Factors Influencing Social and Community Participation of People with Spinal Cord Injury in Karnataka, India

Heavenna Babu, Sheetal Sriraman[1], Suruliraj Karthikbabu[2], Sophia P.[3], Senthil N. S. Kumar[4]

Physiotherapist and Public Health Researcher, Ontario, Canada, [1]Pediatric Resident, SUNY Downstate Health Sciences University, Brooklyn, NY, USA, [2]Principal and Professor, KMCH College of Physiotherapy, Dr. NGP Research and Educational Trust, Coimbatore, The Tamilnadu Dr. MGR University, Chennai, [4]Chief Executive Officer, The Association of People with Disability (APD-India), Bengaluru, [3]Occupational Therapist, Baptist Hospital, Bengaluru, Karnataka, India

Abstract

Background: Social and community participation are major indicators to assess the adequacy of treatment and rehabilitation in patients with spinal cord injury (SCI). This study examined the relationship between functional independence, level of disability, and social and community participation among people with SCI in India. **Materials and Method:** In this cross sectional study, 110 persons with SCI, aged 18 years and above participated in a community setting, in Karnataka, India. Spinal Cord Independence Measure Version III-self-reporting (SCIM III-SR), Craig Handicap Assessment and Reporting Technique (CHART), and WHO Disability Assessment Schedule 2.0 (WHODAS) were the clinical outcome measures. Spearman's correlation and stepwise multiple linear regression were done to determine association and identify the factors determining the community participation of people with SCI. **Results:** CHART physical independence had a positive correlation with SCIM self-care (R = 0.446) and SCIM mobility (r = 0.434). CHART cognitive independence (R = -0.38) and CHART mobility (R = -0.396) had a weak correlation with WHODAS. SCIM self-care and SCIM mobility ($R^2 = 0.34$) were determinants of CHART cognitive independence. SCIM respiratory and sphincter management and SCIM self-care ($R^2 = 0.327$) were determinants of CHART mobility. **Conclusion:** Self-care and mobility of people with SCI determine their ability to successfully reintegrate into the community, warranting a comprehensive community rehabilitation program.

Keywords: Community participation, disability, physical independence, self-care, spinal cord injury

INTRODUCTION

The incidence of SCI ranges from 11.5 per million to 57.8 per million globally and 15–20 million per year in India.[1-3] Rehabilitation and community participation of SCI is a long process, requiring considerable healthcare resources and poses a significant financial burden on patients and their families.[4] Social and community participation of patients with SCI are the indicators of adequate rehabilitation.[5] Community participation is multifaceted and used interchangeably with participation, social participation, and community reintegration in the literature. Participation is defined as "*the process of becoming part of the mainstream of family and community life, participating in normal roles and responsibilities, and being an active and contributing member of one's social groups and society as a whole.*"[6]

The process of community re-integration occurs in three main stages namely withdrawal, re-emergence into society, and stability.[7] Adequate assistance, social support, and access to specialized equipment are found to facilitate community participation among patients with SCI.[8,9] There is a need for community-based rehabilitation because it improves outcomes among patients with disabilities. Many people with SCI in India suffer from various physical, medical, social, employment, and educational deficiencies as most live in rural areas while most of the existing services are confined to cities.[10,11]

Several studies explored various determinants of community reintegration among patients with SCI.[8,11,12] These factors include environmental barriers, exercise, access to mobility

Access this article online

Quick Response Code:

Website:
www.ijcm.org.in

DOI:
10.4103/ijcm.ijcm_421_22

aids, socioeconomic status, and mobility capacity.[11,13] There are limited studies that analyzed the factors associated with functional independence, level of disability, and community participation among people with SCI. Understanding the major factors of community reintegration is imperative to enable clinical practitioners and policymakers to take action to facilitate the reintegration of persons with SCI into the community. The study's primary objective was to examine the strength of the association between functional independence, level of disability, and social and community participation among persons with SCI. The secondary objective was to examine factors associated with social and community participation among people with SCI in India.

METHODS

This cross-sectional analytical study was conducted among people with SCI in Bangalore, South India. The sampling method was nonprobability sampling using a convenience sampling. Using a formula $N = Z2*P (1-P)/E2$, with 8% prevalence of disability ($P = 0.08$) post spinal injury, 95% confidence interval (Z = 1.96), 5% margin of error (E = 0.05), we determined a sample size of 113. The sample of persons with SCI was drawn from a community center of The Association of People with Disability (APD), Karnataka, India. The APD is a 60-year-old organization that provides rehabilitation services to persons with disabilities from different parts of South India. The study received ethical approval from the Institutional Ethical Review Board of APD India (Ref No: SRN01/12/01). Persons with SCI who were enlisted in the database of the SCI rehabilitation program of the APD were contacted requesting them to participate in the study. Informed consent was obtained from all participants before the commencement of the study. The study's inclusion criteria were people aged 18 years and above, who sustained SCI more than six months ago and underwent in-patient rehabilitation therapy between 2015 and 2019. The exclusion criteria were those who had an acute illness or infection and were hospitalized in the last three months.

Data were collected using a structured questionnaire. The questionnaire was divided into five parts -- socio-demographic details, details of the SCI, a measure of functional independence, an objective measure of participation, and a measure of functional disability. The Craig Handicap Assessment and Reporting Technique (CHART-SF) was used to assess community reintegration.[13] It ascertains the degree to which the participant can fulfill the roles that they normally would in a nondisabled state. It has a total of 32 questions under six domains - physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. The SCIM III was used to assess the functional independence among the participants.[14] It has a total of 19 questions under three domains - self-care, respiratory and sphincter management, and mobility. The WHODAS 2.0 was used to assess the severity of disability among participants with SCI.[15] It has a total of 36 questions. It has

six domains - cognition, mobility, self-care, getting along, life activities, and participation.

RESULTS AND DISCUSSION

One hundred and ten persons with SCI participated in the study. Table 1 shows the demographic details and clinical characteristics of the study participants. Of them, 91% sustained a traumatic injury and 89% had paraplegia and 11% had quadriplegia. Most of them were males (94%). Table 2 shows the correlation between the various sub-scores of CHART, SCIM, and WHODAS. There is a moderate positive correlation between CHART physical independence and SCIM self-care (R = 0.446) with a statistical significance ($P < 0.05$).

Table 1: Demographic and clinical characteristics of study participants

Demographic characteristics of the study participants

Variables	Category	*n* (110)	(%)
Age	18-60	104	95
	Above 60	6	5
Gender	Male	103	94
	Female	7	6
Area of Residence	Rural	84	76
	Urban	26	24
Marital Status	Single	44	40
	Married	66	60
Cause of Injury	Traumatic	100	91
	Non-Traumatic	10	90
Presentation	Quadriplegic	12	11
	Paraplegic	98	89
Type of injury	Complete	57	52
	Incomplete	53	48
Level of Injury	C5- C8	12	11
	T1-T4	8	7
	T5-T10	24	22
	T11-S4	66	60
Mobility Aid	Wheelchair	20	18
	Assistive devices	33	30
	Both	51	46
	None	6	6

Clinical characteristics of the study participants

Variables	Median (IQR 25-75)	IQR 25-75	Range
WHODAS	34	21-49	0-114
SCIM_SC	20	16.75-20	0-23
SCIM_RC	28	19.75-37	5-40
SCIM_Mob	22	16.75-27	0-40
CHART_TA	99	99-99	97-99
CHART_Cog	16	13-18	5-30
CHART_Mob	06	4-8	4-8
CHART_Prod	14	12-18	2-36
CHART_SI	10	7-11	4-100

SCIM_SC- SCIM_Self Care; SCIM_RC- SCIM_ Respiratory and Sphicter management; SCIM_Mob- SCIM_Mobility; CHART_TA- CHART_Total Assistance; CHART_Cog- CHART_Cognitive; CHART_Mob- CHART_Mobility; CHART_Prod- CHART_Productivity; CHART_SI- CHART_Social Interaction

The CHART cognitive independence had a weak negative correlation with WHODAS (R = -0.38). CHART mobility had a weak correlation with WHODAS (R = -0.396) and SCIM mobility sub score (R = -0.321), but moderate correlation with self-care (R = -0.441), respiratory and sphincter management (R = -0.466) of SCIM. CHART occupation and CHART social interaction did not show any statistically significant correlation with WHODAS or any SCIM sub-scores. Table 3 shows the findings of multiple stepwise multiple linear regression analysis. The major determinants of CHART cognitive independence are SCIM self-care and SCIM mobility (R^2 = 0.34). The determinants of CHART mobility are respiratory and sphincter management (R^2 = 0.259) and self-care (R^2 = 0.327) subscales of SCIM. The F test in a regression model fits the dataset more than the intercept model as the *P* values were found to be significant.

Table 2: Correlation between CHART, SCIM, and WHODAS

	WHODAS	SCIM_SC	SCIM_RS	SCIM_Mob
CHART_TA	-0.293*	0.446*	0.294	0.434
CHART_Cog	-0.38*	0.069	0.113	0.154
CHART_Mob	-0.396*	-0.441*	-0.466*	-0.321*
CHART_Prod	-0.052	0.003	-0.015	-0.034
CHART_SI	-0.027	-0.003	-0.104	-0.021

*$P<0.005$; SCIM_SC- SCIM_Self Care; SCIM_RC- SCIM_ Respiratory and Sphicter management; SCIM_Mob- SCIM_Mobility; CHART_TA- CHART_Total Assistance; CHART_Cog- CHART_Cognitive; CHART_Mob- CHART_Mobility; CHART_Prod- CHART_Productivity; CHART_SI- CHART_Social Interaction

Table 3: Findings of multiple stepwise multiple linear regression analysis

Dependent variable	Model	Independent variables	R^2	P
CHART_TA	1	Constant WHODAS	0.117	0.005
	2	Constant WHODAS SCIM_SC	0.072	0.001
CHART_Cog	1	Constant SCIM_SC	0.277	0.001
	2	Constant SCIM_SC SCIM_Mob	0.340	0.001
CHART_Mob	1	Constant SCIM_RS	0.259	0.001
	2	Constant SCIM_RS SCIM_SC	0.327	0.001
CHART_Prod	1	Constant Gender	0.070	0.005

SCIM_SC- SCIM_Self Care; SCIM_RC- SCIM_ Respiratory and Sphicter management; SCIM_Mob- SCIM_Mobility; CHART_TA- CHART_Total Assistance; CHART_Cog- CHART_Cognitive; CHART_Mob- CHART_Mobility; CHART_Prod- CHART_Productivity

This study showed a positive correlation between CHART physical independence and the self-care domain of SCIM. The patient's ability to care for themselves independently (SCIM self care) and their mobility (SCIM mobility) were the major determinants of CHART cognitive independence. The participant's ability to perform respiratory and sphincter care (SCIM respiratory and sphincter management) and self care (SCIM self care) strongly determine their CHART-mobility sub scores. Participants who were more likely to participate self care activities such as bathing, grooming feeding, and dressing, were more likely to have better physical independence scores. Participants were found to have lower levels of disability when they show physical and cognitive independence, and mobility, measured using the domains of CHART. Few studies are in line with our study findings. Atobatele *et al*.[16] showed a positive correlation between functional ability and community reintegration in people with SCI. Callaway and colleagues reported that patients with SCI were less integrated into their homes and occupations as compared to matched controls.[17] There was a steady decline in community integration over time, concerning physical independence, mobility, social interaction, and occupation. This was associated with a decline in life satisfaction over time.[12]

We included the participant's age, gender, area of residence, type of injury, level of injury, marital status, employment status, members in the family, presence of contractures or deformities, WHODAS score, and SCIM sub-scores as the independent variables in the model. Published papers in the last decade reported that factors such as age, years since injury, gender, ethnicity, education, and neurological classification of SCI could mostly influence community reintegration.[12,18] Although the occupation sub score of CHART was mainly influenced by gender, this association was not strong. After SCI, an individual's mobility capacity and ability to meet self-care needs and manage their respiratory and sphincter care, and gender are the key factors associated with community and social participation. This finding is in line with Sekaran *et al*.[11] who reported a general decline in community reintegration in terms of physical independence, social integration, and mobility of the South Indian population with SCI. Besides fulfilling self-care (feeding, bathing, grooming, and dressing) needs of people post SCI, their ability for indoor and outdoor mobility, respiratory and sphincter care and gender are some of the crucial factors associated with different sub-scores of community and social participation. Mobility and economic constraints are the critical barriers that limit one's community integration.

The study's strengths lie in the fact that it provided insights into the factors that determine the social and community participation of people with SCI in India. The study being community-based survey, made it able to view people with SCI through a wholistic community-based lens. Findings from our study can enable care-givers and policy makers to target strategic interventions in crucial area to help re-integration of patients with SCI. Secondly, we also did not consider the role of exercise, psychological factors, perceived emotional

support, perceived environmental barriers, economic burden of the disease, and socioeconomic status. The scores of CHART, WHODAS, and SCIM are the subjective reporting of study participants. As these findings are based on their perception, the actual objective measure of community reintegration is lacking. Future studies should shed more light on the deficiencies in rehabilitation and long-term management of patients with SCI, therefore, potentially giving direction to aid better rehabilitation efforts and community participation.

Conclusion

Self-care and mobility of people with SCI determine their ability to successfully reintegrate into the community, warranting a comprehensive community rehabilitation program.

Conflicts of interest

There are no conflicts of interest.

References

1. Singh A, Tetreault L, Kalsi-Ryan S, Nouri A, Fehlings MG. Global prevalence and incidence of traumatic spinal cord injury. Clin Epidemiol 2014;6:309-31.
2. Ackery A, Tator C, Krassioukov A. A global perspective on spinal cord injury epidemiology. J Neurotrauma 2004;21:1355-70.
3. Srivastava RN, Singh A, Garg RK. Epidemiology of traumatic spinal cord injury: A SAARC perspective. Int J Mol Biol Biochem 2015;3:9-22.
4. Fehlings MG, Tetreault LA, Aarabi B, Anderson P, Arnold PM, Brodke DS, *et al.* A clinical practice guideline for the management of patients with acute spinal cord injury: Recommendations on the type and timing of rehabilitation. Global Spine J 2017;7 (3 Suppl):231S-238S.

doi: 10.1177/2192568217701910.
5. Ned L, Cloete L, Mji G. The experiences and challenges faced by rehabilitation community service therapists within the South African Primary Healthcare health system. Afr J Disabil 2017;6:311. doi: 10.4102/ajod.v6i0.311.
6. Carpenter C, Forwell SJ, Jongbloed LE, Backman CL. Community participation after spinal cord injury. Arch Phys Med Rehabil 2007;88:427-33.
7. Barclay L, Lentin P, Bourke-Taylor H, McDonald R. The experiences of social and community participation of people with non-traumatic spinal cord injury. Aust Occup Ther J 2019;66:61-7.
8. Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: A critical review. Int J Rehabil Res 2015;38:1-19. doi: 10.1097/MRR.0000000000000085.
9. Kader M, Perera NKP, Sohrab Hossain M, Islam R. Socio-demographic and injury-related factors contributing to activity limitations and participation restrictions in people with spinal cord injury in Bangladesh. Spinal Cord 2018;56:239-46.
10. Silver J, Ljungberg I, Libin A, Groah S. Barriers for individuals with spinal cord injury returning to the community: A preliminary classification. Disabil Health J 2012;5:190-6.
11. Sekaran P, Vijayakumari F, Hariharan R, Zachariah K, Joseph SE, Senthil Kumar RK. Community reintegration of spinal cord-injured patients in rural South India. Spinal Cord 2010;48:628-32.
12. Charlifue S, Gerhart K. Community integration in spinal cord injury of long duration. Neuro Rehabil 2004;19:91-101.
13. The Craig Handicap Assessment and Reporting Technique (chart). Available from: https://scireproject.com/wp-content/uploads/Clinician-Summary-v. 5.0_CHART.pdf. [Last accessed on 2022 May 16].
14. Spinal Cord Independence Measure (SCIM). Spinal Cord Injury Research Evidence. 2021. Available from: https://scireproject.com/outcome-measures/list-sci/self-care-daily-living/spinal-cord-independence-measure-scim/. [Last accessed on 2022 May 16].
15. WHO Disability Assessment Schedule (WHODAS). Spinal Cord Injury Research Evidence. 2021. Available from: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule. [Last accessed on 2022 May 16].
16. Atobatele KO, Olaleye OA, Fatoye FA, Hamzat TK. Relationships between community reintegration and clinical and psychosocial attributes in individuals with spinal cord injury in a Nigerian city. Top Spinal Cord Inj Rehabil 2018;24:306-14.
17. Callaway L, Enticott J, Farnworth L, McDonald R, Migliorini C, Willer B. Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study. Aust Occup Ther J 2017;64:226-34.
18. Whiteneck G, Meade MA, Dijkers M, Tate DG, Bushnik T, Forchheimer MB. Environmental factors and their role in participation and life satisfaction after spinal cord injury. Arch Phys Med Rehabil 2004;85:1793-803.