

# Barriers in social integration of post traumatic spinal cord injury patients

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## Abstract

**Study design:** This was a cross-sectional follow-up study.

**Objective:** The objective of the study was to study barriers in social integration and community participation of post-traumatic spinal injury patients. Secondary objective is to suggest measures to enhance gainful community integration of these victims to lead better quality of life and productive to the society.

**Background:** Spinal cord injury (SCI) is a devastating event in one's life and management of these patients is a challenge not only to treating physicians but also family and society related to patients. Absence of step-down facilities, non-existent insurance policy, lack/unavailability of qualitative assistive devices, and medical and rehabilitation services coupled with almost negligible financial support (disability allowance) from government are serious impediments in continuity of standard care.

**Materials and Methods:** A total of 141 patients who satisfied the inclusion criteria and survived beyond 1 year were included in our study and were assessed on parameters of economic independence, domestic life, physical independence, psychosocial, and spiritual support. A modified form of CHART score was also implemented to assess parameters.

**Results:** On comparison with Craig Handicap Assessment and Reporting Technique-SF parameters, each parameter showed a strong correlation with each other when Pearson correlation coefficient analysis was done. Age, level of education, employment status, and ASIA Impairment Scale showed a significant ( $P < 0.01$ ) when analyzed with parameters for rehabilitation assessment in our study.

**Conclusion:** Significant number of SCI patients remains neglected, largely deserted and non-productive to the society. Certain inexpensive and easy to implement recommendations can remove the impediments and offer them a quality of life they deserve.

**Keywords:** Spinal cord injury, social integration, barrier, developing nation.

## Introduction

Spinal cord injury (SCI), although less in incidence than other musculoskeletal trauma, is more disabling and has profound impact on socioeconomic and psychological status of patients. Traumatic spinal injuries (TSIs) occur at an annual incidence of up to 246 cases per million individuals per year around the globe resulting in an addition of 768,473

new cases every year [1, 2]. There is no permanent cure once a cord is completely damaged hence the burden of the disease is cumulative. Most of these injuries occur in younger productive age group resulting a formidable disability adjusted life year and a huge loss to the nation.

Dijkers [3] eloquently defined community integration as

“acquiring/resuming age/gender/culture appropriate roles/statuses including independence/interdependence in decision-making and productive behaviors in natural community setting.”

Unfortunately, absence of step-down facilities, non-existent

insurance policy, lack/unavailability of qualitative assistive devices, and medical and rehabilitation services coupled with almost negligible financial support (disability allowance) from government are serious impediments in continuity of standard care.

The present cross-sectional follow-up study is conducted to identify and analyze barriers in social integration of SCI patients. Secondary objective is to recommend measures to enhance gainful community integration of these victims to lead better quality of life and productive to the society.

## Material and Method

Ours is a descriptive, cross sectional study carried out over a period of 1 year

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Table 1:		
Variable	No.	%
<b>1. Age group</b>		
Less than 20	7	5.00%
20-40	68	48.20%
41-60	47	33.30%
More than 60	19	13.50%
<b>2. Sex</b>		
Male	98	69.50%
Female	43	30.50%
<b>3. Mechanism of Injury</b>		
Fall from height	76	53.90%
Farmyard injury	5	3.50%
Road traffic accident	52	36.90%
Industrial injury	6	4.30%
Others	2	1.40%
<b>4. Time of arrival</b>		
Within 24 hours	74	52.50%
Within 24-72 hours	47	33.30%
After 72 hours	20	14.20%
<b>5. Level of injury</b>		
Paraplegia	105	74%
Quadriplegia	36	26%
<b>6. ASIA Grade</b>		
A	81	57.40%
B	10	7.10%
C	15	10.60%
D	35	24.80%
<b>7. Associated Injury</b>		
Head injury	19	13.50%
Chest injury	29	20.60%
Long bone fracture	8	5.70%
Pelvic injury	4	2.80%
Abdominal injury	5	3.50%
Maxillofacial injury	2	1.40%
<b>8. Comorbidities</b>		
Diabetes mellitus	21	14.90%
Hypertension	15	10.60%
H/o Stroke	1	0.70%
Bronchial asthma	2	1.40%
Epilepsy	2	1.40%
Others		
<b>9. Treatment Given</b>		
<b>Operated patients</b>	139	98%
Cervical spine(36)	34	94%
Dorsolumbar spine(105)	105	100%

and 6 months (January 2017–June 2018) at a level 1 trauma center. Ethical clearance was obtained from the Institutional Ethics Committee (IEC) and informed consent was obtained from all the study participants.

All SCI patients with American Spinal Injury Association (ASIA) neurological Grade A to D who presented in our emergency were included in the study.

Patients with concomitant severe head injury with GCS 8–10 were excluded from the study.

Demographic data, mechanism of injury, general health status, and comorbidities were retrieved from hospital computer record. Mechanism of injury, delay in reaching hospital, associated injuries, ASIA grade, time, and type of surgery were meticulously documented. All patients received protocol-based treatment, which included operative intervention (posterior pedicle instrumentation and fusion with or without decompression) within 24 h of

presentation in patients with unstable spine injury and/or neurological deficit. Patients were discharged with regular follow-up with contact number of one coauthor for any emergency.

From the most recent follow-up records, patient's current neurological status, functional recovery, and independent activity of daily living were retrieved. All patients were subsequently seen by treating team of physician, senior nursing staff who was earlier involved in management of the patient. Those patients who were not regular in follow-up were interviewed on phone and

Table 2: Quality of Life Scoring			
Parameters	Questions	No.	%AGE
<b>MOBILITY STATUS(141)</b>	1. Bedridden	11	8%
	2. Wheel-chair (can't propel)	38	0.27
	3. Wheel-chair (can propel himself)	29	20%
	4. Walks with support	15	11%
	5. Walks without support	48	0.34
<b>ECONOMIC INDEPENDENCE(141)</b>	1. Completely dependent	74	0.52
	2. Partially dependent	11	8%
	3. Completely independent for self but cannot raise family	9	0.07
	4. Can raise family	33	0.23
	5. Can contribute economically for social causes	14	0.1
<b>DOMESTIC LIFE(141)</b>	1. Deserted	21	0.15
	2. Stays with family but feels isolated	69	0.49
	3. Stays with family and feels integrated as before trauma	51	0.36
<b>SOCIAL INTEGRATION (141)</b>	1. Outcast	38	0.27
	2. Accepted but not as before injury	54	0.38
	3. Accepted as before injury	27	19%
	4. Society is encouraging and inspires me to do better	22	16%
<b>SPIRITUAL LIFE /PSYCHOLOGICAL STATUS (141)</b>	1. Feels like death would have been better	20	14%
	2. Often feels depressed	64	45%
	3. Usually cheerful but feels victim of destiny	25	17%
	4. Motivated to do better as per capacity and opportunities	32	22%

**Table 4: Outcome Descriptive Summary**

COMPLICATIONS	No. (N=141)	%
DVT	2	1.4
Bedsore	35	25%
Sexual/erectile dysfunction	56	40%
Pneumonia	17	12.1
Multiple organ failure(MOF)	12	8.5
Urinary tract infection	18	12.8
Dementia	8	5.7
Infection	8	5.7
Unplanned reoperation	3	2.1
Mortality	35	24.8
Composite (mortality, complication, reoperation)	0	0
Lost to follow up	10	7.1

documented in modified short form of Craig Handicap Assessment and Reporting Technique (CHART-SF). As many domains in both these formats are not possible in our set up, institute prepared a structured questionnaire (as per Tables 2 and 3) and pilot tested before using it as a tool for interview.

### Statistical analysis

Statistical analysis was performed using SPSS version 20 (IBM, New York, US). Two-tailed Student's t-tests and Fisher's exact tests were used to compare means for normally distributed data.  $P < 0.01$  was considered statistically significant. Pearson's correlation coefficient was used to assess the relation between each dependent variable and the quantitative parameters. Multiple linear regression analysis with enter method was performed for a multivariate summary model of determinants for each outcome variable. A score of 75 was used as a cut point for the CHART-SF as recommended by earlier studies [4].

### Result

A total of 186 patients were initially

included in our study out of which 35 had mortality. Early mortality was seen in 14 patients possibly due to high injury severity score (ISS more than 60) while 15 patients had mortality within 6 months at home and another 7 patients between 6 and 12 months post-injury. One hundred and twenty-five patients received operative treatment which included 44 cervical injury patients. The indication of surgery was neurological compromise with unstable spine (radiological criteria).

Most common age group was 20–40 years (48.2%) followed by 41–60 years (33.3%). About 57% of patients sustained ASIA A neurology followed by ASIA C neurology in 25%.

Most common mode of accident in our study was falls from height while working (53.9%) followed by road traffic accidents (36.9%). Majority of them were youngsters mean age 35 years, with injury to males being twice than female.

Mean follow-up was 24.6 months range being 12 months–42 months. In the last follow-up, 74 out of 141 (52%) were completely dependent for their livelihood, 23% were able to raise family

while only 10% were able to contribute economically to society. Overall, 65 (50%) patients were employed before injury and were financially independent lost their source of income after the injury.

In our study, out of 141 patients, although 8% were completely bedridden and a significant no. (27%) were unable to propel wheelchair independently. Approx. 34% of patients were able to ambulate independently. Another 30% of patients had non-functional wheelchair, which was being used for a sitting chair rather than mobility.

Mild depression was present in 82% of patients of which 45% of patients were having clinical depression and getting appropriate anti-depressive treatment and another 14% were irregular in treatment with suicidal thoughts.

A significant number of patients 67 (48%) had no clue regarding disability allowances given by government and those having knowledge only 21 (31%) of them had their disability certificates issued or approved by a medical board which is mandatory for such disability pensions. Out of these 21, only 15 had started receiving their pensions.

Familial support is an important pillar in the rehabilitation process but 15% of patients were nearly deserted by their families. About 49% were staying with family but had a feeling of isolation and in depression while another 36% were integrated with family as before trauma. About 34% of paraplegic patients and quadriplegic patients had issues with bowel and bowel issues and occasional incontinence.

### Study parameters and their correlation

On comparison with Craig Handicap Assessment and Reporting Technique (CHART-SF) parameters, each parameter showed a strong correlation with each other when analyzed on Pearson correlation coefficient.

**ASIA Impairment Scale (AIS) – A**

significant correlation was found between increasing ASIA score and all other parameters were seen in our study as evident from Table 5. Quadriplegics were much behind than paraplegics when evaluated on every parameter.

**Pre-injury profession** - Patients who were able to sustain their jobs post rehabilitation showed a significant ( $P < 0.01$ ) on all parameters as compared to those who were not working or lost their livelihood post-injury.

**Level of education**- Patients having tertiary education were much ahead of

those having primary and secondary education in terms of economic independence. They also fared better when evaluation was done on other parameters ( $P < 0.01$ ).

**Pain**- Patients who were having no pain had a significant impact on rehabilitation as compared to other having nociceptive or neuropathic pain.

**Bed sore**- Patients with no bedsores showed a significant correlation on all parameters ( $P < 0.01$ ) as compared to those with no bedsores.

**Functional independence**: Regarding

functional status as evident quadriplegics needed much more assistance for daily functioning such as feeding, grooming, dressings, transfers, and bladder and bowel care.

### Discussion

SCI is a devastating event in one's life and these patients often suffer from "four D Syndrome" which are dependency, depression, drug addiction, and divorce. Two more "Ds" – debilitation and demanding can also be added to this list [1,2].

Spinal trauma, with a global incidence of up to 246 cases per million annually, has profound impact on socioeconomic and psychological status of patients. This morbidity and its impact are all the more evident in developing world where an organized system to help them overcome socioeconomic independence is alarmingly lacking.

At present, there is lack of definitive curative treatment after SCI. It is clear therefore that fixing the spine and mobilizing patient on wheelchair before discharge is the minimum thing a trauma center is to offer. Chances of neurological recovery after complete paraplegia and quadriplegia are dismal and hence disability caused is permanent. Meaningful social integration, therefore, should be the optimum rehabilitation goal so that they can lead a reasonable independent quality of life and productive to the society.

Changes in public policy, awareness, and measures such as independent living services and technological advancements like targeted neurotechnology have greatly improved community participation in developed nations such as the USA and Europe [5, 6]. However, rehabilitation program launched in developing nations like India failed to achieve adequate target.

The barriers in social integration of these patients are discussed in six sub-headings; they are achieving economic independence, community mobilization

**Table3: Distribution according to functional status**

Activity	Functional status among paraplegics(n) 105		
	Independent	Requires assistance	Dependent
Feeding	91	10	4
Grooming	91	10	4
Dressing lower body	63	31	11
Dressing upper body	90	11	4
Transfers	78	22	5
Wheelchair propulsion(24)	16	6	2
Bladder & Bowel functions	61	40	4
	Functional status among tetraplegics (36)		
Feeding	2	2	32
Grooming	2	2	32
Dressing lower body	1	2	33
Dressing upper body	3	1	32
Transfers	2	2	32
Wheelchair propulsions(33)	0	1	32
Bladder & Bowel functions	2	2	32



Table 5: CHART finding and comparison of variables

Variable		Mobility		Economic self sufficiency		DOMESTIC LIFE		Social integration		Physical independence	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
SEX	Male	56.9	23	35.1	28.6	69.6	23.7	49.5	22.8	69.1	26.9
	Female	52.9	25.4	31.8	27	61.1	24.8	42.2	24.8	59.8	30.4
	Significance	t=0.92, p=0.359		t=0.63, p=0.530		t=1.94, p=0.055		t=1.72, p=0.088		t=1.80, p=0.075	
PARA/ QUADRI	Paraplegia	65	19.1	39.6	29.7	75	19.9	54.4	22.2	79.9	14.8
	Quadriplegia	28.7	12.7	17.9	13.4	43.7	20.7	26.6	13	26.9	19.6
	Significance	t=10.58, p<0.001		t=4.23, p<0.001		t=8.05, p<0.001		t=7.12, p<0.001		t=14.85, p<0.001	
Age Group	< 20 yr	56.3	12.2	32.9	20.4	61.6	16.6	35.7	12.2	82.6	9.5
	20 - 40 yr	57.7	24.9	35.4	30.3	69.4	23.5	49.3	22.7	67.6	28.5
	41 - 60 yr	53.7	26	36.9	28.9	68.3	26.8	49.7	27.2	62.6	31.3
	> 60 yr	53.3	16.5	22.6	16.7	57.3	21.6	38.5	17.6	64.3	22.5
	Significance	F=0.34, p=0.798		F=1.28, p=0.285		F=1.42, p=0.241		F=1.81, p=0.149		F=1.12, p=0.342	
AIS	A	40.7	14.5	19.3	15.4	55.8	23.4	35.8	18.6	54.6	29
	B	49.6	19.4	28.5	17.4	69	16	47.2	18.7	59	29.3
	C	71.8	7.6	38.4	22.3	77.3	16.2	54.9	14.9	80.5	9
	D	85.3	11.7	67.9	26.3	87.9	13	70.7	19.6	89.7	6.9
	Significance	F=94.28, p<0.001		F=50.82, p<0.001		F=22.33, p<0.001		F=29.86, p<0.001		F=19.40, p<0.001	
EDUCA.	Primary	46.3	21.1	23.5	22.1	54.9	24.8	36	20.8	57.9	30.8
	Secondary	52.1	23.2	24	21.3	61.3	22.1	40.3	17.7	63	29
	Tertiary	69.6	20.9	58.2	27	86.5	12.6	67.8	20.5	78.9	19.6
	Significance	F=12.88, p<0.001		F=32.01, p<0.001		F=27.73, p<0.001		F=33.68, p<0.001		F=6.73, p=0.002	
WORKING / NOT	Working	77.2	16.7	65.3	22	88	12	69.4	17.6	85.9	9
	Non Working	43.2	17.4	15.8	7.7	54.7	21	34.4	15.7	55	29.4
	Significance	t=11.36, p<0.001		t=19.38, p<0.001		t=10.47, p<0.001		t=12.24, p<0.001		t=7.30, p<0.001	
PAIN	No Pain	70.2	21.1	56.1	29.8	85.5	15.4	67.3	20.4	82.3	15.2
	Neuropathic	39	19.4	17	10.9	49.7	22.5	31.5	15.7	46.9	30.5
	Nociceptive	60.6	19.6	33.7	26.7	70.3	19.1	47.8	20.5	72.4	22.6
	Significance	t=25.63, p<0.001		t=25.65, p<0.001		t=34.09, p<0.001		t=33.87, p<0.001		t=23.87, p<0.001	
Bed sores	No	63.4	21.1	39.7	29.9	75.2	20.2	54.8	22.1	76.9	19.9
	Yes	33.4	15.6	17.6	10.8	43.1	18.6	25.4	10.8	35.4	26.3
	Significance	t=7.82, p<0.001		t=4.33, p<0.001		t=8.39, p<0.001		t=7.66, p<0.001		t=9.87, p<0.001	

and transportation, lack of psychosocial and spiritual support, lack of awareness of existing facilities, family (domestic) life and community participation, and marital disharmony (sexual/erectile dysfunction).

### 1. Economic independence

About 80% of our patients lost their job after injury as they were either non-skilled to semi-skilled workers. This resulted in a very difficult financial constraint in the family causing school drop out of children and even begging. Furthermore, only 6% of them received a paltry sum of USD 16.31 per month (INR 1200/- month) as a compensation which was inadequate for meeting basic needs.

Loss of job in our study was much higher than earlier study of Khazaeipour et al. The disability pension scheme in our country (USD 16.31 per month) is much less than developed countries such as the

USA and France (1300\$–2200 \$, i.e., Rs. 96,000–Rs. 184,000). On comparison with the previous studies, economic dependence on family members and caregivers was found much higher as compared to Singh et al., 2006, 34% [7] but was similar to Khazaeipour et al., 67% [8].

**Recommendations**-In developing countries like India, male members are often sole bread earner, so physical disability significantly reduces earning of the family for survival and children education on the one hand while increases expenditure on the disabled care. The prevailing financial sufferings may be mitigated if a separate on-line grievance addressal system is available which can liaise with government and charity organizations. A grievance addressal cell in the tertiary referral hospital can effectively and smoothly help the victim overcome such pathetic situations. We, therefore, recommend

revision of scheme for a decent living of disabled fellow.

### 2. Community mobilization and Transportation

Only 0.5% had a motorized appropriate wheelchair, 35% of patients had non-functional wheelchair, which was being used for a sitting chair rather than mobility. Inability to ambulate is a root cause for a majority of medical complications (bed sores, respiratory diseases, depression, etc.) in TSI patients. Equipment and maintenance issues in our studies were 23% which is much higher than Silver et al., 2012 [9]. These constraints along with poor public transport facilities were often cited as reasons for not coming for either regular follow-up or even for necessary bed sore or serious respiratory issues. This is despite Suganya Bharat Abhiyan as a nation-wide flagship campaign for achieving universal accessibility that

targets at enhancing the accessibility of built environment, transport system, and information and communication ecosystem. Prabhaka and Thakker [10, 11] described an effort to reach people in rural villages in India, which they called the Paraplegia Safari. Burns and O’Connell [12] suggested that development of peer support networks might improve community reintegration and long-term well-being.

**Recommendations-** Strengthening of a mobile-trained nursing team, improved ambulance service, and strengthening primary health-care system are need of the hour. The nursing staff and/or volunteer can attend the patients need in terms of educating him wound care, bowel and bladder care, spiritual teaching, and motivating the victim toward doing appropriate job.

Low-cost options for vital equipment (e.g., pressure relieving wheelchair cushions) can be offered to all needy patients as a policy in collaboration with national governments, non-profit local and international organizations.

### 3. Psychosocial and spiritual support

Adjustment in the changed scenario from a bread earner to a disabled dependent person leads to depression and a sense of despondency. About 45% of our patients were having clinical depression which is much higher than Frank et al. (22.7–38%) [13] and Kennedy and Rogers [14] but lower than Shin et al. (63.5%) [15] and Wang et al. (62.5%) [16]. This is a huge number and can be attributed to inability to cope with the future consequences of injury. It is an important aspect, which is completely ignored by our system and gets missed even by the treating physician.

Psychiatric assessment done using beck depression inventory showed that incidence of post-traumatic stress disorder of 27% was quite higher than of earlier studies of Otis et al. [17]. This study also noted that higher level of education was associated with lower levels of depression which was in line with the previous studies of Khazaeipour et al. [18] and Krause et al. [19].

Finally, other problems such as anxiety, lack of concentration, decreased attention span, memory loss, learning disorders, and other neuropsychogenic

disorders were observed even in patients with incomplete deficit or who were able to ambulate independently. The ability to execute daily mental tasks and performance levels of these patients showed a downward trend in our follow-up patients. This was seen more common in females although their number was less in our study.

Due to non-availability of psychiatric specialist, transportation difficulties, and lack of motivation, majority of patients discontinued their follow-up for psychological consultation.

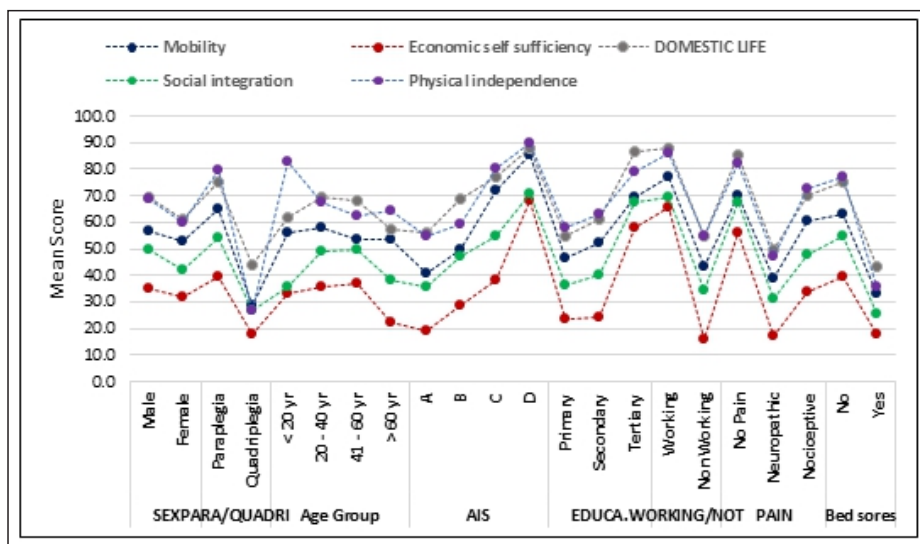
**Recommendations-** Development of a society of plegic patients will act as peer support network, foster a sense of community participation and prevention of isolation. It can easily be coordinated in today's world of social media. Similarly, group effective training program as described by Frank and Lazarus et al. [20] should be implemented.

### 4. Lack of awareness of existing facilities

A significant number of patients 67 (48%) of patients had no clue regarding disability allowances given by government and those having knowledge only 21 (31%) of them had their disability certificates issued or approved by a medical board which is mandatory for such disability pensions. Out of these 21, only 15 had started receiving their pensions.

**Recommendations-** A national awareness program integrated with government health schemes like Ayushman Bharat must be stressed as a major policy change for welfare of these patients. Furthermore, educational and vocational campaigns through print and social media should be done for a wider outreach. Furthermore, tertiary care rehabilitation center managed by specialists in physical medicine and rehabilitation along with teams of allied health professionals is need of the hour.

### 5. Family( domestic) life and



Pearson's Correlations	Mobility		Economic self		DOMESTIC LIFE		Social	
	r-value	p-value	r-value	p-value	r-value	p-value	r-value	p-value
Economic self sufficiency	0.759	<0.001	-	-	-	-	-	-
DOMESTIC LIFE	0.771	<0.001	0.702	<0.001	-	-	-	-
Social integration	0.79	<0.001	0.798	<0.001	0.898	<0.001	-	-
Physical independence	0.828	<0.001	0.51	<0.001	0.719	<0.001	0.652	<0.001

### community participation

Dissolution of marriages and strained relationships was seen in 31% of our patients. Loss of intimacy was seen in 24% of our patients. This is attributed to newer realities faced by patients who become disabled. This gets complicated further by social attitudes which devalue individuals with significant disabilities. Low self-esteem and depressive disorders economic and physical dependence may start a vicious cycle which may hinder the long and tedious process of rehabilitation in SCI patients. Patients with a low cervical injury (C6-8) are dependent for almost everything such as bowel and bladder, bathing with adaptive equipment, mobility out of bed oral hygiene, writing, typing, and operating a power wheelchair. Authors agree with Kennedy et al. who emphasized the importance of family support. However, 39% of the patients in our study were having an amiable relationship with their respective partners. This was higher in compared to Singh et al. [7], but lower than Franceschini et al. [21].

**Recommendations-** Since the family members (mostly spouses) become

primary care providers with no previous experience, a comprehensive teaching program for them should be emphasizing on developing additional skills and education should be part of rehabilitation program.

### 6. Marital disharmony (sexual/erectile dysfunction)

About 61% of patients had normal erection after SCI which is comparable to the previous studies [15, 22]. In the present study, normal ejaculation function was found to be 44% in sync with the previous studies [22, 23]. About 11% had sexual intercourse every time they engaged in sexual activity out of 46 sexually active couples. About 52% reported a drop in frequency sexual activity compared to before injury. Sexual satisfaction was reported by 23% of the patients which is low in comparison to Sharma et al. [7]. Decrease in sexual desire was noted in 61% of the patients.

Emotional closeness and sexual intimacy are the pillars for a marital relationship. A significant number of disabled patients were deprived of a blissful married life.

**Recommendations-** Psychologist

consultation and rehabilitation programs to overcome the social taboo are required. They should be encouraged to spend intimate time together, leisure activities, role-play, etc.

Are first, inherent weakness of a cross-sectional observational study, the period of follow-up is only 2 years, small number of patients. Besides, in developing nations, where affordable population prefer private nursing home, the data may not accurately represent the complete scenario.

### Conclusion

Absence of step-down facilities, non-existent insurance policy, lack/unavailability of qualitative assistive devices, and medical and rehabilitation services coupled with almost negligible financial support (disability allowance) from government are serious impediments in continuity of standard care. Every possible effort should be made to socially integrate post-traumatic paraplegia patients who are otherwise normal human beings.

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**Conflict of Interest: NIL**  
**Source of Support: NIL**

#### How to Cite this Article

Azam Q, Sarkar B, Dubey S, Khan J, Lamba S. Barriers in social integration of post traumatic spinal cord injury patients. *Journal of Clinical Orthopaedics* Jan-Jun 2021;6(1):6-13.