

ORIGINAL ARTICLE

Community reintegration of spinal cord-injured patients in rural south India

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Study design: Cross sectional follow-up survey.

Objective: To ascertain the factors influencing community reintegration, of individuals with spinal cord injury living in rural environment, and to suggest measures to enhance community participation.

Setting: Bangalore, Karnataka, India.

Methods: Thirty-five individuals who were admitted under Physical Medicine and Rehabilitation Department of St Johns Medical College Hospital and rehabilitated to their functional level based on their level of injury; individuals living in rural environment were included in the study. The study was conducted by means of a standardized questionnaire and environmental and home assessments carried out during follow-up home visits after 12 months of discharge from the hospital. The main outcome measures were Craig Handicap Assessment and Reporting Technique (CHART) and Craig Hospital Inventory of Environmental Factors (CHIEF). The home visits and assessments were carried out by a rehabilitation team, which consisted of community-based rehabilitation worker, medico-social worker, physiotherapist and occupational therapist, and headed by a physiatrist.

Results: The findings of the study indicate a general decline in community reintegration in terms of physical independence, mobility, occupation and social integration. Mobility issues were the greatest perceived barrier and economic issues also significantly influenced the community participation.

Conclusion: Our study showed significant decline in community reintegration in subjects living in rural south India. Architectural and environmental barriers, poor socio-economic status and comorbidities significantly affected the level of community participation.

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Keywords: spinal cord injury; community reintegration; rural south India

Introduction

Community integration has been eloquently defined by Dijkers¹ as 'acquiring/resuming age/gender/culture appropriate roles/statuses including independence/interdependence in decision making and productive behaviors carried out as a part of multi-varied relationships with family, friends and others in natural community settings'.

Reintegration according to Steins *et al.*,² extends beyond the person, it promotes his/her fullest inclusion and participation within the physical and psychosocial environment. For persons with spinal cord injury (SCI), reintegration is a key issue in the entire rehabilitation process because in most instances SCI happens to persons who were healthy and actively integrated into social life.

Although the rehabilitation process is assumed to have substantial influence on the extent of one's performance or

participation in the community by either the process of functional restoration or environmental modification,³ factors such as lack of transportation, physical and architectural barriers, diminished availability and inaccessibility of healthcare pose significant barriers to people with SCI living in rural areas of India, as they strive to be integrated into their community.

Measures such as Independent Living Services⁴ in the United States of America and changes in public policy in many developed countries have greatly improved the level of community participation of these patients by minimizing barriers including geographical, architectural and cultural. Although community reintegration was considered as an essential part of Community Based Rehabilitation program launched in developing countries such as India, most programs have found it difficult to achieve adequate levels of community participation.

Despite its importance, few studies have focused on measuring the concept of community reintegration and the effects of various factors on promoting or facilitating community reintegration after SCI. With no documented

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studies on Indian population, the objective of this paper is to document the various factors that influence the extent/level of community reintegration in people with SCI living in the rural environment in south India.

Materials and methods

Participants

The sample composed of subjects with SCI who were admitted and rehabilitated to their functional level under the department of physical medicine and rehabilitation of St Johns Medical College Hospital. A total of 35 subjects living in rural environment were included in the study.

Data collection

All data were collected during the follow-up house visits conducted 1 year post injury by the rehabilitation team of the hospital. Demographic and injury-related information was derived from the initial hospitalization medical records. Neurological classification was carried out using the American Spinal Injury Association⁵ impairment groupings and standard classification by neurological level of lesion. All outcome measure information was collected through personal interviews. The main outcome measure was the short form of Craig Handicap Assessment and Reporting Technique (CHART-SF), which measures the extent of community participation and the short form of Craig Hospital Inventory of Environmental Factors (CHIEF-SF). Architectural barriers were assessed by an occupational therapist. General health status and the influence of comorbidities were documented through routine clinical examination. Economic issues were assessed and documented by a medico-social worker.

Instruments

CHART. Craig Handicap Assessment and Reporting Technique⁶ was used to measure community participation. As a proxy measure, it quantifies the degree to which individuals with disabilities are reintegrated back to the community. Its development was based on WHO's 1980 disablement model.⁷ For this study, we used the CHART-SF, a 20 item shortened version of CHART. The CHART-SF subscale quantifies the extent of community participation across five domains including physical independence, cognitive independence, mobility, social integration and economic self-sufficiency. The physical independence scale assesses the degree of assistance that an individual needs with completion of tasks related to meeting of physical needs such as dressing or bathing. The mobility subscale measures the ease with which the person can physically move within his/her environment. The occupation subscale measures the degree to which a person occupies time in socially beneficial activities such as work, school, housekeeping or active recreational activities. The social integration scale reflects how extensively an individual interacts with others. The economic self-sufficiency scale measures the economic independence of the person's household unit. Each domain is scored from 0–100. The maximum score of 100 represents the participation level of most people without disabilities

and who would be expected to have no handicap. Lower scores indicate less than full participation in the community.

CHIEF. The CHIEF⁸ is a 25-item instrument designed to quantify the frequency, magnitude and overall impact of perceived environmental barriers. As conceptualized in the development of the measure, environmental barriers are barriers that keep people with disabilities from functioning within the household and community and from doing what they need or want to do. These include social, attitudinal and policy barriers, as well as physical and architectural barriers. Subjects are asked to provide information about the frequency of their encounters with each type of barrier listed (daily, weekly, monthly, less than monthly and never) and the magnitude of the problem when it occurs (big or little). Scores for each of the items are calculated by multiplying the frequency score (range: never-0; daily-4) by the magnitude score (range: little problem-1; big problem-2) to yield a product or overall impact score. Items relating to work and school, when the subjects are neither working nor in school, are considered 'not applicable' and are not scored. We used the CHIEF-SF in this study. This is a 12-item version of the CHIEF composed of those items with the greatest conceptual clarity and discriminant validity.⁸

Statistical analysis

The analysis focuses on changes in community integration as measured by CHART-SF. Based on observations from previous studies,^{9–11} a score of 75 was used as a cut point for the CHART-SF subscales (separating those with mild participation restriction from those with substantial restriction). Age and duration of injury were transformed from continuous to categorical variables. Age groups were age 40 years and less, and age 41 years and more. Duration of injury was also dichotomized as less than 2 years post injury and more than 2 years post injury. Two neurological groups included those with functionally complete paraplegia (American Spinal Injury Association ABC) and individuals with functionally incomplete paraplegia (American Spinal Injury Association D). Regression analyses using age, duration of injury and neurological group were done to identify if there were demographic predictors of CHART-SF scores.

Descriptive statistics used to examine the frequency and magnitude of reported barriers measured by CHIEF-SF scores. A score of 1 was the cut point for the CHIEF-SF variables⁹ (separating those reporting no barriers or only infrequent small barriers from those reporting more substantial barriers).

Results

Table 1 summarizes the demographic and injury characteristics of the study sample.

Mean CHART-SF scores are presented in Table 2. There was significant decline in occupation, mobility, social integration and physical independence CHART-SF scores. The dimension of occupation had wide variability and the lowest mean score (36.6) among all injury groups followed by

Table 1 Demographic and injury characteristics of patients

Basic characteristics	Number (n = 35)	Percentage
<i>Age in years</i>		
<40 years	25	71.4
≥40 years	10	28.6
<i>Gender</i>		
Male	31	90.3
Female	4	9.7
<i>Duration of illness</i>		
<2 years	12	34.3
>2 years	23	65.7
<i>ASIA classification</i>		
ASIA A, B and C	26	74.3
ASIA D	9	25.7

Abbreviation: ASIA, American Spinal Injury Association.

Table 2 Mean CHART-SF scores

Subscale	Mean score
Physical independence	75.2 (15.6)
Mobility	56.3 (29.2)
Occupation	36.6 (32.4)
Social integration	58.6 (18.7)

Abbreviation: CHART, Craig Handicap Assessment and Reporting Technique.

mobility (56.3) and social integration (58.6). Physical independence had the highest score across all the group of patients (75.2).

Table 3 indicates the β coefficients in regression analyses to determine the best predictors of the CHART-SF subscale scores using the demographic variables of age, duration of illness and neurological group (severity of injury). Neurological group alone was predictive of mobility score. However, both age and neurological group were predictive of physical independence, occupation and social integration. Duration of illness was not predictive of any of the CHART-SF subscale scores.

Figure 1 graphs the average scores of the major environmental barriers, indicating the average final product of the frequency and magnitude of each environmental barrier. The top five environmental barriers reported by people with SCI in our study (in descending order of product scores) are as follows: barriers in the natural environment, transportation, access to health care, attitude of people at home and help at home. All the subjects reported at least one significant environmental barrier (no scores of 0). The lowest average score was reported in the policy barrier (score 0.05) mainly because of the fact that most of the subjects were not aware of the policies of the government. In all, 40.6% of the subjects reported maximum impact (score 8) of terrain/natural environment and 34.3% of subjects reported maximum impact (score 8) on availability of transportation as their perceived environmental barrier.

At least one architectural barrier was observed in 92% of the subjects' home and out of them, 54% had significant

Table 3 Regression analysis β coefficients

CHART Variable	β coefficients	Significance
<i>Physical independence</i>		
ASIA A, B and C	-0.31	$P = 0.055^*$
Age >40 years	-0.35	$P = 0.043^*$
<i>Mobility</i>		
ASIA A, B and C	-0.36	$P = 0.053^*$
Age >40 years	-0.52	$P = 0.206$
<i>Occupation</i>		
ASIA A, B and C	-0.33	$P = 0.046^*$
Age >40 years	-0.37	$P = 0.014^*$
<i>Social integration</i>		
ASIA A, B and C	-0.48	$P = 0.052^*$
Age >40 years	-0.36	$P = 0.022^*$

Abbreviations: ASIA, American Spinal Injury Association; CHART, Craig Handicap Assessment and Reporting Technique.

*Significance: $P \leq 0.05$.

limitations in space in and around the house limiting their mobility. A total of 71.8% of the subjects had at least one comorbidity affecting their societal participation. Pressure sores (30%) and urinary tract infection (32%) were the key factors for limiting the mobility and participation followed by spasticity (26%) and obesity (12%).

Discussion

Community reintegration assessed by CHART-SF in this study indicate that there is a wide variation in societal participation among people with SCI across different dimensions and there is a general decline in community reintegration in terms of occupation, social integration, mobility and physical independence.

Demographic variables including level and severity of neurological injury, although not thought to be good predictors of many long-term psychological and productivity outcomes in SCI,¹² predict community reintegration after SCI as measured by CHART. Findings of our study demonstrated that individuals with more severe neurological injury and older age had decreased level of community reintegration. Few studies^{10,12} do not generally support the contention that either of these variables have a significant role in determining changes in community reintegration and these outcomes are more strongly affected by factors such as family support, emotional adjustment and coping style. Research has also shown that emotional distress/depression and life satisfaction are important variables explaining restrictions in participation.¹³⁻¹⁵ However our study did not measure the effect of psychological/emotional status of the individuals.

Recent studies on western population have reported that environmental factors have only a small effect on community integration.⁹ The physical accessibility in many communities in the west has improved dramatically in the past three decades and therefore, it is conceivable that the environment in those communities no longer acts as a

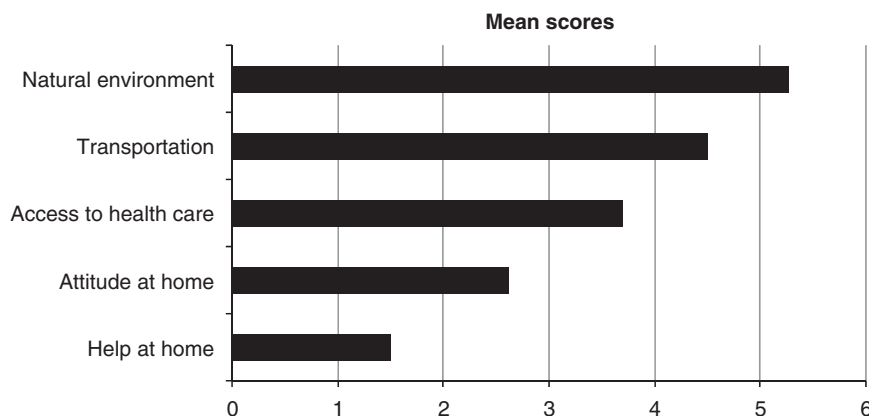


Figure 1 CHIEF-SF subscale scores in descending product score order.

major barrier. Most of these studies tend to be undertaken in urban areas with well-planned architectural and environmental design to accommodate people with disabilities. And these urban areas also could have been covered well under programmes such as Independent Living Services to facilitate and promote community reintegration. This can be understood from the conclusions of the studies undertaken in the rural areas of America,¹⁶ which point out that lack of transportation, physical and architectural barriers, diminished availability and inaccessibility of health care pose significant barriers to people with SCI living in the rural areas of America. In rural Indian communities, such as the one explored in our study, the physical environment remains inaccessible to people with disabilities and continue to be a major barrier. The findings were supported by the high mean scores on the physical/structural environmental barriers measured by CHIEF-SF subscales in our study.

Economic self sufficiency subscale of CHART-SF could not be used for our study population, and hence the poverty line was used to determine the economic status of the subjects.¹⁷ Although most of the subjects (72%) lived in poor economic conditions below poverty line, the data could not be statistically correlated with any of the outcomes of societal participation measured by CHART-SF.

The impact of the comorbidities and architectural barriers, although significant in influencing the level of participation, could not be correlated statistically with any of the outcomes of societal participation measured by CHART-SF.

The study had several limitations; sample size of 35 was not the representative sample of all the SCI patients in rural south India. Although several studies have demonstrated the importance of psychological status and life satisfaction,¹⁰ our study did not assess the significance of these factors in societal participation. The findings of CHART-SF must be interpreted with caution as it only quantifies the extent of community reintegration; however, the context of the quality of which is not assessed. CHIEF-SF only assesses a person's subjective perception, the relation between perceived barrier and actual barrier encountered is not known.¹⁸ Future research is needed to adequately address these issues.

Conflict of interest

The authors declare no conflict of interest.

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