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ORIGINAL ARTICLE

Employment after paraplegia in India: a postal survey

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Study design: This study was carried out as a postal survey.
Objectives: The aim of this study was to ascertain employment after paraplegia in India.
Setting: This study was conducted in India.
Methods: The study was conducted by means of a questionnaire. This questionnaire was mailed to the identified individuals ($n = 600$) on the addresses obtained from the medical records section of hospitals and from various organisations. Data analysis was carried out by using descriptives.
Results: The return rate was 46% (276/600) and the employment rate was 41% (114/276). Among 114 subjects who were employed, 68 (59.6%) were living in centres run by armed force and 46 (40.4%) were living in specialised centres or under the region of non-governmental organisations.
Conclusions: Individuals who were employed were living either in centres run by armed force or in specialised centres. None of the individuals living in community was employed.
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Keywords: sheltered workshops; vocational rehabilitation; return to work; community re-integration; spinal cord injury; quality of life

Introduction

The term 'employment' by definition, includes any trade, economic activity and profession in the organised as well as unorganised sector or any trade that would provide with some monetary remuneration.[1] Employment is one of the most important goals for an individual with spinal cord injury (SCI), especially in cases, in which an individual is the only earning member of the family. It not only helps to achieve economic self-sufficiency but is also associated with personal growth, disability adjustment, social integration and life satisfaction. Most of the studies on vocational resettlement reported relatively lower rate of employment, usually below 40%.[2]

Krause[3] found that only 12% of individuals returned to their same job after injury, individuals with paraplegia were more likely to return to pre-injury job than those with tetraplegia, employment rates were lower in 51–60 years age group and younger age at injury was associated with higher current employment rate. This study emphasised the need for comprehensive rehabilitation and the role of higher education in producing higher employment rates.

Age at injury onset and years since injury were related to increase in barriers to employment, may be because of declining health. The largest number of barriers were reported by those with the older age at injury (45–54 years) and with the most years post injury (>30 years).[4] Level of education, less severe injury and returning to pre-injury employer were associated with shorter interval to initiation of employment with 10 year censoring.[5]

Functional independence is the strong factor predicting return to work. Thus, rehabilitation should be focused on education, self care ability, community mobility, vocational training and environmental modifications that may improve employment after SCI.[6] However, people with disabilities face non-accomodating environments, lack of opportunities and inadequate income support.[7] Early positive expectations of the individual person with a SCI are an important indicator of successful reintegration. The rehabilitation team can have an active role in drawing up a vocational reintegration plan to prepare the patient, employer and all professionals involved for job reintegration.[8]

In India, ~1.5 million people live with SCI. Every year, 10 000 new cases add to this group of individuals and majority of them (82%) are males in the age group of 16–30 years.[9] Gaining employment, economical self-sufficiency and community reintegration after SCI are important to all the victims irrespective of geographical variations. The employment opportunities for persons with disability in organised sectors in India, particularly in rural areas are non-existent. Unorganised sectors may prove to be the most appropriate avenue of employment for individuals with disability. Unorganised sectors include self-employment or

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home work and organised sectors include sheltered workshops, transitory employment centres and on the job training sectors.[1] There is extensive literature available regarding employment after SCI in most of the areas in the world but there is scant literature on India. Thus, this study ascertains employment after paraplegia in India.

Materials and methods

Study design
This study was carried out as a postal Survey

Subjects
Individuals with paraplegia of any cause, either gender with evidence of complete cord lesion who were ≥ 18 years were selected. Subjects included were community dwelling, individuals living in centres run by armed forces and individuals living in specialised centres for SCI victims.

Study period
The study was conducted between 1 August 2004 and 31 May 2006.

Procedure
Part I: Development of questionnaire and validation. We developed a questionnaire in English, which was constructed at the language level of third grade education. The questionnaire was evaluated for face validity by five physiotherapists. Each of the physiotherapists had a minimum of 5 years working experience with SCI, including community-based work with this population. The suggestions put forth by the evaluators were incorporated and the revised questionnaire was pilot tested on 10 SCI individuals for comprehensibility. Changes suggested were incorporated and this version was again pilot tested on five patients who had not participated in the first pilot testing. The final version was translated into Indian languages by means of parallel back translation ensuring that the language level was maintained at the third grade level in all languages.

The final versions of the questionnaire consisted of three sections: The first section included demographic and disease characteristics such as age, gender, education, occupation, level of lesion, duration since injury and ambulation status. The expected responses to this section were open ended except ambulation status, which was dichotomous (walking/not walking).

The second section consisted of questions regarding morbidities and the third section consisted of details of employment following the SCI. The question asked in third section was 'Are you employed? Mention briefly.' The response to this section was open ended.

Part II: Administration of questionnaire. Because of the absence of a national database on SCI, addresses of potential subjects were collected from hospitals and organisations and associations dedicated to the SCI population. Addresses of individuals living in 20 of 28 states in India were collected. The questionnaire in English and the relevant regional language was mailed to the identified individuals ($n = 600$). The mail packet included a covering letter in English and the regional language, clearly outlining the purpose of the questionnaire, the subject's option to participate or not, and the expected return date; the questionnaire itself with instructions for completion and a reply paid self addressed envelope. One reminder was sent a week after the expected date of reply had passed. Those subjects who did not respond to the reminder were not contacted again.

Data analysis
Data were analysed using descriptives.

Results

Return rate
Of the 600 individuals, 276 responded to the mailed questionnaire, with a return rate of 46%. Of the 276 individuals, 156 (56.52%) were living in specialised centres or under the region of non-governmental organisation, 68 (24.64%) were living in the centres run by armed force and 52 (18.84%) were living in the community.

Demographics
The demographic characteristics are shown in Table 1.

Age: Of the 276 participants, 53 (19.2%) were in the age group of 18 to <25 years, 53 (19.2%) in 40 to <50 years, 49 (17.8%) in 25 to <30 years, 41 (14.9%) in 35 to <40 years, 38 (13.8%) in 30 to <35 years, 30 (10.9%) in 50 to <60 years and one each (0.4%) in 70 to <80 and >80 years.

Gender: In all, 233 subjects were men and 43 were women.

Education: In all, 148 subjects (53.6%) belonged to secondary education category, 40 (14.5%) subjects had higher secondary education, 23 (8.3%) subjects were illiterate, 22 (8%) subjects were graduates, 19 (6.9%) subjects were professionals, 19 subjects (6.9%) had primary education and 5 (1.8%) subjects were postgraduates.

Level of lesion: In all, 166 subjects (60.1%) had the lesion at the lumbar level, 39 subjects (14.1%) at the upper thoracic level, and 31 subjects (11.2%) at the lower thoracic level and 40 subjects (14.5%) did not mention about the level.

Etiology: Falls from height was the leading cause for spinal cord insult (25%), followed by road traffic accidents (17.4%), non-traumatic insult (8.3%), fall of an object (6.5%), gun shot injuries (4.3%) and sports-related cause of an insult (0.7%). A total of 38% individuals did not mention the cause for injury.

Duration since injury: The duration since injury was arbitrarily divided into 11 categories, ranging from 1 to <6 months to >25 years. Of the 276 participants, most of the subjects (57, 20.7%) were 1 to <6 months post injury and the least (6, 2.2%) were in 15 to <20 years post-injury period.

Employment
Employment rate was 41%. In all, 162 subjects (59%) were unemployed and 114 subjects (41%) were employed. This is depicted in Figure 1.

Table 1 Demographic characteristics ($n=276$)

Demographics	*Percentage*
Age (years)	
18 to <25	19.2
25 to <30	17.8
30 to <35	13.8
35 to <40	14.9
40 to <50	19.2
50 to <60	10.9
60 to <70	3.5
70 to <80	0.4
>80	0.4
Gender	
Men	84
Women	16
Education	
No education	8.3
Primary	6.9
Secondary	53.6
Higher secondary	14.5
Graduation	8
Postgraduation	1.8
Professional	6.9
Etiology	
Fall from a height	32
Fall of an object	7
Road traffic accident	22.5
Sports related	1
Gun shot injury	4.5
Non-traumatic	11.5
Level of lesion	
Upper thoracic (T1–T6)	14.1
Lower thoracic (T7–T9)	11.2
Lumbar (⩽T10)	60.1
Duration since injury	
1 to <6 months	20.7
6 to <12 months	14.9
1 to <2 years	15.2
2 to <3 years	10.5
3 to <4 years	6.5
4 to <5 years	6.2
5 to <10 years	10.5
10 to <15 years	4.3
15 to <20 years	2.2
20 to <25 years	4.3
>25 years	3.6

Among 114 subjects who were employed, 68 (59.6%) were living in centres run by armed force and 46 (40.4%) were living in specialised centres or under the region of non-governmental organisations. Employment after paraplegia based on the centre the individual was living is depicted in Figure 2.

Discussion

In our study, we found employment rate to be 41%, which is in agreement with Crisp.[2] Among individuals who were employed, 59.6% were living in centres run by armed force and 40.4% were living in specialised centres or under the region of non-governmental organisation. We did not find any association of age, gender, education and duration since injury with the employment but we found association of employment with the place the individual was living. For the ease of discussion, we will discuss employment after paraplegia under three sections:

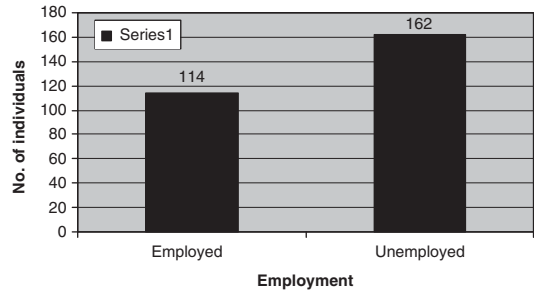

Figure 1 Employment after paraplegia in India ($n=276$).

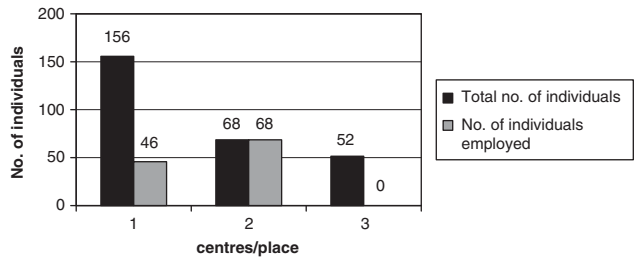

Figure 2 Employment after paraplegia based on the place the individual was living. *Note*: (1) individuals living in specialised centres ($n=156$, employed 46), (2) individuals living in centres run by armed force ($n=68$ and employed 68) and (3) individuals living in community ($n=52$, employed none).

(a) Individuals with paraplegia living in centres run by armed force

All (68/68, 100%) the individuals with paraplegia who were living in centres run by armed force were employed. These individuals had sheltered accommodation, sheltered employment and were given time for sports (basket ball, throw ball and so on) and recreation there in the army set up. Some of the individuals were even taking care of telephone booths and fruit shops. They were getting monthly salary and thus were economically self-sufficient. Sheltered workshop is also considered a permanent or semi-permanent vocational placement for individuals who are unable to find jobs in the community. It is to be considered a job and a place to go to work every day.[1]

Paraplegic rehabilitation centres at Kirkee and Mohali with a capacity of 109 and 34 beds, respectively, are being run for rehabilitation of paraplegic and tetraplegic ex-servicemen. These are being run as charitable trusts registered with the respective State Governments. These institutions are funded by Kendriya Sainik Board, Ministry of Social Justice and Empowerment, AG's Branch and other State Government/private organisations.[10]

The paraplegic rehabilitation centre imparts vocational training to the former soldiers suffering from disabilities to

enable them to live a dignified and economically independent life. The skills include trades, such as weaving, knitting, tailoring, candle making and so on. The objective of paraplegic rehabilitation centres is to rehabilitate 100% disabled paraplegic and tetraplegic army men with a view to motivate them. They also provide them with vocational training so that they can be self-reliant. The centre provides facilities, such as medical treatment, physiotherapy, physical exercise, sports and computer training to enable in-patients to become self-reliant.[11]

(b) Individuals with paraplegia living in specialised centres or under the region of non-governmental organisations

Among individuals who were living in specialised centres or under the region of non-governmental organisations, 29.48% (46/156) were employed. They underwent vocational training programmes. Individuals who were unemployed were either in acute stage of rehabilitation (20.7% of the subjects in our study were in 1 to <6 months post-injury period) or were undergoing vocational rehabilitation. Individuals who were in the acute stage had their main goal to achieve functional independence as much as they could, and they were not sure about their employment in future.

Vocational training department in specialised centres have an important role in boosting confidence in individuals with SCI. They help them to explore their hidden talents. The department offers training in soft toys making, cutting and tailoring, clay modelling, decorative items, paper items, paintings and different kinds of arts and crafts. Peer counselling is also carried out in specialised centres. They also help in placing the individual for a job, as they have information regarding various governmental policies and facilities, such as vocational rehabilitation centres, district rehabilitation centres, regional rehabilitation research centres and special employment exchanges for physically handicapped.[9]

The Association of People with Disability provides skill training for persons with disability and for persons who are economically marginalised. Computer training programmes are one approach Association of People with Disability uses to enable trainees to secure jobs, become economically independent and create a meaningful life. The various centres they have are Industrial Training Centre, Orthotic Appliances Training and Production Centre and Urban Slum Out Reach Programme.[12]

(c) Individuals with paraplegia living in community

None of the individuals living in community were employed. This could be because of the of awareness on the part of victim as well as rehabilitation professionals regarding various facilities available in India, such as vocational rehabilitation centres, district rehabilitation centres, regional rehabilitation research centres and special employment exchanges for physically handicapped.[9]

We did not ask reasons for their unemployment in the questionnaire but based on the literature and the comments which were given in the questionnaire in answer to employment status, the other probable reasons for their unemployment could be lack of opportunities to civilians compared with those in armed force, willingness of employer to make a place for those with limitation,[13] cultural biases,[2] financial disincentives to employment,[2] environmental barriers such as uneven terrain or inaccessibility of work place.[14]

A study conducted by Sekaran *et al.*[15] showed that there was a general decline in community re-integration in subjects living in rural south India. Architectural and environmental barriers, poor socioeconomic status and co-morbidities significantly affected the level of community participation. There is significant relationship between perceived environmental barriers and community integration for adults with SCI. Rehabilitation professional need to understand that removal of environmental barriers is the only first step in the more complex effort to facilitate optimal community integration.[16] The top five environmental barriers reported by subjects with SCI, in descending order of importance, were the natural environment, transportation, need for help in the home, availability of health care and government policies. Environmental factors were found to be strongly related to life satisfaction than to societal participation.[17]

Hancock *et al.*[18] in their study had showed that individuals with SCI had lower self-esteem, more helplessness and fatalistic attitude. Much of the literature is based on depression following SCI. Family relationships strongly influence life satisfaction of people with SCI. Young *et al.* (2000) suggested that 48% of individuals with SCI had clinical symptoms of depression at a year or more after injury. Suicides were common among civilians with SCI.[19] Thus, there should be a provision of structured psychological programme in the rehabilitation stage for individuals with SCI, especially for those who feel that there is little control over their lives.[20]

Response from 60 to 80% of a sample is usually considered excellent. Realistically, researchers can expect return rates between 30 and 60% for most studies.[21] Response rate to a survey in India was reported to be 23,[22] 43.2%[23] in studies conducted on medical practitioners. In our study, the response rate from the community was low. The possible reasons could be inadequate addresses, change in the address, illiteracy, death of the patient, mail being sent by an unfamiliar person and no incentives being offered.

Employment rate found in the study was 41% and none of the individuals living in the community was employed. These figures could be representative of wider Indian scenario though majority of the individuals were resident of sheltered living and working environments and the response rate from the community was low. In India, majority of subjects with SCI are rural based, live below the poverty line and are unable to afford the cost of rehabilitation. In addition, >50% of the patients get adequate rehabilitation during initial hospitalisation, 81.82% of institutions have no facilities for a pre-discharge home visit by staff to understand specific requirements of the patients and 73.9% of institutions have no facilities for follow-up home care services.[24] The majority of these clients seek repeated medical treatment lifelong owing to various morbidities.[9]

Limitations of the study

Small sample size, thus it may not represent the general population in India. Specific questions such as employment history, salary levels, length of time between injury and employment were not asked.

Questions regarding quality of life of an individual after paraplegia were not asked.

Questions regarding socioeconomic status of individual with paraplegia in India were not asked.

Individuals with paraplegia were not asked questions regarding their return to rehabilitation centres for regular follow-ups.

As it was a postal survey, personal visits in the community was not made. Personal visits or face to face interaction would have had given information regarding accessibility/barriers in the environment.

Future research

In future studies, it would be worthwhile to add more questions on initial management strategies, functional aspects, quality of life and psychosocial aspects in the questionnaire. Questions should be constructed to glean information about cause and effects and attempts to increase the sample size must be made.

Information regarding socioeconomic status of individual with paraplegia in India should be gathered, though in one study, it was mentioned that majority of individuals with SCI in India are living below the poverty line and are unable to afford the cost of rehabilitation.[24]

Information should be gathered regarding structured follow-up programmes offered by specialised centres or the centres working for individuals with SCI in India.

Personal visit in the community should be made which will give more information regarding their quality of life, socioeconomic status, mobility indoor and outdoor as well as barriers in the environment.

Conclusion

Employment rate in our study was 41%. Individuals who were employed were living either in centres run by armed force or in specialised centres. None of the individuals living in community was employed.

Implications

(a) There is a need for comprehensive rehabilitation.[2]
(b) Regular and long-term follow-up services need to be maintained by vocational and rehabilitation counsellors.[2]
(c) Provision of structured psychological programme in the rehabilitation stage.[15]
(d) Rehabilitation professionals must have knowledge regarding various facilities/policies available to individuals with SCI.
(e) Early positive expectations of the individual person with a SCI are an important indicator of successful reintegration. The rehabilitation team can have an active role in drawing up a vocational reintegration plan to prepare the patient, employer and all professionals involved for job reintegration.[8]
(f) Government should make more provisions of employment for civilians with SCI/disability.
(g) There is a need to have a barrier free environment.[14]
(h) Rehabilitation professionals need to find creative means to remove barriers to employment among individuals from minority groups.[25]
(i) Emphasis should be given to community reintegration and economic self-sufficiency.
(j) Use of address cards while visiting the hospitals as most of the addresses of the patients taken by the registry clerk is still inadequate.[26–28] This may help to increase the response rate in future studies.
(k) There is a need to address complex challenges like poverty disability links, skewed representation of the urban-centric disabled persons, aid receiving organisations in the policy/decision making body of the government and speedy and effective implementation of the disability policies.[1]
(l) Government should expand outreach services for the poor persons in rural areas.[1]
(m) There is a need to take measures to reduce falls, traffic-related accidents, providing more number of trauma centres and strict adherence of safety norms in hazardous jobs.[1]
(n) There is a need to expand employment opportunities in the government and private sectors as well as reservation provisions on employment need strict monitoring.[1]
(o) Self-employment through concessional loans by various agencies is required.[1]
(p) Poverty alleviation programmes for capacity building, social security and sustainable livelihood programmes and so on need to be taken up effectively in an integrated manner so as to improve the conditions of persons who are poor as well as disabled.[1]

Conflict of interest

The authors declare no conflict of interest.

References

1 Mohapatra CS. Disability management in India-challenges and commitments. [http://www.nimhindia.org/publications/Disability%20Management.pdf].
2 Crisp R. Return to work after spinal cord injury. *J Rehabil* 1990; **56**: 28–35.
3 Krause JS. Employment after spinal cord injury. *Arch Phys Med Rehabil* 1992; **73**: 163–169.
4 Krause JS. Aging and self reported barriers to employment after spinal cord injury. *Top Spinal Cord Inj Rehabil* 2004; **6**: 102–115.
5 Krause JS, Terza JV, Saunders LL, Dismuke CE. Delayed entry into employment after spinal cord injury; factors related to time to first job. *Spinal Cord* 2010; **48**: 487–491.
6 Jang Y, Wang YH, Wang JD. Return to work after spinal cord injury in Taiwan: the contribution of functional independence. *Arch Phys Med Rehabil* 2005; **86**: 681–686.
7 Jongbloed L, Backman C, Forwell SJ, Carpenter C. Employment after spinal cord injury: the impact of government policies in Canada. *Work: J Prev Assess Rehabil* 2007; **29**: 145–154.
8 Schonherr MC, Groothoff JW, Mulder GA, Schoppen T, Eisma WH. Vocational reintegration following spinal cord injury: expectations, participation and interventions. *Spinal Cord* 2004; **42**: 177–184.
9 Awareness and Prevention [http://www.isiconline.org/aware.htm].

10 Rehabilitation of disable soldiers. [http://indianarmy.nic.in/Site/FormTemplete/frmTempSimple.aspx?MnId=YvyIq7AHP/4=&ParentID=JxuNUGCos84=].
11 Disabled soldiers learn to live. [http://living.oneindia.in/insync/disabled-indian-soldierslife-061207.html].
12 Association of people with disability. [http://www.comminit.com/en/node/124165/303].
13 Young AE, Murphy GC, Strasser RC. Rehabilitation following spinal cord injury: the facilitatory impact of the rural social setting. *J Family Studies* 2000; **6**: 231–244.
14 Environmental factors associated with employment post-SCI. [http://www.scireproject.com/rehabilitation-evidence/work-andemployment/environmental-factors-associated-employment-post-sci].
15 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**: 628–632.
16 Lysack C, Komanecky M, Kabel A, Cross K, Neufeld S. Environmental factors and their role in community integration after spinal cord injury. *Can J Occup Ther* 2007; **74**: 243–254.
17 Whiteneck G, Maede 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**: 1793–1803.
18 Hancock K, Craig A, Tennant C, Chang E. The influence of spinal cord injury on coping styles and self-perceptions- a controlled study. *Aust N Z J Psychiatry* 1993; **27**: 450–456.
19 Young W. Family and spinal cord injury. [http://www.apparelyzed.com/forums/index.php?showtopic=3154].
20 Craig A, Hancock K, Chang E, Dickson H. The effectiveness of group psychological intervention in enhancing perceptions of control following spinal cord injury. *Aust N Z J Psychiatry* 1998; **32**: 112–118.
21 Portney LG, Watkins MP. *Foundations of Clinical Research-Applications to Practice*. Appleton & Lange: Norwalk, Connecticut, 1993.
22 Paul Y. Immunization practices amongst pediatricians: a postal survey. *Indian Pediatr* 1994; **31**: 949–955 [Abstract].
23 Kapoor VK, Sikora SS, Bal S. Current practices in biliary surgery: the Indian scenario. *Indian J Gastroenterol* 1994; **13**: 49–51 [Abstract].
24 Chhabra HS. Life after SCI in India-results of a survey of 53 centres. [http://www.iscos.org.uk/abstract13.html].
25 Krause JS, Sternberg M, Maides J, Lottes S. Employment after spinal cord injury: differences related to geographic region, gender and race. *Arch Phys Med Rehabil* 1998; **79**: 615–624.
26 Radhakrishanan S, Satagopan MC, Krishnaswami KV, Tripathy SP, Vidyanathan B, Fox W. A study of accuracy and factors influencing accuracy of home addresses of patients obtained by registry clerks and address cards in 4 large towns in south India. *Tubercle* 1980; **61**: 197–206.
27 Radhakrishanan S, Satagopan MC, Krishnaswami KV, Tripathy SP, Fox W. Efficacy of address cards, experiences health visitors and motivated registry clerks in obtaining the home addresses of urban patients in south India. *Tubercle* 1979; **60**: 151–157.
28 Krishnaswami KV, Satagopan MC, Somasundaran PR, Tripathy SP, Radhakrishanan S, Fox W. An investigation of the accuracy of the home addresses given by patients in an urban community in south India. *Tubercle* 1979; **60**: 1–11.