

Research Paper

Depression and Coping Strategies adopted by Caregivers of Persons with Spinal Cord Injury

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ABSTRACT

Aim: To find the level of depression among persons with Spinal Cord Injury primary caregivers and also explore various coping strategies adopted by them. **Design:** Cross sectional study. **Methodology:** 100 primary caregivers were screened from Paraplegic Foundations, tertiary hospital and general population in Mumbai and Navi Mumbai, Maharashtra, India for inclusion and exclusion criteria. Beck Depression Inventory and Brief COPE Inventory were used as an outcome measure to assess level of depression and various coping strategies adopted by caregivers. **Result:** The results of the study revealed that 23% of caregivers had significant level depression, 39% of caregivers showed moderate level depression & 40% of caregivers had low level depression. There was strong association for problem focused coping strategies ($r = 0.86$) and emotional focused coping strategies ($r = 0.62$) with total brief cope score. **Conclusion:** The study concludes that caregivers of individuals with SCI have high to moderate level of depression and also show significant use of emotional-focused coping strategies more than problem-focused coping strategies that affect Quality of Life of caregivers and ultimately even has a negative impact on the care provided to the care recipients and their quality of life.

Keywords: Caregivers; Spinal Cord Injury; Depression; Coping strategy.

Spinal Cord Injury (SCI) is namely an injury to the spinal cord that can occur anywhere from between the foramen magnum till the cauda equina as a result of compulsion, incision or contusion.¹ The most common causes of SCI in the world are traffic accidents, gunshot injuries, knife injuries, falls and sports injuries.² The global incidence of SCI varies from 8.0 to 246.0 cases per million inhabitants per year and the global prevalence varies from 236.0 to 1,298.0 per million inhabitants.³ SCI culminates not only in the damage of independence and physical function but also is inclusive of many complications that occur from the injury. Neurogenic bladder and bowel, urinary tract infections, pressure ulcers, orthostatic hypotension, fractures, deep vein thrombosis, spasticity, autonomic

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dysreflexia, pulmonary and cardiovascular problems are frequent complications after SCI.⁴ This debilitating condition leads to severe disability resulting in loss of work, which brings psychosocial and economic problems which can leave individuals in need of ongoing assistance and care during all activities inclusive of multifaceted home-based care involving caregivers.⁵

A caregiver are often unpaid family member or friend or attender that provides care to an acute or chronic condition individual to assist them to manage a variety of Activities of Daily Living (ADL's).⁶⁻⁹ The responsibility of a caregiver is to walk alongside those, whom they serve in skillful and perceptive ways to assist others to bear their burdens more effectively.¹⁰ Any aspect of recovery, the challenging prospect for patient and family is re-integration to the community. Caregivers enter into this new role without formal preparation or training for an indefinite period.⁶ As a result, family caregivers often encounter a multitude of problems, including role overload, lack of information, financial strain, impaired quality of life and changes in health status.¹¹⁻¹³ Negative outcomes of caregiver's experiences such as elevated stress levels, emotional stress, burnout, fatigue, anger, resentment and depression has been reported by numerous studies.¹⁴⁻¹⁸

Depression remains common presentation in primary care but not frequently diagnosed.¹⁹ A study Brazil stated SCI caregivers have lower overall health-related quality of life and greater burden.¹⁵ Studies also states there is a high impact association between physical and psychosocial challenges faced by SCI individual and caregiver.²⁰ Colombian SCI caregivers, family needs were associated with psychosocial dysfunction like depression, burden, and dissatisfaction with life.²¹ Studies also states health-related quality of life in SCI individuals has been associated with the mental health of caregivers.²²

Family caregivers of persons with SCI may experience a wide range of changes in lifestyle and quality of life after their transition of role to a primary caregiver.^{16, 23-24} Caregiver depression has been consistently and strongly associated with poor Quality Of Life.²⁵⁻²⁷ According to Oxford Advanced Learner's Dictionary depression means severe dependency and dejection, typically felt over a while and accompanied by feelings of hopelessness and inadequacy. The percentage of caregivers with probable depressive disorder was observed among persons with SCI.²⁸

Essentially, depression coping has been divided into two domains emotion-focused and problem-focused coping strategies. An emotion-focused strategy emphasizes more on emotions based on acting and thinking, while a problem-focused strategy based on the patient situation, caused by disease and resources to manage the current situation.

Understanding the psychological functioning and coping mechanisms of caregivers may enable health professionals to improve Quality Of Life (QOL) among the SCI Patients caregivers.

However, very limited literature has examined these connections in developing countries like India, despite the lack of rehabilitation services and reduced life expectancy after SCI in those regions.²⁹ To attend this gap in the literature the purpose of the study was to find the level of depression among SCI person primary caregivers and coping strategies adopted by caregivers of persons with Spinal Cord Injury.

METHODOLOGY

Permission was obtained from Institutional Ethical Committee (IECB/MGM/COP/2021/89). Participants were screened as per inclusion and exclusion criteria of the study. 100 primary (first degree) caregivers of SCI patients were identified from 2 paraplegic foundations and 1 Tertiary Health Care Hospital and were included in this study. Written informed consent was obtained after screening them for the inclusion and exclusion criteria. First-degree caregivers of SCI Patients (blood-relation/marriage), one who can communicate in a local language or English and of 18 years and above were included. SCI patient-caregiver for less than 1 year, caregivers with any known chronic neurological disorder, musculoskeletal disorder, psychiatry disorder, drugs or alcohol abuse, etc. hearing and visual disorders and whose who were not willing to participate were excluded from the study. All participants were interviewed, and self-reported measures were administered using *the Beck Depression Inventory* and *Brief COPE Inventory* questionnaire which approximately require 40 minutes for administration.

Outcome measures used were 1) *Beck Depression Inventory*: Gold standard 21-item self-report depression inventory that can be administered to 13 years and above age group. It has items on a four-point scale that ranges from 0 to 3 and ratings are summed to provide a total score ranging from 0 – 63 and interpretation was made and 2) *The Brief COPE*, it is a brief form of COPE Inventory (Carver et al., 1989) contains 28-item self-report measure of problem-focused and emotion-focused coping skills, consisting of 14 domains / sub-scales in each and scored by four-point Likert scale.

Statistical Analysis

Data was statistically analyzed using Statistical Package for Social Sciences (version 16.0) Mean and standard deviation of demographic data of caregiver was calculated. Association between Brief Cope score with emotional focused and problem-focused coping strategies and depression was calculated using Spearman's rho (r)

RESULTS

Table 1: The majority of SCI individuals had lumbar level injuries (41%) followed by thoracic (35%) and cervical (24%) level of injury and 53% had received rehabilitation from a rehab centre while 29% received rehabilitation at home and 18% availed no treatment at all. Major proportion of them (41%) stayed in 'chawls' a basic one room tenement with basic facilities only, (30%) flat-system accommodation was next in line, followed by slums (21%) and others which included row houses and bungalows (8%). Majority of the participants belonged to the female gender (52%). The caregiver mean age was 47.43 years ($SD \pm 18.2$), around 56% of caregivers were parents with low economic status (46%) and 37% had a secondary level of education. Expenditure source is mainly from reimbursement 47%, saving 37% and others 16%. Most of the caregivers were parents of the individual with SCI (56%), while the others were a spouse (15%), sibling (17%) and other relatives (12%). The marital statuses of caregivers were as follows: married (81%), single (16%) separated (1%) and others (2%). Majority of SCI individual received care from a caregiver from past 2-5 years (44%) where 53% of caregiver belongs to nuclear, 41% joint and others 6% type of family, and 36% family had 3-5 numbers of children and 39% of the family with 1-2 no. of children.

Table 2: There was a strong level of association for problem-focused coping strategies 0.86 and emotional focused coping strategies 0.62 with a total brief cope score. Also, the caregiver using positive coping and negative coping strategies had a strong level of

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association with EFCS i.e., 0.56 and 0.51 respectively and with PFCS 0.72 and 0.64 respectively.

Table 3: There was a strong positive level of association between active copings, emotional support, instrumental support; positive reframing and planning components of problem-focused coping strategies and Brief Cope score with $r = 0.69, 0.68, 0.70, 0.51,$ and 0.64 respectively. And moderate level of association with humor, acceptance and religion components of PFCS with $r = 0.35, 0.46$ and 0.35 respectively. There was a positive moderate level of association between humor and planning component PFCS with EFCS with $r = 0.43$ and 0.40 respectively and a negative moderate level of association between acceptance and BDI score with $r=-0.30$

Table 4: There was a strong positive level of association between denial and venting components of EFCS and Brief cope score with $r = 0.52$ and 0.62 respectively. And moderate level of association with self-distraction and self-blame components of EFCS with $r = 0.42$ and $r= 0.65$ respectively. There was a positive strong level of association between self-blame and BDI score with $r=0.65$ and a positive moderate level of association between venting EFCS component and BDI scores with $r=0.37$.

DISCUSSION

The present study explored depression and the use of coping strategies among caregivers of persons with Spinal Cord Injury and also various coping strategies adopted by them using the Beck Depression Inventory and Brief COPE Inventory respectively. More than half of the population of caregivers included in our study showed significant (23%) and moderate (39%) levels of depression while only 40% fell into the low-level depression category. This affirms that caregivers of individuals with SCI have probable depression. This is in line with findings that suggest that depression is a common presentation in primary care (Qualitative studies from Goa, India).¹⁹ Different studies showed variation in the percentage of the level of depression. Studies done by Juanet, et al 2010 showed (43 %); Laura, et al 2007 (15.7%); Grant, et al. 2000 (37%) and Elliott, et al 2003 (50%) of people had probable depression. Studies that had used other self-report measures such as studies done by Covinsky, et al. 2003 showed that 32% of the caregivers of persons with dementia had probable depression, Han, et al 1999 showed 40-50% among the caregivers of persons with stroke. However, it is notable that the percentage of depression among caregivers in our study is far more than that of persons with Spinal Cord Injury (Frank, et al. 1992); (Chan 2000). While de Carvalho, et al 1998 reported 60 % and Krause, et al 2000 concluded that 48% of persons with SCI had depression.

This can be attributed to multiple factors. Most caregivers in our study were victims to numerous difficulties, role overload being one of them. Assuming the role of a caregiver, these individuals often neglect their own health, overlooking their basic needs as their availability for the patient becomes their number one priority. Since this role is seldom chosen mostly imposed for an indefinite time frame, the level of frustration and anxiety increases culminating eventually into depression. In our study, most of the caregivers had financial restraints with a meager or very low income just enough to make ends meet as almost all belonged to the lower strata of the society. They relied more on their savings and on reimbursements. All these findings are in line with precedent studies of west that confirm that SCI Caregivers encounter hosts of problems that impair their quality of life.³⁰⁻³²

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The data showed statistical significance but no association between level of depression and educational qualification of the caregiver, annual income, and source of expenditure for the care recipient, care recipients age, duration of the condition of the care recipient and place of rehabilitation of the care recipient. These results are in line with the argument proposed by Rodakowski et al 2012, who stated that regardless of the demographic factors, care giving for a person with SCI is an extremely distressing experience and caregivers more than often feel overwhelmed and burdened by their new found responsibilities.³³

Caregivers who had no, or low educational qualification showed moderate to significant depression levels. After an event of SCI, individuals with profound disability are found to have depression due to untimely change of circumstances for indefinite period. Studies have suggested that unrealistic expectations of SCI recovery from family members turned caregivers following injury further may risk caregiver wellbeing and mental health. Providing care for an individual with disability and depression further makes the role more challenging for the caregivers, forming a vicious cycle.³⁴ This may be due to lack of information and understanding of the condition and prognosis that stems from poor educational background. There may be a relation between unmet expectations from caregivers to poor outcomes for their own well-being which needs to be explored by further research. This will emphasize on the need for education and realistic goal setting in rehabilitation setups.

Low annual income of the family resulted into increase in the level of depression among caregivers as an additional duty of timely repayment of debt and increased dependency for financial stability was implied. This finding is in line with a study conducted by Schulz R et al.³⁵

In our study, majority of caregivers belonged to the age group of 30-40 years. A study done by Wise Young in 2003 documented increased depression among caregivers which is further supported by our results. Longer the duration of the condition less was the depression level noted in the caregivers, whereas the care givers of individuals with the duration of condition less than 5 years showed more depression. This can be explained as during the acute phase caregivers have to cope with an untimely role with inadequate knowledge and insufficient funds at their disposal affecting their own overall well-being.^{6,36-38} After the acute phase, the care recipient usually have adjusted their routines and have come to terms about the level of severity of the injury and the probable associated functional status. Thus, in later stages depression for the caregivers doesn't arise from these factors however if it does persist, it is due to social isolation due to a consuming schedule of providing care.¹⁴

Level of depression was higher among the caregivers of the care recipients who were undergoing rehabilitation in the centre as the care recipients were physically away from the caregivers this may have contributed to the feeling of helplessness.³²

No statistically significant association was seen between level of depression and caregivers' age, caregivers' gender, relation of the caregiver with the care recipient, employment status of the caregiver, marital status of the caregiver, number of children of the caregiver, type of family, type of settlement, care recipients' gender, and level of injury of the care recipient. These findings are in line with a study conducted by Juleen Rodakowski in 2013.¹⁴

Caregiver's life outside of the caregiving relationship was also adversely affected with social isolation, loneliness and a lack of spontaneity which needs to be further explored.⁴⁰ Studies

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have shown that extended support received from others and a positive social interaction is an important protective factor that shields caregivers from depression. Higher social and familial support has shown lower levels of depression.⁴¹ In our study, most caregivers belonged to a nuclear family arrangement however social support from friends and families was not assessed and needs to be explored through further research as it may be an important factor for understanding perceived burden in the care giving role.

An additional goal of the present study was to evaluate the coping strategies of the caregivers. This scale has two types of strategies in it i.e. emotion-focused strategies (Self-distraction 1, Self-distraction 19, Denial 3, Denial 8, Substance use 4, Substance use 11, Behavioral disengagement 6, Behavioral disengagement 16, Venting 9, Venting 21, Self-blame 13 and Self-blame 26) and problem-focused strategies (Active coping 2, Active coping 7, Emotional support 5, Emotional support 15, Instrumental support 10, Instrumental support 23, Positive reframing 12, Positive reframing 17, Planning 14, Planning 25, Humor 18, Humor 28, Acceptance 20, Acceptance 24, Religion 22 and Religion 27).

In this study, it was observed that emotion-focused strategies were used more as compared to problem-focused strategies. However, in other studies where brief COPE was used on caregivers or patients of various other medical conditions, it was found that problem-focused strategies were used more as compared to emotion-focused strategies. Tarik et al (2008) among diabetes patients; Shazia et al (2012) among parents of beta-thalassemia major patient; Yusoff et al (2009) among breast cancer patients. The population of the current study showed higher use of avoidance (emotion-focused) coping & lack of approach (problem-focused) coping. This is in line with literature that reports use of emotion-focused coping strategies which are seen to have associations with negative outcomes, with the primary caregivers being less able to regulate their negative emotions (Ruiz-Robledillo & Moya-Albiol, 2013).⁴²⁻⁴⁴ Generally, emotion-focussed techniques such as distraction, avoidance and venting are considered unhelpful by impact of emotion-focussed coping. However, there are some exceptions where caregivers felt these strategies were helpful, including venting emotion, taking time out and having a 'good cry' to release emotional energy.⁴⁵⁻⁴⁷ This highlights the dynamic and changing nature of coping and the importance of taking into account individual circumstances. Previous research has found that strategies cannot necessarily be categorised into positive or negative approaches and that some stressors, such as those that cannot be changed by way of problem-focussed approaches, benefit most from emotion-focussed techniques.⁴⁸ Thus, information regarding the fit between the stressor and a chosen coping strategy in caregivers warrants further investigation.

Caregivers with maladaptive coping styles and emotional mood disorders might be supported with special interventions to help the adaptation to SCI & to improve the rehabilitation efficacy. The limitations of the study were that the participants were biased towards social desirability and self-selection. The study recommends a longitudinal study of the same. Depression in the caregivers of persons with SCI should be assessed and necessary coping strategies should be taught to improve the Quality of Life of the caregivers and the care recipients.

CONCLUSION

Caregivers of persons with SCI had probable depression and showed predominantly the use of emotion focused strategies rather than problem focused coping strategies.

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Conflict of Interest

The author declared no conflict of interest.

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TABLES

Table 1: Demographic data of caregivers:

Variable	N
Age in years (Mean±SD)	47.43 ±18.2
18 to 30 (N)	19
31 to 45	29
46 to 60	25
>60	27
Relation with the Care recipient (N)	
Parents	56
Siblings	17
Husband	1
Wife	15
Children	9
Other	2
Annual Income (N)	
Less than 10,000	19
10,000-50,000	46
50,000-1 Lakh	16
More than 1 Lakh	19
Education of caregiver (N)	
No education	32
Primary	14
Secondary	37
Graduation and above	17
Type of settlement (N)	
Slums	21
Chawl	46
Flat	30
Row house	3
Source of expenditure for patient (N)	
Savings	37
Reimbursement/Credit	47
Medical insurance/TPA	8
Other	8
Marital Status (N)	
Unmarried	16
Married	81
Divorcee/separated	1
Widow/widower	2
Level of injury (N)	
Cervical	24
Thoracic	35
Lumbar	41
Caregivers Gender (N)	
Male	38
Female	52
Duration of the condition and received care giving in years (N)	
1-2	29

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2+ to 5	44
5+ to 10	11
>10	16
Place of rehabilitation (N)	
Home	29
Centre	53
no treatment	18
Family Type (N)	
Nuclear	53
Joint	41
Extended	1
Single parent	5
Number of children (N)	
None	19
1-2	39
3-5	36
more than 5	6

Table 2: Association of Brief Coping score with emotional focused and problem focused coping strategies and depression

Total Brief Coping Score	Total no. of caregivers N=100		Caregivers using positive strategies n=69		Caregivers using negative strategies n=31	
	Spearman's rho	Level of Association	Spearman's rho	Level of Association	Spearman's rho	Level of Association
EFCS	0.62**	Strong	0.59**	Strong	0.51**	Strong
PFCS	0.86**	Strong	0.72**	Strong	0.64**	Strong
BDI	0.28	Low	0.20	Low	0.08	Nil

Table 3: Association of problem focused coping strategies with total brief coping score, emotional focused coping strategies score and depression.

Components of PFCS	Total Brief Coping	Level of Association	EFCS	Level of Association	Total BDI	Level of Association
Active Coping	0.69**	Strong	0.27	Low	0.06	Low
Emotional Support	0.68**	Strong	0.16	Low	0.12	Low
Instrumental Support	0.70**	Strong	0.19	Low	0.07	Low
Positive Refraining	0.51**	Strong	-0.12	Low	-0.28**	Low
Planning	0.64**	Strong	0.43**	Moderate	0.08	Low
Humor	0.35**	Moderate	0.40**	Moderate	0.05	Low
Acceptance	0.46**	Moderate	-0.04	Low	-0.30**	Moderate
Religion	0.35**	Moderate	0.06	Low	-0.02	Low

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Depression and Coping Strategies adopted by Caregivers of Persons with Spinal Cord Injury

Table 4: Association of emotional focused coping strategies with total brief cope score; problem focused coping strategies score and depression.

Components of EFCS	Total Brief Cope	Level of Association	Total BDI	Level of Association	PFCS	Level of Association
Self Distraction	0.42**	Moderate	0.38**	Moderate	0.18	Low
Denial	0.52**	Strong	0.45**	Moderate	0.26**	Low
Substance Use	0.04	Low	0.08	Low	-0.14	Low
Behavioral Disengagement	0.14	Low	0.37**	Moderate	-0.23*	Low
Venting	0.62**	Strong	0.35**	Moderate	0.37**	Moderate
Self Blame	0.38**	Moderate	0.65**	Strong	0.00	Nil

***. Correlation is significant at the 0.01 level (2-tailed).*

**. Correlation is significant at the 0.05 level (2-tailed).*