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Research article

Factors affecting social participation restriction in individuals with spinal cord injury

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ABSTRACT

Traumatic Spinal Cord Injury (SCI) is considered as a major disability and also life-threatening condition that carries a high risk of morbidity and mortality. The objective of this study was to discover the factors affecting social participation restriction in the individuals with SCI. Traumatic SCI patients details were collected from medical records of S.D.M Hospital, 30 patients in total were interviewed face to face with items of CHART-SF in the vernacular language. Responses were obtained and calculated as per the manual scoring for CHART-SF. Descriptive analysis was used for finding mean, median, a standard deviation and the median scores for the main domains of CHART-SF which were, for physical independence 32 which is considered to be moderately handicap, cognitive independence 100 which is not handicap, mobility 14 severe handicap, occupation 13.75. The statistical tests used were Kruskal Wallis ANOVA and Mann-Whitney U test to compare the variables (each domain of CHART-SF) with demographic variables and by Spearman's rank correlation method. We also found the association in between the variables of CHART-SF. All statistics were done with SPSS version 25. A probability value of $p \leq 0.05$ was considered to indicate a significant difference. Thus, there is a strong need to focus on planning the better rehabilitation and awareness programs for the betterment of quality of life of people with SCI, highlighting on major aspects/factors affected under these domains that is mobility, physical independence, and occupation in and around Hubli-Dharwad.

Keywords: Traumatic Spinal cord injury, Participation, Barriers, Environmental factors, QOL.

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INTRODUCTION

Spinal cord injury is (SCI) a medically complex and life-disrupting condition. SCI occurs more frequently in males compared to females (2:1). In Indian scenario the incidence rate for SCI is noted to vary from 9.2 to 56.1 per million and approximately 20000 new cases of SCI are recorded every year in India. Mean age of male patients referred from one of the studies is 34.81 years and female is 38.60 years are at higher incidence seen in younger, more active, more productive population of country [1].

The significant reasons for Spinal Cord Injury are tumble from stature: trees, building destinations, Road Traffic Accident (RTA-particularly including bikes), brandishing wounds: jumping, kabaddi, attack: Gunshot injury, cut, non-horrendous causes: Tubercular Spondylitis and so on 90% of SCI cases are awful in nature and the significant causes are occurrences like games or falls, car crashes, savagery [2].The significant outcomes of Traumatic spinal string injury (TSCI) are shortcoming, loss of sensation and inside and bladder brokenness. Because of these staggering entanglements, major financial weight is presented on the family and society. Around 10.4 to 83 cases for every million every year is yearly rate for TSCI.5 The level of causes being accounted for as 43-63% RTA, 15-22% games, 12-18% conflict, 29-43% falls, 1-2% attack [3].

The complications of SCI can be spinal shock, pressure sores, DVT (Deep Vein Thrombosis), AD (Autonomic Dysfunction) etc. Spinal cord injury can result in limitation of activity, decreased community participation, all of which will negatively affect the quality of life. Since the work by Post et al, international classification of functioning, disability and Health (ICF) model developed by world health organization was published; this acknowledged the importance of both environmental factors and contextual factors (personal) on body structure and functioning, activity and social participation restriction [4].

Environmental variables and investment are two of the focal ideas utilized by the World Health Organization (WHO) to characterize disablement (Whiteneck and Dijkers-2009; WHO-2001) [5,6]. The WHO model of handicap holds that natural components can either work with or go about as a hindrance to the social interest.

Albeit, the subjective investigations distributed have shown that there is a connection among cooperation and natural boundaries in spinal line injury exhibiting the collaboration with measurable examination has stayed uncertain [7,8,9].

'A NEED' of the local area might be conceptualized as need, or prerequisite requiring strategy and the need to go to social interest and to conquer the obstructions of climate has been demonstrated, adding on the extremely serious need identifying with work was accounted for. Portability needs locally is high just as family and individual relationship needs post release have likewise been found. The requirements of these individuals are seen with absence of social investment, level of debilitation they experience and by recognizing the everyday issues (jobs, exercises and connections), in which they are hindered in contrast with companions of same age, sexual orientation and culture [10,11].

As a community-based rehabilitation therapist, our role is to promote health and wellness in public. CBR personnel gives education regarding the condition, identify the risk factors involved, prescribe exercise, promote physical activity and plan the interventions in the community setup and using available resources, which is consistent with a biopsychosocial paradigm. The physical rehabilitation planned by the CBR personnel includes, high incidence of serious but preventable complications following SCI, that the suitable intervention could yield large health and social benefits at relatively less cost. This type of holistic approaches is important and should be provided to patient's post 1 year of rehabilitation following discharge, as these patients are vulnerable to complications. Hence to change patients' perception regarding their own health and prevention of complication Physiotherapist's must take active participation in health education programs [12,13]. As one of the principles of ICF says that the environmental influence and social factors plays an important role in people's functioning, thus eliminating or minimizing the barriers is essential to maintain the health and well-being, preventing the acute and chronic co-morbidities and maximizing quality of life [14][16].

As would be expected from emerging countries there are many factors as barriers (physical barriers, economic factors, transport facilities), limiting the social participation of the individual with spinal cord injury. To know which barrier is prevailing more in our regional rural area is more important and is focused in this study so as to bring about the awareness in the community level about the services provided by them by the community physiotherapists and our government to overcome these barriers.

Here by, the need and the purpose arise to find the factor as the barrier affecting the participation restriction in the spinal cord injured population in and around Hubli-Dharwad as they attempt to re-integrate into the community. The objective of the study is to identify the factors affecting social participation restriction in the patient with spinal cord injury.

MATERIALS AND METHODS

Ethical clearance for the study was obtained from ethics committee of SDM College of Medical science and hospital, Dharwad. The duration of the study was 1 year. SCI patients, who had been discharged from the SDM hospital post rehabilitation, were recruited from a database of discharged patients list from Medical Record Department of SDM hospital Dharwad.

Approximately 55 patients were discharged as SCI in past 5 years from SDM hospital. The information of all the patients was gathered from the medical records. As this study included only traumatic SCI, the list was segregated. Total of 42 patients with Traumatic SCI were contacted by phone calls. They were briefed about the study and were requested to visit the SDM Physiotherapy department for follow up rehab programmed on their own expenses. A total of 35 patients agreed to participate and expressed their willingness to visit the hospital. The inclusion criteria included SCI patients, who have entered the community post rehabilitation, age group of 18 years to 65 years, both genders, and ASIA (American Spinal Injury Association) score from A-D. And exclusion criteria included patient not willing to participate, recently diagnosed spinal cord injury patients.

Each patient was given an appointment date and time. On their visit to the department, they were assessed for ASIA scores and CHART-SF scoring. All together 30 patients visited the hospital before lockdown period and the analysis of results was done only these 30 patients.

With the consent of patient, which was followed by detailed explanation about the procedure of the study was given to them. Each participant was interviewed personally face to face in their vernacular language and collected the history of each participant initially which included, basic demographic data which included age, gender, education level, onset of injury, duration of injury, (about the management and rehabilitation, follow ups after coming back to home/community, any services granted by the government or any insurance covering was done.) Later, ASIA was performed to classify the traumatic SCI.

The interview continued with the elements of CHART-SF, Craig Handicap Assessment and Reporting Technique- short form was used to measure community participation. Responses for the CHART-SF scorings were scored in 100point scale for each of the domain respectively using the formulas and calculation given with the questionnaire itself. The CHART-SF scoring interpretation were done as the score from 0-25 will be severe handicap, 25-50 will be moderate handicap, 50-75 mild handicap and above 75 as no

handicap. Individual dimension is then calculated for the percentile scores for each domain using the user manual of CHART-SF. The collected information was kept confidential. In the total study duration that is from April 2019- March 2020 (before lockdown), 30 patients of SCI visited the hospital and their data was analysed using descriptive analysis. Convenience Sampling was used in this study. Primary source of data was collected from Medical Records Department of S.D.M Hospital. Sample size considered for analysis is n=30.

RESULTS AND DISCUSSION

Demographic profile of respondent. In the response group, mean age was 48.90years (SD8.78). Gender- Male (% of respondents= 73.33) and Female (% of respondents= 26.67). Time after injury was divided into 4 groups- 2years (% of respondents = 20.00), 3 years (% of respondents= 50.00), 4 years (% of respondents= 16.67), 5+ years (% of respondents=13.33). Location- Rural (% of respondents= 90.00) and Urban (% of respondents= 10.00). Economic status- Class 1 (% of respondents= 13.33), Class 2 (% of respondents= 10.00), Class 3 (% of respondents= 50.00), Class 4 (% of respondents= 26.67). Education- Illiterates (% of respondents= 23.33), Primary (% of respondents= 36.67), Secondary (% of respondents= 20.00), Graduates (% of respondents= 20.00). Asia scale- Asia 1(Grade A- % of respondents= 10.00), Asia 2 (Grade B- % of respondents= 33.33), Asia 3(Grade C- % of respondents= 56.67). And the same data is expressed in the graph below,

Figure 1: Demographic profile of respondents

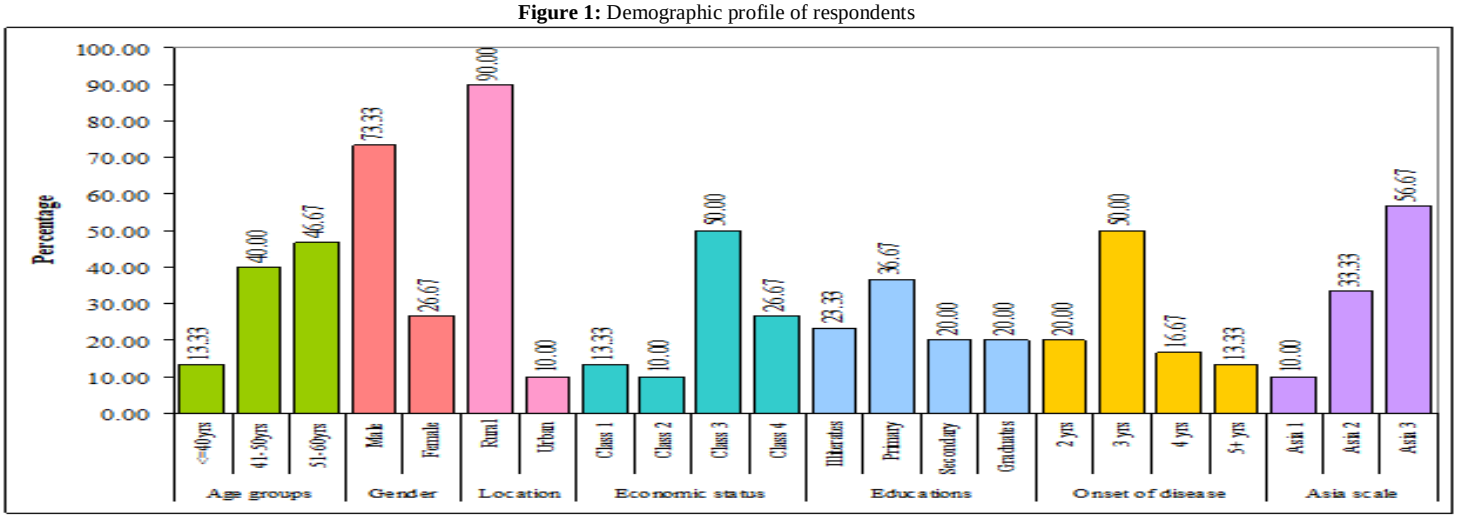


Table 1: Comparison of demographic profile of respondents with Physical independence scores by Kruskal Wallis ANOVA and Mann-Whitney U test

Profile	Mean	Median	SD	H/Z-value	p-value
Age groups					
<=40yrs	33.50	35.00	13.80	1.3050	0.5210
41-50yrs	45.36	40.00	28.60		
51-60yrs	31.00	32.00	11.22		
Gender					
Male	34.92	36.00	20.19	-0.4730	0.6360
Female	43.00	31.00	22.85		
Location					
Rural	39.85	32.00	19.91	-2.4060	0.0160*
Urban	12.10	16.00	10.41		
Economic status					
Class 1	13.08	16.00	8.72	10.4990	0.0150*
Class 2	26.67	30.00	5.77		
Class 3	41.07	40.00	19.97		
Class 4	45.50	36.00	21.67		
Educations					
Illiterates	46.00	48.00	26.31	8.3470	0.0390*
Primary	42.36	32.00	19.90		
Secondary	35.33	40.00	13.95		
Graduates	18.72	18.00	11.05		
Onset of disease					
2 yrs	32.33	31.00	13.53	2.8810	0.4100
3 yrs	42.53	40.00	22.38		
4 yrs	23.66	30.00	15.66		
5+ yrs	40.50	31.00	26.85		
Asia scale					
Asia 1	33.33	32.00	14.05	2.5840	0.2750
Asia 2	45.20	40.00	20.64		
Asia 3	32.96	30.00	21.48		
Total	37.08	32.00	20.84		

*p<0.05

Table 1 summarizes – Education p=0.0390*, Economic status p=0.0150*, location p= 0.0160* show significant results in the above table. The test which we have used is Kruskal Wallis ANOVA and

Mann-Whitney U test.

The Mann Whitney U test, sometimes called the Mann Whitney Wilcoxon Test or the Wilcoxon Rank Sum Test, is used to test whether two samples are likely to derive from the same population (i.e., that the two populations have the same shape). And the graph below represents the same data.

Figure 2: Comparison of demographic profile of respondents with Cognitive independence scores

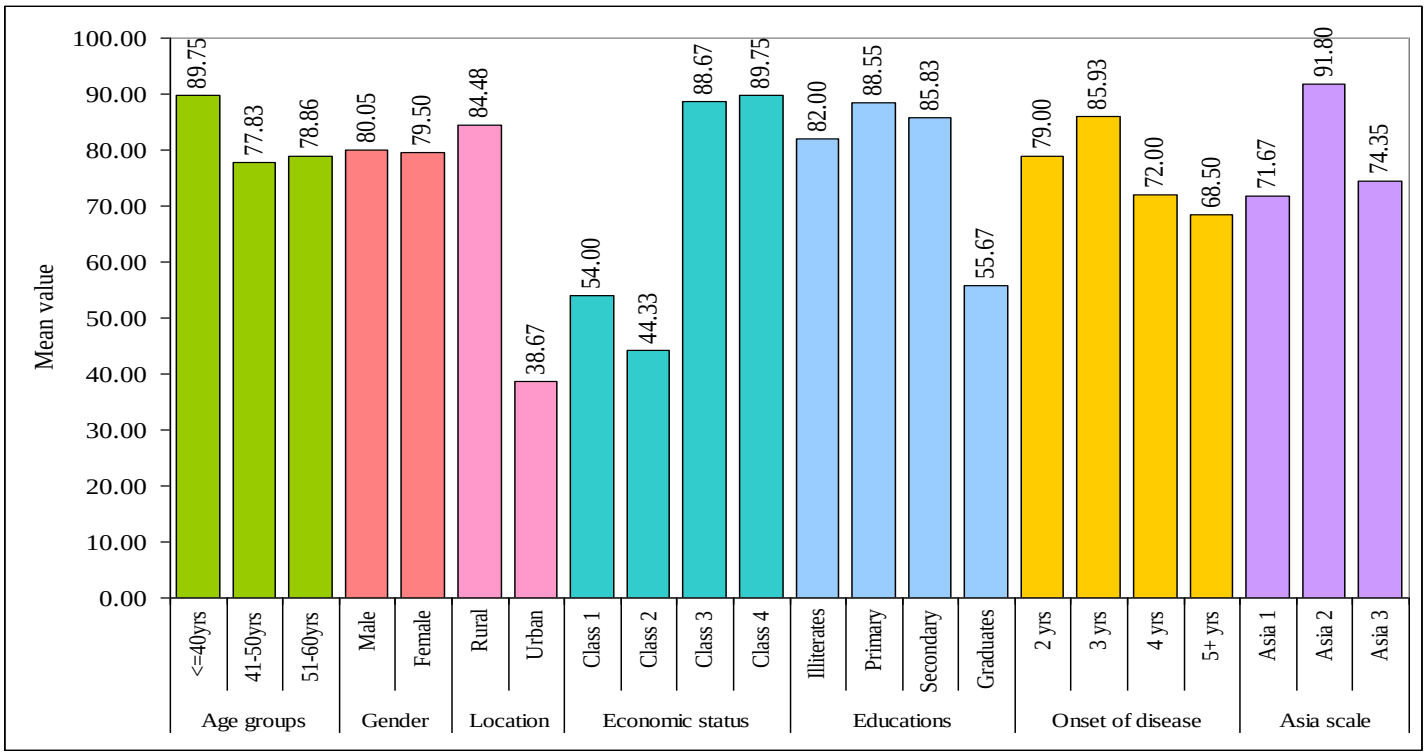


Table 2: Comparison of demographic profile of respondents with Mobility scores by Kruskal Wallis ANOVA and Mann-Whitney U test

Profile	Mean	Median	SD	H/Z-value	p-value
Age groups					
<=40yrs	18.75	16.50	10.78	0.0110	0.9940
41-50yrs	17.77	17.00	9.23		
51-60yrs	17.79	14.50	8.79		
Gender					
Male	16.60	13.00	9.78	-1.9410	0.0520
Female	21.50	21.00	4.57		
Location					
Rural	19.07	16.00	8.41	-2.0240	0.0430*
Urban	7.40	9.00	6.55		
Economic status					
Class 1	7.80	9.00	5.41	11.5970	0.0090*
Class 2	18.33	21.00	4.62		
Class 3	17.00	13.00	8.68		
Class 4	24.50	24.50	6.95		
Educations					
Illiterates	17.57	13.00	8.02	4.2220	0.2390
Primary	20.82	16.00	8.18		
Secondary	18.67	12.50	11.18		
Graduates	12.20	11.00	8.00		
Onset of disease					
2 years	13.33	12.50	4.03	2.6690	0.4460
3 years	20.00	16.00	9.44		
4 years	15.84	16.00	12.37		
5+ years	19.50	18.50	6.56		
Asia scale					
Asia 1	12.67	13.00	0.58	3.3740	0.1850
Asia 2	23.00	24.50	9.40		
Asia 3	15.84	13.00	8.22		
Total	17.91	14.50	8.90		

*p<0.05

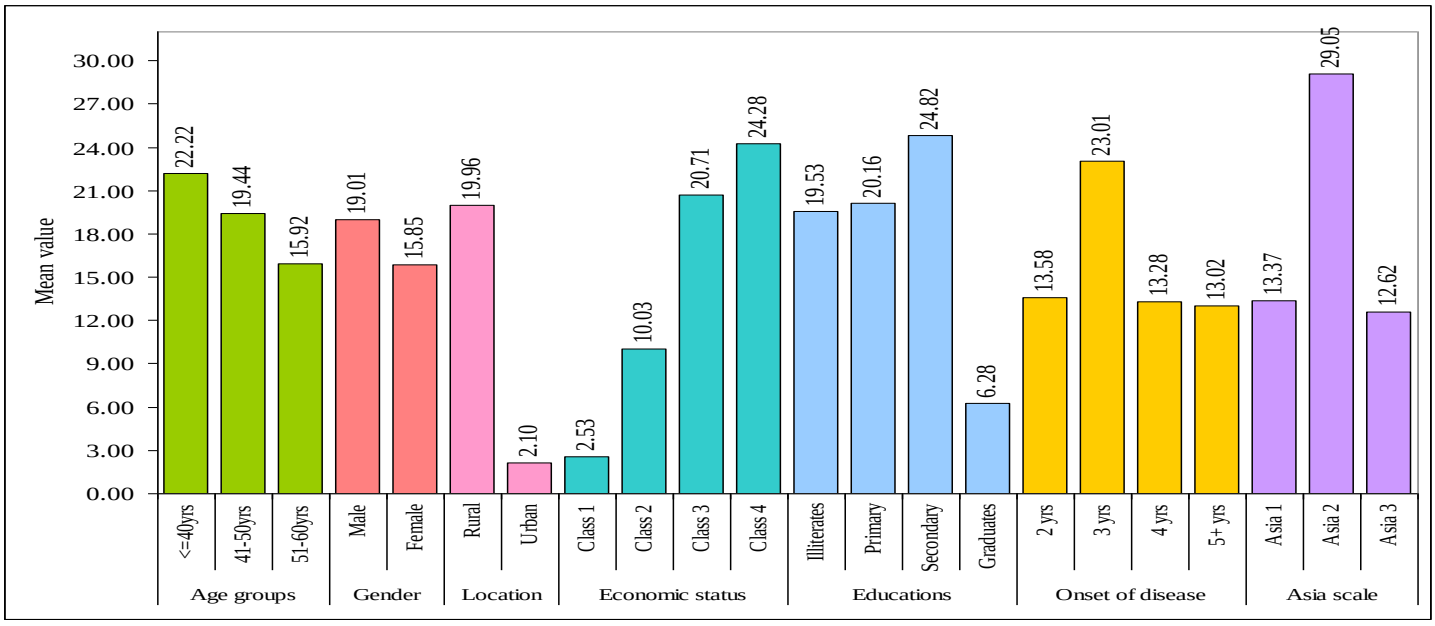
Table 2 summarizes- Location shows significant change in mobility domain p=0.0430* and Economic status is significantly influencing the mobility domain p= 0.0090*.

Table 3: Comparison of demographic profile of respondents with Occupation scores by Kruskal Wallis ANOVA and Mann-Whitney U test

Profile	Mean	Median	SD	H/Z-value	p-value
Age groups					
<=40yrs	22.22	18.80	18.72	1.4050	0.4950
41-50yrs	19.44	18.80	13.31		
51-60yrs	15.92	3.80	18.80		
Gender					
Male	19.01	18.80	17.67	-0.4260	0.6700
Female	15.85	13.80	12.74		
Location					
Rural	19.96	13.80	16.27	-1.9890	0.0470*
Urban	2.10	2.50	1.93		
Economic status					
Class 1	2.53	3.15	1.79	5.2300	0.1560
Class 2	10.03	13.80	6.52		
Class 3	20.71	23.80	15.86		
Class 4	24.28	24.15	19.14		
Educations					
Illiterates	19.53	23.80	13.26	3.8700	0.2760
Primary	20.16	13.80	18.38		
Secondary	24.82	23.80	19.85		
Graduates	6.28	3.80	5.99		
Onset of disease					
2 years	13.58	13.80	9.25	2.9340	0.4020
3 years	23.01	23.80	17.59		
4 years	13.28	3.80	19.88		
5+ years	13.02	8.15	15.38		
Asia scale					
Asia 1	13.37	13.80	10.66	7.1830	0.0280*
Asia 2	29.05	29.15	15.77		
Asia 3	12.62	3.80	14.81		
Total	18.14	13.75	16.36		

*p<0.05

Figure 3: Comparison of demographic profile of respondents with Occupation scores



There is no significant change noted in the social integration domain but values for Asia grades and location value is closer to the p value=0.05. And the graph below represents the same data,

Figure 4: Comparison of demographic profile of respondents with Social integration scores

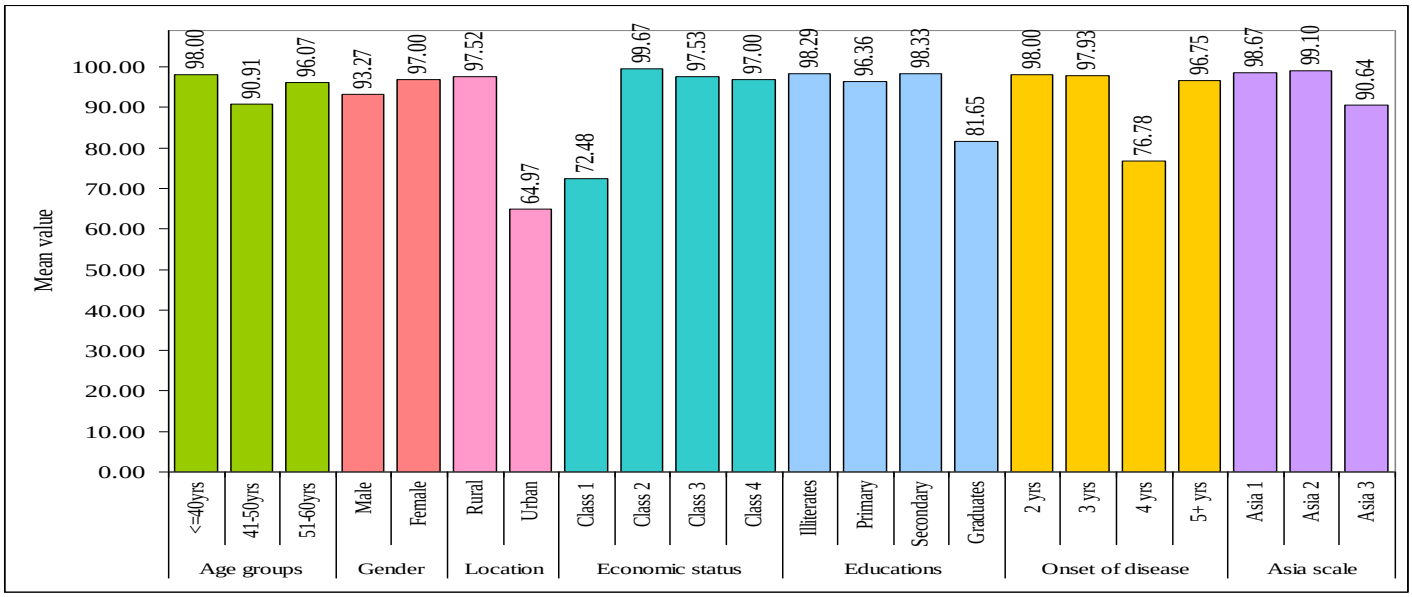


Table 4: Correlation among five variables by spearman's rank correlation method

Variables	Variables	n	Spearman R	t-value	p-level
Physical independence	Cognitive independence	30	0.5575	3.5539	0.0014*
	Mobility	30	0.5182	3.2065	0.0034*
	Occupation	30	0.7312	5.6727	0.0001*
	Social integration	30	0.4360	2.5635	0.0160*
Cognitive independence	Mobility	30	0.1059	0.5635	0.5776
	Occupation	30	0.4972	3.0324	0.0052*
	Social integration	30	-0.0673	-0.3568	0.7239
Mobility	Occupation	30	0.5924	3.8907	0.0006*
	Social integration	30	0.7732	6.4519	0.0001*
Occupation	Social integration	30	0.7120	5.3652	0.0001*

*p<0.05

This above table shows the association within five variables of CHART-SF. Social Integration is negatively associated with the cognitive independence. The p value falls between 0.05-0.01 for all the variables except the variable mobility and social integration when associated with cognitive independence.

The main objective of the study was to find out the factors affecting social participation restriction in the SCI individuals. Significant parts of social investment are: home and family jobs and exercises, other useful jobs (work, school and chipping in), informal communities, recreation exercises, versatility and financial independence. On the off chance that social investment is viewed as the significant point of restoration, the degree to which people with

handicaps need incorporation into every one of these parts of life can be considered to comprise a need of the SCI person. Estimating people groups' degree of social investment can consequently be utilized to distinguish local area needs [17].

In the present study, CHART-SF subscales helped identify the types of barriers that should be prioritized in attempts to improve participation by the SCI population. Whiteneck, Meade, et al. (2004) showed associations between the assistance barrier and some CHART-SF dimensions by cross-dimension analysis, but some associations were not statistically significant [18]. Based on our study results, the type or the factor as barriers, there is the significant finding obtained in the mobility aspect, occupation, physical independence, with comparison to the onset of injury, ASIA grading, gender, educational level, economic status being the major reasons for restricted participation in the society for persons with SCI. In the present study demographic profile of respondents were total of 30 participants were considered, post studies the demographic profile was explained in the results were, mean age was 48.90 years. We found that males were more prone for SCI when compared with females. This could be due to the fact that in most families, males are primary earning member of the family and hence get exposed to greater risk [19]. In our study 90% of SCI patients were from rural area and sustained injuries following fall from height [20].

As the study aimed to identify the factors affecting social participation restriction in SCI individuals, according to CHART-SF, the mean scores i.e., the percentage of handicap of each of the five domains used in the Chart-SF [21]. Accordingly the comparison of demographic profile of respondents with physical independence scores by Kruskal Wallis ANOVA and Mann-Whitney U test, Illiterates had reduced physical independence as they had less knowledge about the services available and also due to illiteracy their economic status is also low due to which they couldn't undergo proper rehabilitative management leading to physical independence. There was significant result obtained i.e. p=0.0390*, class 1 economic status p=0.0150*, rural located people p= 0.0160* have shown significant results as major of them were farmers and illiterates. Comparison of demographic profile of respondents with Cognitive independence scores by Kruskal Wallis ANOVA and Mann-Whitney U test – low economic status p=0.0360* have shown significant results as the individual with SCI who had low income was not given the chance to make decisions as a part of family and was left alone which may be leading to reduced psychological ability leading to reduced cognitive impairment. Research has also shown that emotional distress/ depression and life satisfaction are important variables explaining restrictions in participation.[38] Comparison of demographic profile of respondents with Mobility scores by Kruskal Wallis ANOVA and Mann-Whitney U test Rurally located people had significant change in mobility domain p=0.0430* and Economic status is significantly influencing the mobility domain p= 0.0090*. Comparison of demographic profile of respondents with occupation scores by Kruskal Wallis ANOVA and Mann-Whitney U test- the Rurally located people have shown the significant change in Occupation domain p= 0.0470* and Asia scale have shown the significant change in the Occupation domain p=0.0280*. Comparison of demographic profile of respondents with Social integration scores by Kruskal Wallis ANOVA and Mann-Whitney U test - there is no significant change noted in the social integration domain but values for Asia 1 and rural located patients is close to the set p value≤ 0.05. The association in between the association between variables by Spearman rank test was done which statistically significant was showing the strong percentage of p-value.

The participation restriction assessed by CHART-SF in this study indicates that there is a wide variation in societal participation among people with SCI across different dimensions and there is significant relationship between the variables in terms of occupation, social integration, mobility and physical independence [21,22]. Findings of our study demonstrated that individuals with more severe neurological injury and older age had decreased level participation in the community. Physical capacity is the ability of the cardiovascular system, muscle groups, and the respiratory system to support the desired level of physical activity [23]. Physical capacity is reduced in SCI, its evaluation is an indication of potential levels of participation in physical activity and the physical independence is challenged in SCI which effects higher functional status. Return to work after a neurological injury, spinal cord injury (SCI), is often a focus of rehabilitation interventions, Inability to return to work can put people with neurological injuries at risk for financial strain and other adverse psychosocial outcomes, such as problems with housing, social communication, and depression symptoms (Khazaeipour et al., 2014) [24]. Particularly in persons with spinal cord injury (SCI), it is important as most persons with SCI are relatively young. SCI unfortunately is a devastating event with a major impact on quality of life [25], in our study we have seen the significant affection in the domain of Occupation which is influenced by the reduced mobility and reduced physical independence. Mobility refers to the ability to move around safely and freely.

Some of the previous studies did not analyze data at the individual level (Dijkers et al., 2002; Kennedy et al., 2006; Sekaran et al., 2010) [26,27].

A 'need' might be conceptualized as a situation requiring a strategy, need or necessity. Versatility needs locally can be high and can have a wide-running impact on an individual's capacity to live

locally. As indicated by past research, hindered portability is identified with joblessness, expanded auxiliary conditions and dejection and low confidence [28]. The versatility of individuals with SCI has been recognized to be restricted because of transport issues, keeping individuals from expanding their quality locally. Family and individual relationship needs post-release have been accounted for to be met to differing degrees [29]. Needs in regards to cozy associations with a mate/accomplice and youngster raising have been distinguished as being neglected, albeit the significance set upon these necessities have fluctuated among reads and neglected requirements for peer amusement and friend support bunches have likewise been found. In an examination by Johnson et al, monetary impediments were accounted for by 25% of their example and contained the biggest classification [30]. Nonetheless, given the fundamental significance of cash in paying for home variations, hardware and care when important, Johnson might be incorrect in alluding to monetary limits as a 'optional difficulty'. As far as friendly investment, the social outcomes of SCI produce changes in a singular's social jobs and co-operations, bringing about need in a few regions. In an examination analyzing the neglected necessities of individuals with SCI living locally, a high or extremely significant need identifying with work was accounted for by 22% of the example. Results from such investigations shift because of many elements, for instance, the attributes of the example and the meaning of business utilized [31].

Not many instruments have been intended to gauge social support exhaustively and surprisingly less are straightforwardly identified with the SCI populace [32]. In our examination we have utilized this CHART SCORING as a proportion of cultural working, or how well people are reintegrated once again into the local area, and furthermore it has been utilized to explore the connections among handicap and, and SCI related auxiliary complexities, life fulfillment, actual work, warmth among SCI people.

Diagram legitimacy was apparent by its exhibition in separating gatherings of subjects all around the world assessed by restoration experts as having high or low degrees of impediment. Notwithstanding its unwavering quality and legitimacy, CHART offers a basic, target list of five components of impediment and an all-out score that follows the applied system of debilitation illustrated by the WHO [33,34].

Thus, in this study we mainly focused to find out the factors affecting the participation restriction in the individuals with SCI, where among five domains of our outcome CHART-SF, the three domains that is physical independence as moderately handicap, mobility and occupation were considered to be severely handicap have been reported in and around Hubli-Dharwad. Thus, focusing on these issues during rehabilitation will improve the QOL of the SCI individuals and will have an impact on the active participation of these individuals in the society.

CONCLUSIONS

This study concluded that among the five domains/ factors mobility, physical independence, and occupation had more affection which led to social participation restriction in and around our region that is Hubli and Dharwad.

Many participants were also graded severely handicap for the domain Occupation and main reason being illiteracy and primary education. Affection in the domain of Occupation was also specified which was influenced by the reduced mobility and reduced physical independence. The association among the variables was also determined to state that the spinal cord injury is the devastating state which affects the major aspects of life leading to impaired or challenged participation in the society after they enter the community.

Thus, there is a strong need to focus on planning the better rehabilitation and awareness programs for the betterment of quality of life of people with SCI highlighting on major aspects/factors affected under these domains that is mobility, physical independence, and occupation.

Author's Contribution

All authors contributed equally to the manuscript.

Conflict of Interest

The authors declare no conflict of interest.

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