Duration		
≤2 months	70	66.67
>2 months	35	33.33

Table 2: Severity of psychosocial burden with respect to general characteristics (n=105)

Variables	Psychosocial Burden		
	Mild (n=39)	Moderate (n=58)	Severe (n=8)
Gender			
Male	32 (44.4)	35 (48.6)	5 (6.9)
Female	7 (21.2)	23 (69.6)	3 (9.0)
Education			
Illiterate	6 (35.3)	9 (52.9)	2 (11.8)
≤matric	19 (32.2)	36 (61.0)	4 (6.8)
≥Intermediate	14 (48.2)	13 (44.8)	2 (6.9)
Employment			
Employed	14 (56.0)	10 (40.0)	1 (4.0)
Unemployed	25 (31.3)	48 (60.0)	7 (8.8)
Residence			
Urban	7 (30.4)	15 (65.2)	1 (4.3)
Rural	32 (39)	43 (52.4)	7 (8.5)
Marital Status			
Single	15 (39.5)	20 (52.6)	3 (7.9)
Married	24 (35.8)	38 (56.7)	5 (7.5)
Care Duration			
2 months	29 (41.4)	36 (51.4)	5 (7.1)
>2 months	10 (28.6)	22 (62.9)	3 (8.6)

DISCUSSION

The objective of the study was to identify the levels of psychosocial burden on the caregivers of patients with the spinal cord injuries. The finding of the current study revealed that caregivers are considerably affected by psychosocial burden on account of care of the spinal cord injury patients. The mean age of the participants was 31.39±12.02 years which is not in line with the findings of previous literature of 53.02±14.62 years.[16]

Table 3: Association of psychosocial burden with demographic characteristics (n=105)

Variables	Psychosocial Burden		p-value
	Mild (n=39)	Moderate/Severe (n=66)	
Gender			
Male	32 (44.4)	40 (55.6)	0.022*
Female	7 (21.2)	26 (78.8)	
Education			
Illiterate	6 (35.3)	11 (64.7)	0.336
≤matric	19 (32.2)	40 (67.8)	
≥Intermediate	14 (48.2)	15 (50)	
Employment			
Employed	14 (56)	11 (44)	0.025*
Unemployed	25 (31.3)	55 (68.8)	
Residence			
Urban	7 (30.4)	16 (69.6)	0.451
Rural	32 (39)	50 (61)	
Marital Status			
Single	15 (39.5)	23 (60.5)	0.710
Married	24 (35.8)	43 (64.2)	
Care Duration			
2 months	29 (41.4)	41 (58.6)	0.199
>2 months	10 (28.6)	25 (71.4)	

Chi-Square test applied, *p-value<0.05

The discrepancy might arise from difference in the responsibilities of the young population in our country as compared to the rest of the world. Unemployment may be attributed to play a role in the discrepancy because they are easily available to care for the patients. Of the total sample of 105, 68.6% (n=77) comprised of male whereas previous findings indicated that 71% consisted of female.[17] Another study reported that 54% were male and 64% were female.[18] Cultural norms and traditions may be responsible for the large number of male in the current study. The people of the area do not allow female outside houses in male wards.

A study in the United States indicated that 72% of the population were graduates.[15] The findings of another study showed that 16% were illiterates, 49% were primary educated, secondary school were 24% and university degree holders were 10%.[19] The major reason for the difference of education is the literacy rate of countries in which the studies were carried out. Of the participants of the current study, 23.8% were employed while 76.2% were unemployed. No retired participants were identified in the study. The current findings were different from the previous study which identified that 58% of the participants were employed.[15] One of the studies had identified similar results which showed that 70% of the participants were unemployed.[20] The discrepancy in the findings can be solely linked to the developmental status of various countries.

The current study identified that two months duration of care was reported in 66.7% of individuals, 2 to 6 months in 22.9% of participants, 7 months to 1 year in 3.8% of caregivers and one year and more was revealed in 6.7% of caregivers. This is consistent with what has been found in the previous literature as 64% of participants were involved in patients care currently, while 36% of caregivers were providing care for the last five years.[15] The findings in the current study showed that spouses were 1%, children were 6.7%, mothers were 8.6%, fathers were 7.6% and significant others were 76.2% included siblings, cousins, uncles and grandfathers. A study conducted in Turkey found different relationship among caregivers and patients as 26% were mothers, 60% were fathers, 33% were spouses, 28% were siblings and others (adult child, niece and aunt) were 7%.[18]

The findings of the study revealed that all of the participants were broadly impacted by the psychosocial burden of care. No one of the participants was found with little psychosocial burden. Of the participants, 37% were suffering from mild burden, 55% were experiencing moderate and 8% reported severe psychosocial burden. The previous literature revealed that 40% of the participants had high burden.[20] The dissimilarity can be attributed to the fact of selection of small sample size of 67 participants and differences in cultures as nuclear family exists in Netherland where one member takes up responsibility of patient care along with other household tasks. Moreover, the sample was chosen from the participants who were providing care for the last five years, therefore this fact can be attributed to cause heavy burden in the caregivers.

A study was conducted in Pakistan on caregivers of patients on dialysis, identified little or no burden in 20% of caregivers, mild to moderate burden was identified in 65% of individuals, moderate to severe burden was reported in 13% participants and severe level of burden was revealed in 2% of the caregivers.[22] The study was conducted in the same social contexts where the joint family system prevail and the care of patient is considered religious responsibility, therefore the burden of care is relatively low and the findings are in agreement with the current study.

Incongruent pattern of results were obtained from the previous study which showed that 88% of caregivers had moderate to severe psychosocial burden and 11% were suffering from mild burden.[23] The discrepancy of the results can be due to the fact that majority of the patients with spinal injury survivors were male who were breadwinners besides they had to pay heavy taxes and other household expenses. In another study, there was 47.42±11.91 mean score of burden. Additionally, no association was obtained with demographic characteristics.[15] The findings are broadly in line with the results of the current study. The literature has also identified that the age of caregivers, education level, marital status, household responsibilities, health problems and dependency level of the patients were noteworthy factors to affect the level of burden.[24] In Brazil, a study on the caregivers of neurological patients indicated that 58.09% participants reported mild to moderate burden, 22.70% had no burden and 19.12% had moderate to severe burden.[25] The study also identified that demographic characteristics affected the level of burden including female caregivers, educational level and advance age. The current study also revealed that female gender and the status of unemployment affect the level of psychosocial burden (p-value, 0.022, p-value 0.025 respectively). The female perform caring of children, employment and other activities of household, therefore there is an extra burden on the female caregivers. A study conducted in India revealed that 63.0% of the participants had mild to moderate, 7% were moderate to severely and 2% were severely overburdened.[26] The caregivers in India share similar responsibilities as in our country, therefore basic findings are alike in both studies.

The study is limited in terms of selection of small sample size which may affect the generalizability of the findings. The study could have been extended in duration for data collection which would involve large number of participants in the study.

CONCLUSION

The findings of the study contributed reliable evidences that family caregivers of spinal cord injury patients are markedly challenged by mild, moderate and severe level of psychosocial burden. Moreover the female gender and unemployed caregivers were more prone to psychosocial burden. This fact calls for proper interventions for the caregiver on the part of policy makers, hospital management and health care workers.

ETHICAL APPROVAL: This study was approved by Khyber Medical University Advance Study & Research Board prior to initiation of the research work.

CONFLICT OF INTEREST: None

FUNDING: None

AUTHORS' CONTRIBUTION: HB and SA substantially contributed to the conception and design of the study. HB and AK worked in the acquisition and analysis of the data. SA and DM interpreted the data. HB and AK drafted the manuscript and revised it critically for intellectual contents. SA and DM gave the final approval of the manuscript.

Received: August 15, 2019
Accepted: April 14, 2020

REFERENCES

1. Ozmen S, Yurttas A. Determination of care burden of caregivers of patients with multiple sclerosis in Turkey. Behav Neurol 2018; 2018:7205046
DOI: doi.org/10.1155/2018/7205046
2. Lindberg J, Kreuter M, Persson LO, Taft C. Family members' perspectives on patient participation in spinal cord injury rehabilitation. Int J Phys Med Rehabil 2014;02: 223.
DOI: doi.org/10.4172/2329-9096.1000223
3. Saunders LL, Krause JS, Focht KL. A longitudinal study of depression in survivors of spinal cord injury. Spinal Cord 2011; 50: 72–7.

DOI: doi.org/10.1038/sc.2011.83

4. Priebe MM. Spinal cord injuries as a result of earthquakes: Lessons from Iran and Pakistan. J Spinal Cord Medicine 2007; 30: 367–8. DOI: doi.org/10.1080/10790268.2007.11753953
6. Angel S, Buus N. The experience of being a partner to a spinal cord injured person: A phenomenological-hermeneutic study. Int J Qual Stud Health Well-Being 2011; 6: 7199. DOI: https://doi.org/10.3402/qhw.v6i4.7199
7. Ekechukwu EN, Ikrechero JO, Ezeukwu AO, Egwuonwu AV, Umar L, Badaru UM. Determinants of quality of life among community-dwelling persons with spinal cord injury: A path analysis. Niger J Clin Pract 2017; 20:163–9. DOI: dx.doi.org/10.4103/1119-3077.187328
8. Conti A, Garrino L, Montanari P, Dimonte V. Informal caregivers' needs on discharge from the spinal cord unit analysis of perceptions and lived experiences. Disabil Rehabi 2016; 38: 159-67. DOI: doi.org/10.3109/09638288.2015.1031287
9. Goodridge D, Rogers M, Klassen L, Jeffery B, Knox K, Rohatinsky N, Linassi G. Access to health and support services: Perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. Disabil Rehabil. 2015; 37:1401–10. DOI: doi.org/10.3109/09638288.2014.972593
10. Agtarap S, Carl E, Reynolds MC, Roden-Foreman K, Bennett M, Rainey E, et al. Caregiver expectations of recovery among persons with spinal cord injury at three and six months post-injury: A brief report. J Spinal Cord Med 2018; 1:1–4. DOI: doi.org/10.1080/10790268.2018.1508953
11. Sweet SN, Noreau L, Leblond J, Martin Ginis KA. Peer support need fulfillment among adults with spinal cord injury: relationships with participation, life satisfaction and individual characteristics. Disabil Rehabil 2016; 38: 558-65. DOI: doi.org/10.3109/09638288.2015.1049376
12. Fahimi RS, Salehi G. Effectiveness of strategic training of Neuro-Linguistic Programming on Improving the quality of life of veterans' spouses with injury rate of 25 to 50 percent; A case study of Tehran province. Iran J War Public Health 2018; 10: 181-6. DOI: ijwph.ir/article-1-715-en.html
13. Shah SZA, Rifullah, Ilyas SM. Assessment of the quality of life of spinal cord injury patients in Peshawar. J Pak Med Assoc 2017; 67: 434–7. DOI: jpma.org.pk/article-details/8123
14. Kang Y, Ding H, Zhou H, Wei Z, Liu L, Pan D, et al. Epidemiology of worldwide spinal cord injury: a literature review. J Neurorestoratology 2018; 6: 1-9. DOI: doi.org/10.2147/JN.S143236
15. Bilal H, The Incidence of traumatic spinal cord injury in Khyber Pakhtunkhwa, Pakistan from 2008 to 2012. J Riphah Coll Rehabil Sci 2016; 30–4.
16. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist 1986; 26 :260–6. DOI: doi.org/10.1093/geront/26.3.260
17. LaVela SL, Landers K, Etingen B, Karalius VP, Miskevics S. Factors related to caregiving for individuals with spinal cord injury compared to caregiving for individuals with other neurologic conditions. J Spinal Cord Med 2015; 38:505–14. DOI: doi.org/10.1179/2045772314Y.0000000240
18. Naveen RS. Burden in the Caregivers of Traumatic Spinal Cord Injured. J Evol Med Dent Sci 2016; 5:7310–3. DOI: doi.org/10.14260/jemds/2016/1655
19. Secinti E, Yavuz HM, Selcuk B. Feelings of burden among family caregivers of people with spinal cord injury in Turkey. Spinal Cord 2017; 55 :782–7. DOI: https://www.nature.com/articles/sc20176
20. Scholten EW, Kieftenbelt A, Hillebregt CF, De Groot S, Ketelaar M, Visser-Meily JM, et al. Provided support, caregiver burden and well-being in partners of persons with spinal cord injury 5 years after discharge from first inpatient rehabilitation. Spinal Cord 2018; 56: 436–46. https://www.nature.com/articles/s41393-017-0047-x
21. Karakurt P, Unsal A, Tanriverdi D. Evaluation of Care Burden and Quality of Life of Caregivers of Patients with Stroke. Int J Caring Sci 2018; 11: 529–42. http://www.internationaljournalofcaringsciences.org/docs/61_tarniverdi_original_11_1.pdf
22. Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. Mater Socio Medica 2015; 27: 333–6. DOI: 10.5455/msm.2015.27.333-336
23. Shah HB, Atif I, Rashid F, Babar MW, Arshad F, Qamar W, et al. Assessment of caregiver burden of patients receiving dialysis treatment in Rawalpindi. J Pak Med Assoc 2017; 67: 1498–501. https://www.jpma.org.pk/article-details/ 8383?article_id=8383
24. Kumar R, Kaur S. Burden and coping strategies in caregivers of stroke survivors. J Neurol Neurosci 2015; 06:1–5. DOI: 10.21767/2171-6625.S10001
25. Collins RN. Prevalence of depression and burden among informal caregivers of people with dementia and the effectiveness of mindfulness and acceptance based interventions at reducing these: two meta-analyses. 2018:1–231. https://ueaeprints.uea.ac.uk/68935/
26. Tosun ZK, Temel M. Burden of caregiving for stroke patients and the role of social support among family members: An assessment through home visits. Int J aring. 2017;10:1696–704. ttp://www.internationaljournalofcaringsciences.org/docs/65_8_tosun_10_3.pdf
27. Costa TF, Costa KNM, Martins KP, Fernandes MD, Brito SD. Burden over family caregivers of elderly people with stroke. Esc Anna Nery - Rev Enferm 2015; 19:350–5 DOI: doi.org/10.5935/1414-8145.20150048