

# Caregiver Burden and its Psychosocial Correlates among Caregivers of Traumatic Spinal Cord Injury Survivors in Pakistan

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## ABSTRACT

**Background:** Caring for someone with a spinal cord injury (SCI) has always been a family endeavor in developed as well as developing countries like Pakistan. The majority of people with SCI need assistance from others to carry out daily life activities, i.e., eating, self care, transportation, etc., and this functional dependence of the patient on their attendant affects the Quality of Life (QOL) of caregivers.

**Aim:** To find the relationship between caregiver burden, psychosocial factors, and QOL among caregivers.

**Methods:** A cross-sectional research design with purposive sampling technique was used to gather data from spinal units of various hospitals in Pakistan. Caregiver Burden Inventory (SCI) and WHOQOL were used to measure study variables. Sample size includes 255 family caregivers of SCI patients. Correlation analyses were applied to find the relationship between psychosocial factors, caregiver burden, and QOL.

**Results:** Results showed that caregiver burden was significantly negatively correlated with quality of life and positively correlated with caregiving hours, duration of injury, and number of helpers involved in the caregiving process. Furthermore, female caregivers showed high levels of caregiver burden and low levels of quality of life as compared to their male counterparts. Similarly, married persons scored higher on caregiver burden and whose patients had paraplegic nature of injury.

**Conclusion:** In Pakistan, there are no respite care programs for caregivers. The abovementioned findings are helpful in planning psychotherapeutic interventions and tailored caregiver training programs to lessen the impact of caregiver burden on caregivers and to boost their quality of life.

**Keywords:** Caregivers, caregiver burden, functional dependence, psychosocial factors, quality of life

## INTRODUCTION

Caregivers of survivors with spinal cord injuries (SCI) play a pivotal role in their rehabilitation and reintegration into the community. A single chronically ill person in the family changes the life style, employment status, social relations, choices, and personal life of all other family members.<sup>1</sup> Family members, including children, parents, siblings, and spouses, experience changes in their routine lives as they are actively involved in the caregiving of SCI survivors. Literature reflects that the physical and mental health of family caregivers was affected by care-giving<sup>2</sup>. Caregivers are a considerable resource to their patients and an essential pillar of the health care system, yet their fundamental role and worth to society as a whole have not been valued. This negligence badly affects the mental and physical health of caregivers and causes distress and poor life satisfaction among them<sup>3</sup>.

Traumatic spinal cord injury (tSCI) is a most stressful and catastrophic condition having serious bio-psychosocial effects on individuals' various domains of life. Being a SCI survivor in a developing country like Pakistan is a huge tragedy, as in such countries healthcare resources are not sufficient to support a chronically ill person so that they can play their role as a useful member of the community. Traumatic spinal cord injuries are caused by bruising, crushing, or tearing of the delicate spinal cord tissue. In developing countries like Pakistan, due to the lack of roads and work safety programs, the primary causes of spinal cord injuries are road traffic accidents and history of fall<sup>4</sup>. Such injuries affect patient's independence and they become functionally dependent upon their caregivers for activities of daily living, i.e., eating, bathing, dressing, etc.

Caregiver burden is a commonly implied term used to explain strain or load carried by a caregiver to fulfill his caring responsibilities. It can be defined as a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent patient. It is a multidimensional response to physical, psychological, emotional, social, spiritual, and financial stressors associated with the caregiving experience<sup>5</sup>. Family

caregivers play a vital function in empowering and enabling SCI survivors by providing them assistance in personal care, home accommodations, and transportation. Almost 40% of SCI patients need assistance from others in their personal activities, and almost 50% of these helpers are family caregivers<sup>6</sup>. Family caregivers of SCI report physical exhaustion, emotional burnout, and a lack of support from friends and family<sup>7</sup>. According to existing literature, among caregivers of SCI survivors's physical complaints, fatigue, insomnia, reduced life satisfaction, depression, anxiety, and psychological distress are commonly reported outcomes. Whereas, they also reported social ostracism, loneliness, changes in role, work-family conflict, and marital dissatisfaction as an outcome of care-giving<sup>8-9</sup>. SCI badly impacts the quality of life of family caregivers<sup>1</sup>, particularly physical, psychological, and social aspects of caregiver health<sup>3</sup>.

Caregiving is a full-time job, but caregivers who are doing occupational jobs along with this responsibility reported higher levels of social, emotional, physical, and time-dependent burden<sup>10</sup>. Patients with SCI receive assistance from their caregiver on average seven hours per day, and most of them required passive assistance 24/7<sup>11</sup>. In addition to active hours of caregiving in which caregivers actively provide assistance to their patients, there is an additional 'on-call' time, which is longer than active caregiving duration. This passive caregiving involves the vigilance and alertness of the caregiver, although they are not physically engaged in any task during this time but still experience mental strain. This "on call" care-giving duration has a momentous influence on the vocational life of the caregiver, including their job status, education, social life, leisure, or recreational activities<sup>12</sup>. Level of injury is associated with level of dependency or dependence of patient on caregiver for functional activities<sup>12</sup>.

Caregivers are the backbone of the caring process. The support provided by the caregivers is pertinent to improving the health related quality of life of the patient in their reintegration into society as useful members and to preserve their status as an active member of community<sup>9</sup>. High societal pressure and a lack of preparedness for this huge responsibility of caregiving created significant role strain on caregivers, which caused psychological distress among them. It is also highlighted that caregivers who

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willingly opted for the caregiving role also experience a lack of emotional support, loneliness, and symptoms of anxiety<sup>6</sup>.

The majority of caregivers feel mentally burdened, preoccupied by their care-giving responsibilities, emotional exhaustion, reduced cognitive functionality, psychological distress, burnout, lack of life satisfaction, and poor social connection<sup>7</sup>. In spite of this, there are certain positive aspects of caregiving that are emotionally rewarding for caregivers, i.e. it increases family members connectivity and emotional embeddings with each other<sup>13</sup> and a feeling of psychological warmth in return for shared coping processes<sup>14</sup>. Even though caregivers of people with SCI show an adaptation trajectory characterized by a significant reduction of psychological distress and increased quality of life, the level of caregiver burden remains stable over time<sup>15</sup>. Some other factors contributed to caregiver burden, such as caregiving hours, nature of injury, duration of injury, higher age, female gender, lack of employment, functional dependence of patients, and level of support provided among SCI caregivers<sup>16</sup>.

**Rationale of the study:** Caregiver burden and quality of life are both multi-dimensional and multifaceted phenomena influenced by numerous factors, so it's important to explore these constructs in the context of spinal cord injury caregivers who are providing palliative care to their loved ones. Although there is much research on the quality of life of patients with SCI, there is a dearth of research findings on the impact of caregiving on the quality of life of caregivers. The focus of current research is to get in-depth knowledge on the relationship between caregiver burden and quality of life of caregivers of SCI survivors. Furthermore, in this research, psychosocial factors, i.e., gender, nature of injury, caregiving duration, injury duration, and number of helpers, are also explored to check their impact on caregiver burden and quality of life.

The objectives of the study were to find the relationship between caregiver burden and quality of life of caregivers having patients with traumatic spinal cord injuries and to investigate the role of psychosocial factors on caregiver burden and quality of life of caregivers.

#### Hypotheses

1. There is significant negative relationship between caregiver burden and quality of life among caregivers of patients having traumatic spinal cord injuries.
2. Caregiver burden is positively correlated with care-giving hours, care-giving duration, and injury duration among caregivers of patients having traumatic spinal cord injuries.
3. Number of helpers is negatively correlated with caregiver burden among caregivers of patients having traumatic spinal cord injuries.
4. Females score high on caregiver burden as compared to males and low on quality of life as compared to males.

## METHOD

**Research Design:** A cross-sectional research design (quantitative approach) is used to study the relationship between the study variables, i.e., caregiving burden and quality of life. Purposive sampling technique (non-probability sampling technique) having survey method is used to collect data from participants.

**Sample size and sampling:** In the present study, n=255 caregivers were included; only informal caregivers, i.e., parents, children, siblings, spouses, and son-in-law/daughter-in-law of patients with traumatic spinal cord injuries, were selected. Only those caregivers were taken who have been providing care to their patients for the past year. Caregivers of patients having traumatic spinal cord injury (i.e., history of fall, road traffic accident, bomb blast, firearm, etc.) were eligible to become part of this study. Age of caregiver was 18 or older. Furthermore, formal caregivers, i.e., doctors, nurses, health professionals, etc., were not included in the study. Caregivers who were providing caregiving to their patient for a time duration less than one year are not selected. Caregivers of

patients having any neurodegenerative disease or psychiatric condition were not included.

#### Instruments

**Socio-demographic Sheet:** For the present study, a demographic sheet was designed to get detailed information regarding demographic variables of caregivers, i.e., age, gender, education, family system, marital status, occupation, nature of injury, caregiving duration (in years), care-giving hours, longevity of injury, and number of helpers who provide help in care-giving.

**Caregiver Burden Inventory (CBI-SCI):** CBI-SCI is a self reported questionnaire originally developed by Novak and Guest<sup>17</sup>. In the present study, a modified version of CBI was used that is particularly adapted for caregivers of patients with spinal cord injury<sup>18</sup>. CBI is comprised of five subscales that assess the level of caregiver burden across different aspects. The first subscale is time-dependent burden, which measures burden caused by restriction of individuals' personal time; the second is developmental burden, which measures a person's perception about failure and hopes; the third subscale is physical burden, which measures bodily complaints and physical symptoms; the fourth subscale is social burden, which measures an individual's strive to maintain social connections at home and workplace; and the fifth subscale is emotional burden, which measures feeling of shame or humiliation related to care-recipient. All subscales include five items except the physical burden subscale. Response ranging from strongly disagrees to strongly agree on a five-point Likert scale (0-4). For each subscale, the score ranges from 0 to 20, and the total score of CBI ranges from 0-100, showing no burden to the highest achievable burden level among caregivers. Internal consistency of the total scale comprised of  $\alpha = .90$  and subscales ranges between  $\alpha = .76$  and  $.91$ .

**World Health Organization Quality of Life (WHOQOL-BREF):** WHOQOL-BREF (Urdu translated version) was used to determine the quality of life of caregivers in the present study. It is a self-administered questionnaire that assesses the subjective QOL of patients over the preceding two weeks. This scale was developed by the World Health Organization<sup>19</sup> and translated by Khalid and Kausar in Urdu (20). It is a 26-item scale consisting of four subscales, i.e., physical functioning includes seven items, psychological functioning includes six items, social relationships comprised of three items, and environmental factors includes eight items. Two items in this scale, i.e., 1 and 2, measure perception of QOL and general health status of a person. Each individual item of the WHOQOL-BREF was scored on a five point Likert scale ranging from strongly disagree (1) to strongly agree (5). WHOQOL-BREF consists of three reverse scored items, i.e., 3, 4, and 26. A high score on this scale indicated high levels of quality of life, and a low score indicated poor health functioning. Alpha reliability coefficient of WHOQOL-BREF was  $\alpha = .88$ <sup>20</sup>.

**Procedure:** A sample was approached from spinal units of various hospitals in Pakistan and the community sector. To get the data from hospitals, permission was taken from their higher authorities. They were briefed about the rationale of the study, tions were provided to the participants for giving responses. and informed consent was taken from them. Participants were assured about the confidentiality and privacy of their responses. Directions were provided the scales booklet, pants for giving responses. After completion of scales booklet the study. ivers were thanked for their voluntary participation in study.

**Data Analyses:** SPSS Version 22 was used to analyze the data. Psychometric properties were tested through internal consistency estimates (Cronbach alpha), and descriptive statistics (mean, standard deviation, skewness) were calculated to check the distribution of data. To find the relationship between variables, bivariate correlation analyses were used. To find mean differences across demographic variables, i.e., gender, family system, and type of SCI (paraplegic and quadriplegic), an independent sample t-test was applied.

**RESULTS**

**Reliability Estimates and Descriptive Analysis:** Cronbach alpha was calculated to find the internal consistency between the items of scales. Table 1 shows that reliability of all scales and subscales was above the acceptable value of .70 as per specified criteria and ranges from .78 to .96. Reliability estimates of subscales of caregiver burden inventory range from .82 to .91, i.e., high reliability. Similarly, the Cronbach alpha reliability of Quality of Life and subscales ranges from .78 to .89, i.e., high reliability. Table also shows values of mean, SD, and other parameters, which revealed that our data is normally distributed and fulfilling the normality assumption of parametric testing as values of skewness range from -.01 to .93, which was statistically acceptable. Values of skewness range between -1 and +1. However, the negative values of skewness for care-giving burden and various subscales of quality of life show that the distribution had relatively high scores stack on the right side of the mean. Whereas positive values of skewness on care-giving hours, care-giving duration, and duration

of injury indicated that the distribution had most of the score on the left side of the mean or greater than the mean.

**Correlation Analyses:** Table 2 indicates that caregiving hours were significantly positively correlated with caregiving burden, which reflects that as the number of hours increases, caregivers experience a high level of burden in various domains of their life, including social, emotional, and physical. Whereas, caregiving hours were significantly negatively correlated with quality of life and its subscales, which indicated that as the number of hours increases, caregivers experience changes in their physical, psychological, social, and environmental domains of life. Duration of injury was also significantly positively correlated with caregiver burden and negatively correlated with quality of life. Furthermore, duration of injury was negatively correlated with emotional burden, which indicates that as duration of injury increases, caregivers adopt their role of care-giving and experience less emotional burden..

Table 1: Cronbach alpha, Mean, standard deviation and skewness of Care-giving burden, Quality of Life scale and psychosocial factors (n=255)

Variable	No of Items	Cronbach $\alpha$	M	SD	Skew
Care-giving Burden	24	.93	56.94	17.37	.08
Time Dependent Burden	5	.91	15.89	3.74	-.31
Developmental Burden	5	.91	13.56	5.39	-.21
Physical Burden	4	.91	9.89	4.44	-.07
Social Burden	5	.82	12.48	5.26	-.20
Emotional Burden	5	.83	5.02	3.76	.61
Quality of Life	26	.96	88.31	20.94	-.37
Physical Health	7	.89	24.27	6.16	-.50
Psychological Health	6	.84	20.51	5.31	-.48
Social Relations	3	.78	10.32	3.12	-.50
Environment	8	.87	25.63	6.91	.24
Care-giving Hours	-	-	12.77	4.83	.26
Care-giving Duration	-	-	3.92	2.67	.93
Duration of Injury	-	-	3.89	2.70	.91
Number of Helpers	-	-	1.54	.96	-.01

Table 2: Pearson correlation between Care-giving burden, Quality of Life and psychosocial factors (N=255)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Care-giving Hours	-	-.02	-.01	-.44**	.67**	.71**	.43**	.54**	.49**	.41**	-.64**	-.52**	-.63**	-.57**	-.59**
2. Care-giving Duration		-	.99**	.50**	.27**	.16**	.49**	.34**	.15*	-.25**	-.15*	-.11	-.24**	-.18**	-.10
3. Duration of Injury			-	.51**	.29**	.17**	.50**	.37**	.18**	-.23**	-.17**	-.12	-.26**	-.18**	-.11
4. Number of Helpers				-	-.18**	-.27**	-.02	-.04	-.18**	-.28**	.29**	.18**	.28**	.38**	.22**
5. Care-giving Burden					-	.74**	.84**	.90**	.78**	.51**	-.78**	-.76**	-.77**	-.58**	-.66**
6. Time dependent Burden						-	.59**	.63**	.39**	.27**	-.66**	-.46**	-.64**	-.54**	-.71**
7. Developmental Burden							-	.82**	.51**	.17**	-.67**	-.58**	-.68**	-.58**	-.59**
8. Physical Burden								-	.60**	.33**	-.59**	-.59**	-.57**	-.39**	-.49**
9. Social Burden									-	.34**	-.62**	-.67**	-.66**	-.47**	-.41**
10. Emotional Burden										-	-.43**	-.57**	-.35**	-.19**	-.31**
11. Quality of Life											-	.89**	.93**	.86**	.89**
12. Physical Health												-	.77**	.67**	.68**
13. Psychological Health													-	.81**	.79**
14. Social Relations														-	.71**
15. Environment															-

\*\*=  $p \leq .01$ ; \* =  $p \leq .05$

**Mean Differences**

Table 3: Mean differences across Gender on Care-giving burden, Quality of Life and Psychosocial Factors (N=255)

Variables	Male (n=115)		Female (n=140)		t (253)	p	95%CI		Cohen's d
	M	SD	M	SD			LL	UL	
Care-giving Hours	9.40	3.01	15.54	4.27	-13.01	.00	-7.07	-5.21	.84
Care-giving Duration	3.63	2.78	4.16	2.65	-1.54	.12	-1.18	.14	-
Duration of Injury	3.58	2.74	4.14	2.66	-1.66	.09	-1.24	.10	-
Number of Helpers	1.81	.94	1.32	.92	4.16	.00	.26	.71	.52
Care-giving Burden	46.64	12.31	65.40	16.34	2.33	.00	-22.39	-15.12	.65
Time dependent Burden	14.13	3.42	17.32	3.39	-10.16	.00	-4.02	-2.33	.93
Developmental Burden	11.18	4.61	15.51	5.20	-6.96	.00	-5.56	-3.10	.88
Physical Burden	7.42	3.74	12.09	3.83	-9.77	.00	-5.60	-3.72	.61
Social Burden	10.21	4.44	14.34	5.16	-6.75	.00	-5.32	-2.92	.85
Emotional Burden	3.68	2.44	6.12	4.26	-5.47	.00	-.33	-1.57	.70
Quality of Life	96.21	15.52	81.82	22.57	5.80	.00	9.51	19.28	.74
Physical Health	26.36	4.30	22.56	6.89	5.13	.00	2.33	5.24	.66

Psychological Health	22.28	3.67	19.07	4.98	5.02	.00	1.95	4.46	.73
Social Relations	11.19	2.42	9.61	3.46	4.12	.00	.82	2.32	.52
Environment	27.98	6.27	23.71	6.84	5.14	.00	2.63	5.90	.65

Table 4: Mean differences across Nature of Injury on Care-giving burden, Quality of Life and Psychosocial Factors (n=255)

Variables	Paraplegic (n=107)		Quadriplegic (n=148)		t (253)	p	95%CI		Cohen's d
	M	SD	M	SD			LL	UL	
Care-giving Hours	13.03	4.88	12.58	4.81	-.74	.46	-.75	1.67	-
Care-giving Duration	4.76	2.97	3.32	2.56	4.36	.00	7.99	2.09	.51
Duration of Injury	4.79	2.97	3.23	2.30	4.65	.00	.89	2.20	.58
Number of Helpers	1.63	.98	1.48	.95	1.22	.22	-.09	.38	-
Care-giving Burden	60.65	18.12	54.26	16.36	2.94	.00	2.11	10.67	.37
Time dependent Burden	16.39	3.97	15.52	3.54	1.84	.06	-.06	1.80	-
Developmental Burden	14.53	5.56	12.86	5.16	2.47	.01	.34	3.00	.15
Physical Burden	10.59	4.65	9.55	4.25	1.84	.06	-.07	-2.14	-
Social Burden	13.88	4.99	11.47	5.23	3.69	.00	1.12	3.69	.47
Emotional Burden	5.21	3.79	4.85	3.73	.86	.39	-.52	1.34	.09
Quality of Life	80.40	19.13	94.03	2.38	-5.40	.00	-18.56	-8.67	.99
Physical Health	22.12	5.89	25.83	5.88	-5.96	.00	-5.18	-2.23	.63
Psychological Health	18.84	4.29	21.72	5.65	-4.44	.00	-4.17	-1.60	.48
Social Relations	9.28	3.02	11.08	2.99	-4.72	.00	-2.55	-1.04	.59
Environment	23.29	6.05	27.33	7.01	-4.80	.00	-5.70	-2.39	.61

Multiple helpers in the care-giving process were also significantly negatively correlated with time-dependent social and emotional burden and positively correlated with quality of life and its subscales. In addition, caregiver burden, i.e., time-dependent, developmental, social, physical, and emotional, was negatively correlated with all domains of quality of life.

Table 3 illustrates mean differences across gender on caregiver burden, quality of life, and psychosocial factors, i.e., care-giving hours, care-giving duration, duration of injury, and number of helpers. Table indicated significant mean differences across gender on all variables except care-giving duration and duration of injury. Female caregivers scored higher on care-giving burden ( $M=65.40$ ;  $p<.00$ ) and its subscales as compared to male caregivers ( $M=46.64$ ;  $p<.0$ ). Whereas, male caregivers scored higher on quality of life ( $M=96.21$ ;  $p<.00$ ) and its subscales as compared to female caregivers ( $M=81.82$ ;  $p<.00$ ). Furthermore, females scored higher on caregiving hours as compared to males.

Table 4 illustrates mean differences across the nature of injury on caregiver burden, quality of life, and psychosocial factors, i.e., care-giving hours, care-giving duration, duration of injury, and number of helpers. Table indicated significant mean differences across nature of injury on all variables except care-giving hours, number of helpers, time-dependent, physical, and emotional burden. Caregivers whose family member had a paraplegic nature of injury experience more caregivers' burden and poor quality of life as compared to caregivers whose patient had a quadriplegic nature of injury.

## DISCUSSION

This research was planned to investigate the association between caregiver burden, quality of life, and other psychosocial factors involved in the caregiving process, i.e., caregiving hours, injury duration, duration of injury, number of helpers, nature of injury, etc. As we know, caregiving is a multifaceted, complex process influenced by multiple factors, so it's pertinent to explore the factors that play a vital role in influencing the general health of caregivers. Caring of a spinal cord injury survivor is different and stressful than other diseases or disabilities<sup>7</sup>, and it altered the daily life practices of caregivers either positively or negatively<sup>3</sup>. Functional dependence of a patient on their caregiver is one of the most exhausting things that a caregiver experiences, as it involves physical, psychological, social, and emotional burden<sup>10,16</sup>.

Findings of the present study showed that caregiver burden negatively influences the quality of life of caregivers. Physical burden effects physical functioning; likewise, emotional, time-dependent, and developmental burden effects psychological health; and social burden had a negative impact on the social life

connections of caregivers. Findings also show that every domain of caregiver burden changes various domains of caregivers' quality of life. These results were aligned with the previous research conducted to explore these phenomena. Almost half of the caregivers experience stressfulness because of their caregiving responsibilities that lead them towards depression. Symptoms of Depression in caregivers worsen the psychological health of spinal cord injury survivors and influence their rehabilitation process, management, or care at home<sup>6,21</sup>.

Results of the current study confirmed that family caregivers perceive more burdens, contrary to the formal caregivers who get reimbursement for their caregiving services. In developing countries like Pakistan, mily caregivers not consistent, ributed in providing care-giving services, although they are also involved in their reintegration into society and rehabilitation<sup>23</sup>. these results are consistent as our healthcare system is not well equipped and family members are the only source of providing palliative care to their loved ones having spinal cord injuries<sup>22</sup>. These family caregivers not only contributed in providing care-giving services, although they are also involved in their reintegration into society and rehabilitation<sup>23</sup>.

In previous research, it has been established that caregiving leads to a decrease in social engagement and depletion of sources that provide positive emotions and feelings to caregivers. This decrease in social capital negatively impacts the psychological health of caregivers, including their social functioning<sup>2,3</sup>. Findings of the present study also showed similar statistics, on the basis of which we can suggest that mental health professionals should actively work on preventing depression and enhancement of support systems for SCI caregivers. So that better rehabilitation outcomes can be achieved among SCI survivors as the health of the caregiver predicts the general health of the patient.

Functional dependence of SCI survivors results in physical exhaustion, insomnia, psychological distress, and unemployment among caregivers<sup>9,12</sup>. Level of injury or impairment predicts severity of functional dependence of SCI survivors on their caregivers and this cause caregiver burden among them<sup>24</sup>. In present research, physical burden was strongly negatively correlated with the physical domain of QOL, which is concordant with previous literature<sup>8-9,25</sup>. It can be inferred from past and current research that as caregiver burden level increases, they lose control in their lives, which causes poor life satisfaction and general health among them<sup>26-27</sup>.

The SCI patient-caregiver relationship is quite complex as compared to other diseases and disabilities, i.e., cerebral palsy, dementia, Parkinson's disease, cancer, schizophrenia, epilepsy, etc. According to literature, younger age, female gender, unemployment status, and caregiving hours are risk factors of

caregiver burden and poor quality of life among SCI caregivers, particularly as compared to other neurological conditions<sup>3</sup>. Caregivers who spend more hours in caregiving reported poor life satisfaction as their care recipient needs more assistance in their daily life activities<sup>8</sup>.

The nature of injury also predicts caregiving regarding strain and quality of life among caregivers of SCI survivors. According to this, caregivers whose patient had quadriplegic level of injury were more prone to poor mental and physical health. Findings of our research were contrary to this, as caregivers whose patients had paraplegic levels of injury experienced more burdens and had poor quality of life<sup>29</sup>.

Available literature presents that similar to other medical conditions, i.e., cancer and stroke, among SCI, mostly caregivers are females, and most of them are either mothers or spouses<sup>3</sup>. Globally, women have a traditional role as caretakers of house and family, so it's very common to assign her an additional responsibility to look after ill family member<sup>8</sup>. Caregiving of SCI survivors is a longtime, ongoing process sometimes comprised of decades. In such a scenario, females are the most available person in the family to offer caregiving services to ill family members. This pattern is common across developing and developed countries regardless of cultural differences and the nature of the disease<sup>10,22,24</sup>. Findings of present research were concordant with existing literature, as most SCI caregivers were females and they experienced more burdens and decline in general health.

According to the National Alliance for Caregiving, out of ten family caregivers, six were mostly females, and they spend more hours providing care, and it's more likely they quit their job to fulfill this new role of caregiving as a mother or a spouse<sup>29</sup>. Care-giving responsibility limits persons' life choices, social interactions, and recreational activities; females who are already engaged in household responsibility feel extra-burdened because of this new unprepared challenge of care-giving. Most of the female caregivers lack psychic resources to express themselves and their emotional pain towards the injury of a loved one; in return, they feel emotional exhaustion, psychological burnout, and depression<sup>8</sup>.

Family support in providing care services to SCI survivors buffers the impact of caregiver burden and improves the physical and psychological health of primary caregivers [30]. Similarly, in our study, the number of helpers involved in the care-giving venture is significantly negatively correlated with caregiver burden and positively correlated with quality of life, including all its domains. Family support helps in providing respite care to the primary caregiver and is helpful in reducing subjective burden, which ultimately improves family functioning<sup>10</sup>. The healthcare system in Pakistan is not advanced like in other developed and developing countries; it lacks health insurance, social support programs, easy access rehabilitation services, and tailored trainings to deal with SCI like adversities. This is the main reason informal caregivers experience high levels of caregiver stress and decline in their general health.

**Limitations and Suggestions:** Although this study provides us basic information about the risk factors involved in the care-giving process and how adversely they affect the health of caregivers, despite its strengths, this study has certain limitations. As already mentioned, caregiving is a complex, ongoing, multifaceted concept influenced by multiple psychosocial factors, so it's more pertinent to study this phenomenon by using a longitudinal research design to get in-depth information on changes experienced by caregivers at different timeframes. In the future, a mixed-methods approach will be better applied to get a more detailed picture of caregiving experiences through interviews and focus group discussions.

## CONCLUSION

The present study helps in the identification of factors involved in influencing quality of life among informal caregivers of SCI survivors. The quality of the healthcare system can be improved by

using comprehensive caregiver training programs and psychoeducation of caregivers after identification of these precursors. As caregiving is a complex, unique experience that varies from person to person, a tailored, person centered caregiver training is required so that the rehabilitation of SCI survivors can be improved. For this purpose, mental health professionals are required to timely address the psychological challenges experienced by caregivers and provide them with psychic support services. Findings of this study are helpful in making policies including respite care programs and formal online or in-person support group forums for caregivers of SCI survivors.

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