
Caring for Carers: Association between Care-giving and Quality of Life of Family Carers of Spinal Cord Injury Survivors in Pakistan

Neelam Bibi^{1*}, Naeem Aslam²**Abstract**

Caring for someone with a spinal cord injury (SCI) has always been a family endeavor in developed as well as developing countries like Pakistan. Majority of people with SCI need assistance of others to carry out daily life activities i.e., eating, self-care, transportation and this functional dependence of patients on their attendant affect Quality of Life (QOL) of caregivers. Present study was designed to find the relationship between caregiver burden, psychosocial factors and QOL among caregivers. Caregiver Burden Inventory-SCI and WHOQOL was used to measure study variables. Cross-sectional research design having purposive sampling technique was used to gather data from spinal units of various hospitals of Pakistan. Sample size includes $N= 255$ family caregivers of SCI patients. Correlation analyses were applied to find the relationship between psychosocial factors, caregiver burden and QOL. Results showed that caregiver burden was significantly negatively correlated with quality of life and positively correlated with care-giving hours, duration of injury, and number of helpers involved in care-giving process. Furthermore, female caregivers showed high level caregiver burden and low levels of quality of life as compared to male counterparts. Similarly, married persons scored higher on caregiver burden and whose patients had paraplegic nature of injury. In Pakistan, there are no respite care programs for carers, 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

Received: 09 August 2024; Revised
Received: 27 September 2024; Accepted: 29
September 2024

^{1*}PhD Scholar, National Institute of Psychology, Quaid-i-Azam University, Islamabad, Pakistan.

²Assistant Professor, National Institute of Psychology, Quaid-i-Azam University, Islamabad, Pakistan.

***Corresponding Author Email:**

neelam.yaseen@ymail.com

Introduction

Caregivers of survivors with spinal cord injuries (SCI) plays pivotal role in their rehabilitation and reintegration into community. A single chronically ill person in

family changes the life style, employment status, social relations, choices and personal life of all other family members (Backx et al., 2018). Family members including children, parents, siblings and spouse experiences changes in their routine life as they are actively involved in care-giving of SCI survivors. Literature reflects that physical and mental health of family caregivers was affected by care-giving (Pinqart & Sorensen, 2003). Caregivers are a considerable resource to their patient and an essential pillar of the health care system, yet their fundamental role and worth to society as a whole haven't been valued. This negligence badly affects the mental and physical health of caregivers and causes distress and poor life

This article is distributed under the terms of the Creative Commons Attribution Non Commercial 4.0 International License (<https://www.creativecommons.org/licenses/by-nc/4.0/>) which permits non-Commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified.

© Copyright: The Authors (2024)

satisfaction among them (Lynch & Cahalan, 2017).

Traumatic spinal cord injury (TSCI) is a most stressful and catastrophic condition having serious bio-psychosocial effects on individuals' various domains of life. 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 (Shah et al., 2017). 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 community (Darain & Arsh, 2019). In Pakistan, there is no spinal cord injury registry maintained to find the nationwide prevalence and epidemiology of SCI survivors (Bilal, 2016). This topic was highlighted after earthquake 2005 which struck the northern region of the country. In this disaster, more than 120000 people lost their lives and a huge number of survivors sustained injury to spinal cord (Raja et al., 2001). In Pakistan, relatively younger population in the second and third decade of life was predominately affected by SCI. In this age group, life is characterized by high risk activities such as rash driving, climbing on trees and on moving vehicles resulting in an increased risk for SCI (Qureshi et al., 2001; Rathore et al., 2008).

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 primary causes of spinal cord injuries are road traffic accidents and history of fall (Darain & Arsh, 2019; Lenehan et al., 2012). Such injuries affect patient's independence and they become functionally dependent upon their caregivers for activities of daily living i.e., eating, bathing, dressing.

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 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 care-giving experience (Pearlin et al., 1981). Family caregivers play 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 of others in their personal activities and almost 50% of these helpers are family caregivers (Elliott et al., 2014). Family carers of SCI reports physical exhaustion, emotional burnout and lack of support from friends and family (Charlifue et al., 2016). According to existing literature, among carers of SCI survivor'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 (Gajraj-Singh, 2011; Nogueira et al., 2016). SCI badly impacts quality of life of family caregiver's particularly physical, psychological and social aspects of caregiver health (Lynch & Cahalan, 2017).

Care-giving is a although 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 (Farajzadeh et al., 2021). Patients with SCI receive assistance of their caregiver on average seven hours per day and most of them required passive assistance 24/7 (Department of Physical Medicine and Rehabilitation, 2023). In addition to active hours of care-giving in

which carers actively provides assistance to their patient there is an additional ‘on-call’ time, which is longer than active care-giving duration. This passive care-giving involves vigilance and alertness of caregiver although they are not physically engaged in any task during this time but still experience mental strain. This “on call” care-giving duration have a momentous influence on the vocational life of caregiver including their job status, education, social life, leisure or recreational activities. Level of injury is associated with level of dependency or dependence of patient on caregiver for functional activities (Samsa et al., 2001).

Family caregivers are backbone of caring process. The support provided by the carers is pertinent to improve health related quality of life of patient, in their reintegration into society as useful member and to preserve their status as an active member of community (Nogueira et al., 2016). High societal pressure and lack of preparedness for this huge responsibility of care-giving created significant role strain on caregivers which cause psychological distress among them. It is also highlighted that carers who willingly opted for care-giving role also experience lack of emotional support, loneliness and symptoms of anxiety (Elliott et al., 2014).

Majority of caregivers feels mentally burdened, pre-occupied by their care-giving responsibilities, emotional exhaustion, reduced cognitive functionality, psychological distress, burnout, lack of life satisfaction and poor social connection (Lynch & Cahalan, 2017). In spite of this, there are certain positive aspects of care-giving which are emotionally rewarding for caregivers i.e. it increase family members connectivity and emotional embeddings with each other (Tarlow et al., 2004) and a feeling of psychological warmth in return of shared coping processes (Dickson et al., 2012). Even though caregivers of people with SCI show

an adaptation trajectory characterized by a significant reduction of psychological distress and increased quality of life although level of caregiver burden remains stable over time (Middleton et al., 2014).

Some other factors contributed in caregiver burden such as care-giving 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 (Post & Van Leeuwen, 2012). Caregiver burden is not only linked with nature of illness of patient but also the length and time involved in care-giving, involvement in extra care demands, and expectations for care from primary caregiver regardless of his/her other household responsibilities (Xu et al., 2021). Caregivers get fatigued and exhausted when they don’t get assistance from someone else in providing care to their patient, when they feel less potential of helping patient, either physically, psychologically or financially (El-Nady, 2012).

National Spinal Cord Injury Statistical Center in the United States indicates that those individuals with SCI using assistance receive an average of 7 hours per day of help, 7 days a week. In addition to the visible, quantifiable amount of time spent in active care-giving, it has been identified that there is additional ‘on-call’ time, which may involve long periods of passive vigilance. For the family caregivers, the degree of this quantifiable and on-call time can have a significant impact on the ability for the caregiver to maintain employment or schooling and engage in other social, leisure or productive activities (Samsa et al., 2001).

Rationale of the Study

Caregiver burden and quality of life both are multi-dimensional and multifaceted phenomenon influenced by numerous factors so it’s important to explore these constructs in context of spinal cord injury carers who are providing palliative care to their loved ones.

Although there are many researches on quality of life of patients with SCI but there is dearth of research findings on impact of care-giving on quality of life of caregivers. Focus of current research is to get an in-depth knowledge on the relationship between caregiver burden and quality of life of carers of SCI survivors. Furthermore, in this research psychosocial factors i.e., gender, nature of injury, care-giving duration, injury duration and number of helpers are also explored to check their impact on caregiver burden and quality of life.

Objectives

1. To find the relationship between caregiver burden and quality of life of caregivers having patients with traumatic spinal cord injuries.
2. To examine 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

Cross-sectional research design (quantitative approach) is used to study the relationship between the study variables i.e., care-giving 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 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 are providing care to their patients from past one 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, and health professionals were not included in study. Caregivers who were providing care-giving to their patient from time duration less than one year are not selected. Caregivers of patients having any neuro-degenerative disease or psychiatric condition were not included.

Instruments

Caregiver Burden Inventory (CBI-SCI)

CBI-SCI is a self-reported questionnaire originally developed by Novak and Guest (Novak & Guest, 1989). In present study modified version of CBI was used that is particularly adapted for caregivers of patients with spinal cord injury (Conti et al., 2019). CBI comprised of five subscales which assess the level of caregiver burden across different aspects. First subscale is time-dependent burden which measures burden caused by restriction of individuals' personal time, second is developmental burden which measures a person's perception about failure and hopes, third subscale is physical burden which measures bodily complaints and physical symptoms, fourth subscale is social burden which measures an individuals' strive to maintain social connections at home and workplace and fifth subscale is emotional burden which measures feeling of shame or humiliation related with care-recipient. All subscales include five items except physical burden subscale. Response ranging from

strongly disagrees to strongly agree on a five-point likert scale (0-4). For each subscale score ranges from 0 to 20 and total score of CBI ranges from 0-100, showing no burden to highest achievable burden level among caregivers. Internal consistency of total scale comprised of $\alpha=.90$ and subscales ranges between $\alpha=.76$ to $.91$.

World Health Organization Quality of Life (WHOQOL-BREF)

WHOQOL-BREF (Urdu translated version) was used to determine quality of life of caregivers in present study. It is self-administered questionnaire which assesses the subjective QOL of patients over the preceding two weeks. This scale was developed by World Health Organization Quality of Life (WHOQOL, 1998) and translated by Khalid and Kausar in Urdu language (Khalid & Kausar, 2008). 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 measures perception of QOL and general health status of a person. Each individual item of the WHOQOL-BREF was scored on 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. High score on this scale indicated high levels of quality of life and low score indicate poor health functioning. Alpha reliability coefficient of WHOQOL-BREF was $\alpha = .88$ (Khalid & Kausar, 2008).

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, care-giving duration (in years), care-giving hours, longevity of injury and number of helpers who provide help in care-giving.

Procedure

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

Ethical Considerations

Formal permission of this study was taken from Institutional Review Board of National Institute of Psychology, Quaid-i-Azam University, Islamabad. Ethical guidelines provided by American Psychological Association were strictly followed in present study for data collection.

Data Analyses

Statistical Package for Social Science (SPSS-IBM Version 22) was used to analyze the data. Psychometric properties were tested through internal consistency estimates (Cronbach alpha), descriptive statistics (mean, standard deviation, skewness) was 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) independent sample *t*-test was applied.

Results

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 α	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

Cronbach alpha was calculated to find the internal consistency between the items of scales. Table 1 show that reliability of all scales and subscales were above the acceptable value of .70 as per specified criteria and ranges from .78 to .96 (George & Mallery, 2019). Reliability estimates of subscales of caregiver burden inventory ranges from .82 to .91 i.e., high reliability. Similarly, 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 its fulfilling normality assumption of parametric testing as values of skewness ranges from -.01 to .93 which was

statistically acceptable. Values of skewness range between -1 to +1 (Groeneveld & Meeden, 1984). 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 distribution had most of score on left side of mean or greater than mean. Positive skewness indicated that mostly caregivers spend more than average number of hours in care-giving and they score high on care-giving duration and injury duration.

Table 2

Bivariate 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															-

**= $p < .01$; *= $p < .05$

Table 2 indicates that care-giving hours were significantly positively correlated with care-giving burden which reflects that as number of hours increase, caregivers experience high level of burden in various domains of their life including social, emotional and physical. Whereas, care-giving hours were significantly negatively correlated with quality of life and its subscales which indicated that as number of hours increases caregivers experience changes in their physical, psychological, social and environmental domain 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 increase caregivers adopt their role of care-giving and experience less emotional burden. Multiple helpers in 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 were negatively correlated with all domains of quality of life.

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 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 care-givers 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 care-giving hours as compared to males.

Table 4

Mean Differences across Marital Status on Care-giving Burden, Quality of Life and Psychosocial Factors (N=255)

Variables	Single (n=78)		Married (n=177)		t (253)	p	95%CI		Cohen's d
	M	SD	M	SD			LL	UL	
Care-giving Hours	9.85	3.69	14.05	4.73	-6.95	.00	-5.39	-3.01	.99
Care-giving Duration	3.41	2.12	4.16	2.86	-2.06	.04	-1.46	-.03	.29
Duration of Injury	3.42	2.12	4.10	2.91	-1.89	.06	-1.41	.02	-
Number of Helpers	1.69	.99	1.49	.94	1.58	.11	-.05	.46	-
Care-giving Burden	46.77	14.17	61.42	16.78	-6.72	.00	-18.94	-10.36	.94
Time dependent Burden	14.32	3.47	16.58	3.67	-4.60	.00	-3.22	-1.29	.63
Developmental Burden	11.96	4.57	14.26	5.58	-3.20	.00	-3.72	-.89	.45
Physical Burden	7.08	3.26	11.27	4.29	-7.69	.00	-5.27	-3.12	.55
Social Burden	9.94	5.34	13.59	4.83	-5.38	.00	-4.99	-2.31	.71
Emotional Burden	3.46	3.10	5.71	3.81	-4.58	.00	-3.21	-1.28	.64
Quality of Life	98.15	18.09	83.98	20.68	5.23	.00	8.84	19.51	.72
Physical Health	28.82	3.69	22.27	5.96	8.97	.00	5.11	7.99	.67
Psychological Health	22.18	3.96	19.79	4.83	3.38	.01	1.01	3.79	.54
Social Relations	11.49	3.25	9.81	2.94	4.05	.00	.86	2.49	.54
Environment	27.27	5.90	24.92	7.21	2.52	.01	.51	4.18	.35

Table 4 represents mean differences across marital status 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 marital status on all variables except care-giving duration. Married caregivers scored higher on care-giving burden ($M = 61.42$; $p < .00$)

and its subscales as compared to single caregivers ($M = 46.77$; $p < .0$). Whereas, single care-givers scored higher on quality of life ($M = 98.15$; $p < .00$) and its subscales as compared to married caregivers ($M = 83.98$; $p < .00$). Furthermore, married persons spend more hours in care-giving as compared to single caregivers.

Table 5

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

Table 5 illustrates mean differences across 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 paraplegic nature of injury experience more caregivers' burden and poor quality of life as compared to caregivers whose patient had 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 care-giving process i.e., care-giving hours, injury duration, duration of injury, number of helpers, nature of injury etc. As we know, care-giving is a multifaceted-multidimensional complex process influenced by multiple factors so it's pertinent to explore the factors which plays vital role in influencing general health of caregivers. Caring of a spinal cord injury survivor is different and stressful than other

diseases or disabilities (Charlifue et al., 2016) and it altered the daily life practices of caregiver either positively or negatively (Lynch & Cahalan, 2017). Functional dependence of patient on their caregiver is one of most exhausting issue which a caregiver experience as it involved physical, psychological, social and emotional burden (Farajzadeh et al., 2021; Post & Van Leeuwen, 2012).

Findings of present study showed that caregiver burden negatively influence quality of life of caregivers. Physical burden effects physical functioning likewise emotional,

time-dependent and developmental burden effect psychological health and social burden had negative impact on 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 researches conducted to explore these phenomena. Almost half of the caregivers experienced stressfulness because of their care-giving responsibilities that lead them towards Depression. Symptoms of Depression in caregiver worsen the psychological health of spinal cord injury survivors and influence their rehabilitation process, management or care at home (Elliot et al., 2014; Raj et al., 2016).

Results of current study confirmed that family caregivers perceive more burdens contrary to the formal caregivers who get reimbursement for their care-giving services. In developing countries like Pakistan 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 (Embrahimzadeh et al., 2013). These family caregivers not only contributed in providing care-giving services, although they are also involved in their reintegration into society and rehabilitation (Bhan et al., 2020).

In previous researches, it has been established that care-giving lead towards decrease in social engagement and depletion of sources that provide positive emotions and feelings to caregivers, this decrease in social capital negatively impact psychological health of caregiver including their social functioning (Lynch & Cahalan, 2017; Pinquart & Sorensen, 2003). Findings of present study also showed similar statistics as abovementioned 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 health of caregiver predicts general health of patient.

Functional dependence of SCI survivors results in physical exhaustion, insomnia, psychological distress and unemployment among caregivers (Nogueira et al., 2016; Samsa et al., 2001). Level of injury or impairment predicts severity of functional dependence of SCI survivors on his caregiver and this cause caregiver burden among them (Dreer et al., 2007). In present research physical burden was strongly negatively correlated with physical domain of QOL which is concordant with previous literature (Blanes et al., 2007; Gajraj-Singh, 2011; Nogueira et al., 2016). It can be inferred from past and current research as caregiver burden level increases, they lose control in their life which causes poor life satisfaction and poor health among them (Dalkey et al., 2017; Duggleby et al., 2016).

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 care-giving hours are risk factors of caregiver burden and poor quality of life among SCI caregivers particularly as compared to other neurological conditions (Lynch & Cahalan, 2017). Caregivers who spend more hours in care-giving reported poor life satisfaction as their care-recipient need more assistance in their daily life activities (Gajraj, 2011).

Nature of injury also predicts care-giving 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 towards poor mental and physical health. Findings of our research were contrary to this as caregivers whose patients had paraplegic level of injury experienced more burden and

have poor quality of life (National Family Caregivers Association and Family Caregivers Alliance, 2004).

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 spouse (Lynch & Cahalan, 2017). Globally, female have traditional role as caretaker of house and family so it's very common to assigned her an additional responsibility to look after ill family member (Gajraj-Singh, 2011). Care-giving of SCI survivor is a longtime, ongoing process sometimes comprised of decades. In such scenario females are most available person in family to offer care-giving services to ill family member. This pattern is common across developing and developed countries regardless of cultural differences and nature of disease (Dreer et al., 2007; Ebrahimzadeh et al., 2013; Farajzadeh et al., 2021). Findings of present research were concordant with existing literature, as most of SCI caregivers were females and they experienced more burdens and decline in general health. According to National Alliance for Care giving, out of ten family caregivers six were mostly females and they spend more hours in providing care and it's more likely they quit their job to fulfill this new role of care-giving as a mother or a spouse (National Family Caregivers Association and Family Caregivers Alliance, 2004). 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 loved one; in return they feel emotional exhaustion, psychological burnout and Depression (Charlifue et al., 2016; Post & Van Leeuwen, 2012).

Family support in providing care services to SCI survivors buffers the impact of caregiver burden and improves physical and psychological health of primary caregivers (Coleman et al., 2013). Similarly, in our study, number of helpers involved in care-giving venture is significantly negatively correlated with caregiver burden and positively correlated with quality of life including its all domains. Family support helps in providing respite care to primary caregiver and helpful in reducing subjective burden which ultimately improves family functioning (Farajzadeh et al., 2021). Healthcare system in Pakistan is not advanced like other developed and developing countries, it lacks health insurances, social support programs, easy access rehabilitation services and tailored trainings to deal with SCI like adversities. This is 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 care-giving process and how adversely they affect health of caregivers despite its strengths, this study has certain limitations. As already mentioned, care-giving is a complex ongoing multifaceted concept influenced by multiple psychosocial factors so it's more pertinent to study this phenomenon by using longitudinal research design to get in-depth information on changes experienced by caregivers at different timeframes. In future, mixed method approach is better to applied to get more detailed picture of care-giving experiences through interviews and focus group discussions.

Implications and Conclusion

The Present study helps in identification of factors involved in influencing quality of life among informal carers of SCI survivors. Quality of healthcare system can be

improved by using comprehensive caregiver training programs and psycho-education of caregivers after identification of these precursors. As care-giving is a complex unique experience that varies from person to person so a tailored person centered caregiver training is required so that 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 in providing them 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.

Contribution of Authors

Neelam Bibi: Conceptualization, Investigation, Methodology, Data Curation, Formal Analysis, Writing – Original Draft
Naem Aslam: Methodology, Writing - Reviewing & Editing, Supervision

Conflict of Interest

There is no conflict of interest declared by the authors.

Source of Funding

The authors declared no source of funding.

Data Availability Statement

The datasets of the current study are not available publicly due to ethical reasons but are available from the corresponding author [N.B.] upon the reasonable request.

References

Backx, A. P. M., Spooren, A. I. F., Bongers-Janssen, H. M. H., & Bouwsema, H. (2018). Quality of life, burden and satisfaction with care in caregivers of patients with a spinal cord injury during and after rehabilitation. *Journal of Spinal Cord*, *56*(9), 890–899. <https://doi.org/10.1038/s41393-018-0098-7>

- Bhan, N., Rao, N., & Raj, A. (2020). Gender Differences in the Associations between Informal Caregiving and Wellbeing in Low- and Middle-Income Countries. *Journal of Women's Health*, *29*(10), 1328–1338. <https://doi.org/10.1089/jwh.2019.7769>
- Bilal, H. (2016). The Incidence of traumatic spinal cord injury in Khyber Pakhtunkhwa, Pakistan from 2008 to 2012. *Journal of Riphah College of Rehabilitation Sciences*, *3*, 30-34.
- Blanes, L., Carmagnani, M. I. S., & Ferreira, L. M. (2007). Health-related quality of life of primary caregivers of persons with paraplegia. *Journal of Spinal Cord*, *45*(6), 399–403. <https://doi.org/10.1038/sj.sc.3102038>
- Charlifue, S. B., Botticello, A., Kolakowsky-Hayner, S. A., Richards, J. S., & Tulskey, D. S. (2016). Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits. *Journal of Spinal Cord*, *54*(9), 732–736. <https://doi.org/10.1038/sc.2016.25>
- Coleman, J. A., Harper, L. A., Perrin, P. B., Olivera, S., Perdomo, J. L., Arango, J. A., & Arango-Lasprilla, J. C. (2013). Examining the relationship between health-related quality of life in individuals with spinal cord injury and the mental health of their caregivers in Colombia, South America. *International Journal of Rehabilitation Research*, *36*(4), 308–314. doi.org/10.1097/MRR.0b013e3283634e7f
- Conti, A., Clari, M., Garrino, L., Maitan, P., Scivoletto, G., Cavallaro, L., Bandini, B., Mozzone, S., Vellone, E., & Frigerio, S. (2019). Adaptation and validation of the Caregiver Burden

- Inventory in Spinal Cord Injuries (CBI-SCI). *Journal of Spinal Cord*, 57(1), 75–82. <https://doi.org/10.1038/s41393-018-0179-7>
- Dalky, H. F., Qandil, A. M., Natour, A. S., & Janet, M. C. (2017). Quality of Life, Stigma and Burden Perception Among Family Caregivers and Patients with Psychiatric Illnesses in Jordan. *Community Mental Health Journal*, 53(3), 266–274. <https://doi.org/10.1007/s10597-016-0028-0>
- Darain, H., & Arsh, A. (2019). Spinal cord injury and its associated challenges to rehabilitation of patients in Pakistan. *Rehman Journal of Health Sciences*, 1(1), 1-20.
- Department of Physical Medicine and Rehabilitation (2023). *National Spinal Cord Injury Statistical Centre*. <https://www.uab.edu/medicine/physicalmedicine/research/national-spinal-cord-injury-statistical-center>
- Dickson, A., Brien, O., G. Ward, R., Flowers, P., Allan, D., & O'Carroll, R. (2012). Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: an interpretative phenomenological analysis. *Journal of Health Psychology*, 17(2), 247–257. <https://doi.org/10.1177/1359105311411115>
- Dreer, L. E., Elliott, T. R., Shewchuk, R., Berry, J. W., & Rivera, P. (2007). Family caregivers of persons with spinal cord injury: Predicting caregivers at risk for probable depression. *Journal of Rehabilitation Psychology*, 52(3), 351–357. <https://doi.org/10.1037/0090-5550.52.3.351>
- Duggleby, W., Williams, A., Ghosh, S., Moquin, H., Ploeg, J., Markle-Reid, M., & Peacock, S. (2016). Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. *Health and Quality of Life Outcomes*, 14, 81. <https://doi.org/10.1186/s12955-016-0486-7>.
- Ebrahimzadeh, M. H., Shojaei, B. S., Keshtan, F., Moghaddas, S. H., Fattahi, A. S., & Mazloumi, S. M. (2013). Quality of life and the related factors in spouses of veterans with chronic spinal cord injury. *Health and Quality of Life Outcomes*, 11, 48 <https://doi.org/10.1186/1477-7525-11-48>
- Elliott, T. R., Berry, J. W., Richards, J. S., & Shewchuk, R. M. (2014). Resilience in the initial year of caregiving for a family member with a traumatic spinal cord injury. *Journal of Consulting and Clinical Psychology*, 82(6), 1072–1086. <https://doi.org/10.1037/a0037593>
- El-Nady, M. T. (2012). Relationship between caregivers' burnout and elderly emotional abuse. *Scientific Research and Essays*, 7(41), 3535-3541.
- Farajzadeh, A., Akbarfahimi, M., Maroufizadeh, S., & Lavasani, N. (2021). Factors Associated with Quality of Life among Caregivers of People with Spinal Cord Injury. *Occupational Therapy International* (pre-print), 9921710. <https://doi.org/10.1155/2021/9921710>
- Gajraj-Singh P. (2011). Psychological impact and the burden of caregiving for persons with spinal cord injury living in the community in Fiji. *Journal of Spinal Cord*, 49(8), 928–934. <https://doi.org/10.1038/sc.2011.15>

- George, D., & Mallery, P. (2019). *IBM SPSS statistics 26 step by step: A simple guide and reference*. Routledge.
- Groeneveld, R. A., & Meeden, G. (1984). Measuring skewness and kurtosis. *Journal of the Royal Statistical Society Series D: The Statistician*, 33(4), 391-399.
- Khalid, T., & Kausar, R. (2008). Depression and quality of life among caregivers of people affected by stroke. *Asia Pacific Disability Rehabilitation Journal*, 19(2), 103-110.
- Lenehan, B., Street, J., Kwon, B. K., Noonan, V., Zhang, H., Fisher, C. G., & Dvorak, M. F. (2012). The epidemiology of traumatic spinal cord injury in British Columbia, Canada. *Journal of Spine*, 37(4), 321-329.
<https://doi.org/10.1097/BRS.0b013e31822e5ff8>
- Lynch, J., & Cahalan, R. (2017). The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. *Journal of Spinal Cord*, 55(11), 964-978.
<https://doi.org/10.1038/sc.2017.56>
- Middleton, J. W., Simpson, G. K., Wolf, A. D., Quirk, R., Descallar, J., & Cameron, I. D. (2014). Psychological distress, quality of life, and burden in caregivers during community reintegration after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 95(7), 1312-1319.
<https://doi.org/10.1016/j.apmr.2014.03.017>
- National Family Caregivers Association and Family Caregiver Alliance (2004). *Prevalence, hours and economic value of family care-giving, updated state-by-state analysis*.
https://www.caregiver.org/resource/do-you-need-caregiving-resources/?gclid=EAIaIQobChMIpoWD45SxgAMV2QkGAB2E0AJ1EAAYAAiAAEgJLdvD_BwE.
- Nogueira, P. C., Rabeh, S. A. N., Caliri, M. H. L., & Dantas, R. A. S. (2016). Health-Related Quality of Life among Caregivers of Individuals with Spinal Cord Injury. *The Journal of Neuroscience Nursing*, 48(1), 28-34.
<https://doi.org/10.1097/JNN.000000000000177>.
- Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Journal of Gerontologist*, 29(6), 798-803.
<https://doi.org/10.1093/geront/29.6.798>
- Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social Behavior*, 22(4), 337-356
<https://doi.org/10.2307/2136676>
- Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of care-giving with caregiver burden and depressive mood: a meta-analysis. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 58(2), 112-128.
<https://doi.org/10.1093/geronb/58.2.112>
- Post, M. W. M., & van Leeuwen, M. C. (2012). Psychosocial issues in spinal cord injury: a review. *Journal of Spinal Cord*, 50(5), 382-389.
<https://doi.org/10.1038/sc.2011.182>
- Qureshi, A. A., Irfan, A., & Memon, M. A. (2001). Spinal Injuries: A Prospective Study. *Biomedica*, 17, 27-29.
- Raja, I. A., Vohra, A. H., & Ahmed, M. (2001). Neurotrauma in Pakistan. *World Journal of Surgery*, 25, 1230-1237.
- Raj, E. A., Shiri, S., & Jangam, K. V. (2016). Subjective burden, psychological

- distress, and perceived social support among caregivers of persons with schizophrenia. *Indian Journal of Social Psychiatry*, 32(1), 42-49. <https://doi.org/10.4103/0971-9962.176767>
- Rathore, M. F., Hanif, S., Farooq, F., Ahmad, N., Mansoor, S. N. (2008). Traumatic spinal cord injuries at a tertiary care rehabilitation institute in Pakistan. *Journal of Pakistan Medical Association*, 58(2), 53-57.
- Samsa, G. P., Hoenig, H., & Branch, L. G. (2001). Relationship between self-reported disability and caregiver hours. *American Journal of Physical Medicine & Rehabilitation*, 80(9), 674-684. <https://doi.org/10.1097/00002060-200109000-00007>
- Shah, S. Z. A., Rifullah, H., & Ilyas, S. M. (2017) Assessment of the quality of life of spinal cord injury patients in Peshawar. *Journal of Pakistan Medical Association*, 67, 434-437.
- Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Ruber, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of care-giving: Contributions of the REACH project to the development of new measures for Alzheimer's care-giving. *Research on Aging*, 26(4), 429-453. <https://doi.org/10.1177/0164027504264493>
- The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. (1998). *Journal of Social Science & Medicine*, 46(12), 1569-1585. [https://doi.org/10.1016/s0277-9536\(98\)00009-4](https://doi.org/10.1016/s0277-9536(98)00009-4)
- Xu, L., Liu, Y., He, H., Fields, N. L., Ivey, D. L., & Kan, C. (2021). Caregiving intensity and caregiver burden among caregivers of people with dementia: The moderating roles of social support. *Archives of Gerontology and Geriatrics*, 94, 104334.