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Depressive Disorders and Emotional Status in Caregivers of Spinal Cord Injured Individuals: A Referral Center Report

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Background: Depression is a major health problem that has been shown to cause decreased function and associated with several chronic states of disability.
Objectives: The aim of this study was to investigate the prevalence of depression in caregivers of spinal cord injury patients in Iran.
Patients and Methods: Caregivers of patients with spinal cord injury (SCI), who were referred to the Brain and Spinal Injury Research Center (BASIR), were interviewed to assess the existence of depression based on DSM-IV criteria. Patients' injury characteristics, including; injury level, etiology and independence scores, based on the Spinal Cord Independence Measure (SCIM), were entered into the analysis.
Results: Among the caregivers; 82.6% (n = 119) had no depressive disorder, while 9.7% (n = 14) revealed mild depression, 5.6% (n = 8) had moderate depression, and 2.1% (n = 3) suffered from a severe depressive disorder. Caregivers of patients with lower SCIM scores had significantly higher rates of depressive episodes ($P < 0.001$). Higher injury levels were also associated with higher depression rates among caregivers ($P < 0.004$).
Conclusions: The incidence of depression in the caregivers of spinal cord injured patient does not differ significantly from the general population in Tehran, Iran. It seems that the major predictor of developing depression in caregivers is the dependency level of the patient. Our study recommends developing screening programs to diagnose and treat depression, which target caregivers of spinal cord injury individuals with severe injuries, particularly those with higher levels of dependency, in order to reduce the burden and consequences of depression in this sensitive population.

*Keywords:*Depression; Spinal Cord Injuries; Caregivers

1. Background

Spinal cord injury (SCI) imposes tremendous stress on injured individuals and their families. Not only are the patients susceptible to developing major depression, but also their caregivers, who may also reveal levels of disturbed emotional status. The loss of function which occurs in SCI patients makes them dependent on their caregivers and as a result, this creates significant changes in the caregivers' life due to the time and effort that they must dedicate. A noticeable reduction in quality of life occurs (1, 2) and this contributes to reduction of psychological health in this population. The devastating impact of SCI on family members and caregivers, along with their increased responsibilities, create stressful conditions in which appropriate management is required.

Studies have reported lower self-esteem scores and emotional quality of life in SCI patients (3, 4). Apart from the severity and level of injury, which are major determinants of patients ability and independency, other social factors, such as; being employed (3, 5), having financial and social support (6), and being involved in social activities (7), contribute in generating a specific level of life quality and satisfaction. Coping with SCI over time may cause emotional changes in both patients and caregivers. Previous studies have revealed that coping style plays an important role in determining functional status and quality of life (8), so the importance of emotional support, which is mainly provided by caregivers, is clear. In order to determine interventions to increase mood levels in caregivers, estimating the prevalence of existing depressive disorders is essential. The importance of this issue is highlighted when we consider that family support affects rehabilitation outcomes (9). In fact, understanding and improving emotional disorders in caregivers is particularly important, not only because they are sus-

Implication for health policy/practice/research/medical education:
This study is the first investigation evaluating the prevalence of depression in caregivers of individuals with spinal cord injuries. We also assessed the effect of various factors, including; patients' injury severity, level and dependency, along with social factors, such as; patients and caregivers' gender, educational level and marital status, on the emotional status of the caregivers.

ceptible to mood disturbances, but their role in patients' coping with SCI is also very important.

2. Objectives

In this study we investigated the prevalence of depression in the caregivers of individuals with SCI in a referral center in Iran. Moreover, we tried to determine the effect of various factors including patients' injury characteristics (level and independency scores) and social features of both patients and caregivers (education, employment, etc.), on the emotional status of caregivers.

What we assumed was that depressive disorders incidents would be elevated in the caregivers of SCI patients due to the additional imposed burden on this population. However, what is not yet known is the prevalence and factors affecting depression in caregivers in Iran.

3. Patients and Methods

3.1. Participants

All patients with SCI who were referred to the Brain and Spinal Injury Research Center (BASIR), from August 2012 to August 2013, were invited to participate in the study and their caregivers were assessed for the existence of depression. Our inclusion criteria were: 1. Caregivers who had primary responsibility for the patient's care. 2. Caregivers who accompanied the patient most of the time, and who were responsible for their financial support. Our exclusion criteria were: caregivers who had a previous history of depressive disorders, bipolar mood disorders, psychosis or obsessive compulsive disorders, before the injury had occurred. Those with chronic diseases (diabetes, hypertension, cardiovascular disorders, etc.) were also excluded to omit the bias effect of deteriorative influences of chronic diseases on mood.

3.2. Study Design

This cross-sectional study was designed to obtain data based on direct interviews with the caregivers over a one year period. The interviews took place during the patients' routine visits and caregivers were asked to accompany their patient. Participation in the interviews was voluntary. Data, including; patients' and caregivers' age, educational level, post-injury duration, occupation, marital status and the etiology of the injury, were collected during the interviews. Preliminary assessment of the existence of depressive disorders was performed by physicians based on DSM-IV criteria and confirmed by an expert psychologist. This study was ethically approved by the Research Ethics Committee of Tehran University of Medical Sciences. As this study was a descriptive observation, the power of this study was limited and it is recommended that the interpretations be confirmed by controlled studies.

3.3. Spinal Cord Independence Measure (SCIM)

The standard method used to evaluate SCI patients' independency and ability to perform conventional daily activities and routine tasks is the Spinal Cord Independence Measure III (10). The third version of this measure has a higher validity and reliability in comparison with the previous two versions (11, 12). The SCIM III consists of three subscales: self-care (feeding, bathing, dressing and grooming), motility (bed mobility, bed–wheelchair transfer, wheelchair–toilet–tub transfer, indoor mobility, outdoor mobility over a 10-100 meter distance, outdoor mobility more than 100 meter mobility, stair management, wheelchair-car transfer and wheelchair-ground transfer), respiration and sphincter management (bladder and bowl management, toilet use and respiration). Maximum score is 100 and higher scores indicate greater independency.

3.4. Assessment of Depressive Disorders and Emotional Status

We used DSM-IV criteria to assess the existence of a major depressive disorder (MDD) and depressive episodes in the caregivers. This measure evaluated depressive disorders based on nine criteria, which are as follows:

1. Depressed mood or irritable
2. Decreased interest or pleasure
3. Significant weight change (5%) or change in appetite
4. Change in sleep
5. Change in activity
6. Guilt/worthlessness
7. Fatigue or loss of energy
8. Concentration
9. Suicidality

We also screened conditions that may mimic or be accompanied by major depressive disorder, including; substance use, existence of specific medical illness in caregivers, and other psychiatric disorders. Severity of depressive episodes was classified into three grades; mild, moderate and severe, according to functional impairment. Function assessment included five domains; family relationships, school or work, peer relationships, stress and anxiety level, suicidal ideation and other self-harms.

3.5. Analysis

We reported frequencies and mean scores ± standard deviations using SPSS (version 21) (IBM Corporation, USA). Independent t-test and one-way analysis of variances (ANOVA) were used to compare quantitative values with the categorical data. P value < 0.05 was considered as statistically significant.

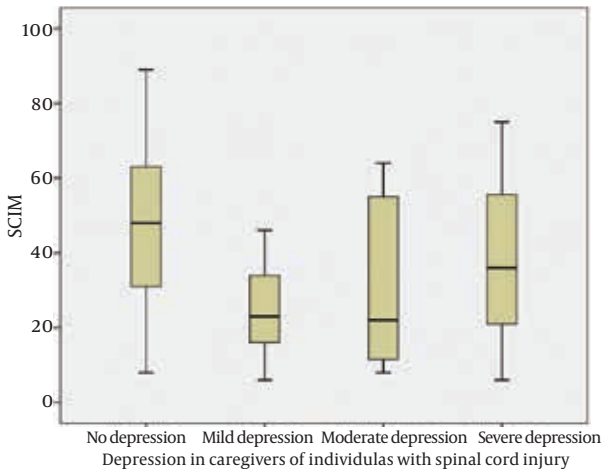
4. Results

Caregivers with a previous history of depression and

anxiety before the injury incidence were excluded. A total of 144 patients along with their caregivers were entered into the study. Patients were slightly younger than their caregivers (Table 1). While most patients were male (75%), the dominant gender in the caregivers was female (79.2%), and consisted mostly of mothers (36.1%) and spouses (Table 2). The majority of caregivers were married (80.6%), while the rate of single patients was relatively high (41%). Most caregivers were housekeepers (68.8%) which enabled them to dedicate enough time to their patients. Patients were slightly more educated than their caregivers. Tables 1 and 2 summarize the characteristics of patients and their caregivers.

Among the caregivers 82.6% (n = 119) had no episodes of depressive disorder, while 9.7% (n = 14) revealed mild depression, 5.6% (n = 8) had moderate depression, and 2.1% (n = 3) suffered from severe depressive disorders. Post-injury duration and patients and caregivers' age showed no relationship with the existence of depression in caregivers. However, an increased SCIM score was significantly associated with a lower incidence of depression in caregivers ($P < 0.004$) (Figure 1). Caregivers' occupation, income level, gender, educational level and type of familial relationship with the patient, showed no significant effect on the prevalence and severity of depression. Moreover, patients' gender, marital status, occupation and educational level revealed no significant influence on caregivers' mood. The etiology of the injury also showed no association with the incidence of depression in the caregivers, but the injury level had a noticeable effect on the caregivers' emotional status. In fact, caregivers of patients with an injury at cervical level experienced more severe episodes of depression (0.001) (Table 3).

Figure 1. Higher Scores in Spinal Cord Independence Measure (SCIM) is Significantly Associated With Lesser Incidence of Depression in Caregivers of Individuals With Spinal Cord Injury



Higher scores in the Spinal Cord Independence Measure (SCIM) are significantly associated with a lower incidence of depression in caregivers of individuals with a spinal cord injury.

Table 1. Patients and Caregivers Characteristics Referred to the Brain and Spinal Injury Research Center [a]

	Caregiver (n = 144)		Patient (n = 144)	
	Mean ± SD (Range)	**Frequency**	**Mean ± SD (Range)**	**Frequency**
Age, y	38.8 ± 11.44 (18 - 67)		32.6 ± 11.52(4 - 88)	
Gender				
Male		30 (20.8)		108 (75)
Female		114 (79.2)		36 (25)
Marital Status				
Single		15 (10.4)		89 (41)
Married		116 (80.5)		69 (47.9)
Dead Spouse		6 (4.2)		6 (4.2)
Divorced		4 (2.8)		6 (4.2)
Separated		3 (2.1)		4 (2.8)
Occupation				
Housekeeper		99 (68.7)		16 (11.1)
Student		6 (4.2)		17 (11.8)
Unemployed		7 (4.9)		88 (61.1)
Other		32 (22.2)		23 (16)
Years of education, y	7.93 ± 5.35 (0 - 18)		9.96 ± 4.08 (0 - 18)	

[a] Frequencies are presented as No. (%)

Table 2 . Injury Etiology, Severity and Patients' Dependency Level in Spinal Cord Injured Individuals Referred to the Brain and Spinal Injury Research Center [a]

	Mean ± SD (Range)	Frequency
Injury etiology		
Motor vehicle accidents		90 (62.5)
Fighting		2 (1.4)
Sport		1 (0.7)
Falling		29 (20.1)
Lifting heavy objects		2 (1.4)
Smashing under heavy objects		7 (4.9)
Iatrogenic		3 (2.1)
Other traumatic events		10 (6.9)
Injury Level		
Cervical		42 (29.2)
Thoracic		88 (61.1)
Lumbar		14 (9.7)
Post injury duration, mo	42.8 ± 44.5 (1-216)	
SCIM score	44.2 ± 21.6 (6-89)	
Care giver familial relationship with patient		
Spouse		58 (40.3)
Mother		52 (36.1)
Sister		5 (3.5)
Daughter		5 (3.5)
Father		2 (1.4)
Brother		13 (9.0)
Son		2 (1.4)
Other		7 (4.9)
Satisfaction of income		
Weak		61 (42.4)
Medium		76 (52.8)
High		7 (4.9)

[a] Frequencies are presented as No. (%)

Table 3. The Effect of Various Social Factors and Injury Characteristics on the Incidence and Severity of Depression in Caregivers of Spinal Cord Injured Patients [a,b,c,d]

	No Depression	Mild Depression	Moderate Depression	Severe Depression	P-value (95% CI)
Caregivers' occupation (n)					
Housekeeper	81	10	5	3	0.87
Student	6	0	0	0	
Unemployed	9	0	1	0	
Other	26	4	2	0	
Caregivers' gender					
Male	28	1	1	0	0.35
Female	91	13	7	3	
Satisfaction of income					
Weak	48	5	6	2	0.55
Medium	65	8	2	1	

High	6	1	0	0	
Caregivers' years of educational	8.18 ± 5.32	7.23 ± 6.12	6.50 ± 4.89	4.67 ± 4.50	0.54
Type of familial relationship between caregivers and patient					
Spouse	50	6	2	0	0.32
Mother	36	8	6	2	
Father	2	0	0	0	
Daughter	4	0	0	1	
Son	2	0	0	0	
Brother	13	0	0	0	
Sister	5	0	0	0	
Other	7	0	0	0	
Patients' gender					
Male	90	11	6	1	0.40
Female	29	3	2	2	
Patients' marital status					
Single	48	4	5	2	0.20
Married	59	8	2	0	
Dead spouse	6	0	0	0	
Divorced	3	1	1	1	
Separated	3	1	0	0	
Patients' occupation					
Housekeeper	15	1	0	0	0.68
Student	15	1	1	0	
Unemployed	68	10	7	3	
Other	21	2	0	0	
Patients' years of education	9.72 ± 4.12	11.93 ± 1.63	11.13 ± 4.91	7.0 ± 6.08	0.11
Injury level					
Cervical	26	8	6	2	0.001
Thoracic	81	5	2	0	
Lumbar	12	1	0	1	
Injury etiology					
Motor vehicle accidents	76	8	3	3	0.11
Fighting	2	0	0	0	
Sport	0	0	1	0	
Falling	25	2	2	0	
Lifting heavy objects	1	1	0	0	
Crushed under heavy objects	4	2	1	0	
Iatrogenic	3	0	0	0	
Other traumatic events	8	1	1	0	
SCIM score	47.23 ± 20.8	28.14 ± 16.5	31.13 ± 23.0	39.0 ± 34.5	0.004

[a] CI, confidence interval; SCIM, spinal cord independence measure
[b] Data are presented as No. or mean ± SD
[c] Injury level at cervical level was associated with a higher incidence of depression in caregivers.
[d] Lower SCIM score indicates greater patients' dependency which was significantly related to higher rates of depression in caregivers.

5. Discussion

Many physical disabilities and conditions are known to be associated with an increased incidence of depression. As the prevalence of depression is related to many factors including social support and environmental circumstances, the specific relationship of disability condition with depressive episodes occurrence varies between different countries. Previously, increased depression prevalence (DP) in specific populations in Iran, such as; elderly individuals in nursing homes (DP = 90.2%) (13), postpartum women (DP = 25.3%) (14), infertile couples (DP = 47%) (15), and patients with diabetes mellitus (DP = 43.2%) (16), have been reported. Not only physical disability, but certain social circumstances may also cause emotional changes and the occurrence of depressive episodes, for example a high prevalence of depression (34%) has been reported among students in high school and pre-university adolescents in Iran (17). Caregivers are also prone to develop emotional disorders. Sharghi et al. (18) reported a higher prevalence of depression in mothers of children with thalassemia and blood malignancy in Iran. In addition, mothers with primary school children in Tehran also revealed higher emotional deterioration (19). Our study showed that caregivers of spinal cord injured patients do not generally suffer from depression (82.6%) based on DSM-IV criteria. Moreover, unemployment which has been shown to be related to an increased incidence of depression in patients (3, 5), does not seem to affect the caregivers' mood. According to our data, depression prevalence in caregivers of spinal cord injured individuals does not differ from the general population living in Tehran (20). Although the type of measures used to assess depression (Beck Questionnaire, Patient Health Questionnaire (PHQ-9) or DMS-IV criteria) make an accurate comparison between populations less feasible, it is obvious that many specific populations, who are dealing with a chronic condition, are susceptible to depression.

Depression is a major health problem which leads to social dysfunction and important life-threatening consequences, such as suicide (21). In this regard some individuals with sensitive responsibilities, such as taking care of spinal cord injured patients are very susceptible to developing depression. Moreover, the caregivers' important role in the injured patient life requires the diagnosing and treating of this disorder as soon as possible. Individuals who take care of injured patients with injury levels at cervical spinal cord are even more prone to developing emotional deterioration. In fact, caregivers whose patients have lower SCIM scores, which illustrate higher dependency, have an increased risk of depression. Although the total incidence of depression was not significantly different from the general population of Tehran, there were noticeably higher depressive episodes in caregivers of patients with lower independency, which highlights the importance of developing screening programs to decrease the depression burden in this population.

Caregivers of individuals with SCI have a lower quality of life (22, 23) and experience greater psychological stress (24). Previous reports have revealed that poorer caregiver outcomes were associated with lower education (24) and being female (25), whereas our study found no effect of caregivers' educational level or gender on the incidence of depression. Post et al. (25) demonstrated that injury severity was associated with poor psychological characteristics in caregivers, which is in line with our findings, whereas some studies have not detected such a relationship (24). Kelly et al. (26) reported that 21% of spinal cord injured patients' caregivers experience depression in the USA, whereas our study showed lower depression prevalence in Iranian caregivers (17.4%). Although differences in assessment measurements do not provide a proper comparison, in general it seems that the incidence of depression in caregivers of patients with SCI between Iran and USA are comparable and does not exceed 20%. Moreover, Kelly et al. (26) reported higher depression rates among female caregivers, however, we did not find any gender effect. This discrepancy could be the result of the small sample of males in Kelly's study, and also the increased possibility of underreporting psychological symptoms in males. Kelly also found no effect of caregivers' educational level, marital status or their patients' age, with psychological outcomes, which is in line with our results.

Another study showed the relatively high prevalence of depression in Colombian caregivers of patients with spinal cord injury (43%), which was assessed by using PHQ-9 questionnaire (27). As many social and environmental factors contribute to the formation of psychological disorders, it is expected that various prevalence and incidence levels of depression among different nations will be observed. However, the importance of providing sufficient social support should be considered and this issue is highlighted when we see the number of reports indicating that emotional support, along with community support for the caregivers of individuals with SCI, mostly remain unmet (28).

To our knowledge this is the first investigation to assess the prevalence of depression and severity in caregivers of spinal cord injured individuals in Iran. We recommend the development of screening programs in order to diagnose and treat depression in this sensitive population. Fast initiation of treatment is essential as it has been shown that delayed treatment makes it harder to maintain a sufficient response (29). In general, our data suggest that intervention should target caregivers of spinal cord injured patients with more severe injuries, higher injury levels and greater dependency.

This study is a cross-sectional descriptive study but its power is limited to observation. However, as our center is a referral center for spinal cord injured patients and the investigated population represents Iranian individu-

als with SCI, the selected study design appears to be adequate for the study's aim of reporting the prevalence of depressive disorders in SCI patients' caregivers. The preliminary incidence of depressive disorders was assessed by general practitioners based on DSM IV criteria and the results were confirmed by an expert psychologist, so the lack of psychiatric visits is a limitation of this study.

The incidence of depression in Iranian SCI patient caregivers does not differ significantly from the general population in Tehran. However, the caregivers of patients with lower SCIM scores and an injury at cervical level, revealed significantly higher depressive mood. This indicates that higher patients' dependency on their caregivers makes them more susceptible to developing emotional changes. It seems that the major predictor of depression development in caregivers is the dependency rate of the patient. Our study recommends developing screening programs to diagnose and treat depression as soon as possible and to reduce the burden and consequences of depression in this sensitive population.

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Authors' Contribution

Dr. Taheri Otaghsara contributed in patients' recruitment and study design. Dr. Matin contributed in data collection and study design. Dr. Latifi contributed in analyzing the data and writing the manuscript. Dr. Norouzi Javidan contributed in the editing process of the paper. Dr. Koushki contributed in statistical analysis and editing the manuscript.

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