
Spinal Cord Injury and Employment: Lived Experiences of Individuals with Paraplegia

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Abstract: *Spinal cord injury that damages the spinal cord causes loss of muscle function, sensation, or autonomic function in the body parts of a person with paraplegia. The injury affects their life physically, mentally, socially and economically. As time progresses, they should make adjustments for survival. A steady income and employment which provides self-identity are of utmost importance in this situation. But acquiring a job and maintaining it, is very difficult now, as there is competition in every field. This study explores the experiences in employment of persons with paraplegia. The study tries to explore the influencing factors that helped the individuals to continue their employment, their perceived advantages of working after becoming paraplegic and major challenges of work. The study adopted a qualitative framework. Five case studies are conducted. The findings of the study reveal that apart from financial independence, employment helps spinal cord injured persons to gain confidence, self-esteem and create a good identity for them. This improves their quality of life and increases social interactions. The study suggests that it is high time to improve the vocational rehabilitation facilities for spinal cord injury in the state and to consider their participation with improved societal and environmental development.*

Key Words: *Spinal Cord Injury, Employment for Spinal Cord Injured Persons, Paraplegia.*

1. Introduction

The term ‘Spinal Cord Injury’ (SCI) refers to damage to the spinal cord on account of trauma or from disease or degeneration that blocks communication between the brain and the body. After a spinal cord injury, a person’s sensory, motor and reflex messages are affected and not be able to get past, the damage within the spinal cord. Every year 250000-500000 people suffer

from SCI globally (WHO, 2013). SCI commonly results from a sudden, traumatic impact on the spine that fractures or dislocates vertebrae (Alizadeh, A., Dyck, S. M., and Karimi-Abdolrezaee, S., 2019). SCI can be classified as either complete or incomplete. In complete SCI, neurological assessments show no motor or sensory function below the level of injury. Incomplete spinal cord injuries are more usual than complete injuries. Over 60% of all injuries to the spinal cord are incomplete. (Sonarspine, 2016). There are three types of spinal cord injuries. They are Tetraplegia, Paraplegia and Triplegia. Higher the level of injury, greater is the paralysis and loss of body functions. About 78% of Spinal line injury patients are men (WHO, 2013). Majority of these cases are due to avoidable causes such as road traffic accidents, falls, and violence. SCI resulting into paralysis has devastating physical, mental, social, sexual and vocational consequences for the injured. However, inadequate precautions during transportation can cause further injury to the already compromised spinal cord in spinal injured patients (Burney, R. E., Waggoner, R., and Maynard, F. M. 1989).

Quality of life after a spinal cord injury depends on the way a patient learns to adapt to the fundamental changes in his life. Active involvement in activities found to be strongly related to health and wellbeing. Employment has been associated with a productive lifestyle that brings both intrinsic and extrinsic impacts. In addition to the financial burden that accompanies unemployment, life satisfaction and sense of well-being have been closely linked to occupational status (James Middleton, 2007).

2. Employment and Spinal Cord Injury

Differently abled people are a minority within the active population; intrinsically, they need organize themselves to fight for and defend their rights, including employment. Employment is viewed as among the primary indications of successful rehabilitation and the pinnacle of community integration. Considering the approximate count of 1.5 million people living with spinal cord injury in India it is very important to explore about their views on employment. Employment has psychological, social, financial, and political implications. Psychologically, employment is positively related to life satisfaction and quality of life. From a social point of view, return to figure is considered one among the foremost important outcomes of reintegration in society. With regard to overall health, those employed have been found to be behaviourally more

active, to require fewer medical treatments, to complete more years of education, to perceive themselves as having fewer problems, to report being more satisfied with their lives, and to rate their overall adjustment above those that were unemployed. Financially, employment provides a means of supporting one's self and family, facilitates access to health care services, and serves as a basis for relationships and personal identity (Meade, M. A., Lewis, A., Jackson, M. N., and Hess, D. W., 2004).

People with disabilities face non-accommodating environments, lack of opportunities and inadequate income support. Early positive expectations and motivation 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 into job reintegration (Schönherr, M. C., Groothoff, J. W., Mulder, G. A., Schoppen, T., and Eisma, W. H., 2004). Gaining employment, economic self-sufficiency and community reintegration after SCI are important to all the victims. Unorganised sectors may prove to be the most appropriate avenue of employment for individuals with disability. Unorganised sectors include self-employment or homework and organised sectors include sheltered workshops, transitory employment centres and on the job training sectors. (Mohapatra, 2004).

According to the reports of spinal cord society (1995), 68% of victims of spinal cord injuries fall in the most productive age group in India. Work after the injury is a challenging situation for these persons. Several Non-Governmental Organisations and government policies are trying to support the population with various vocational rehabilitation programs. There is extensive literature available regarding employment after SCI in most of the areas in the world but there is scant literature on India especially in the population of Kerala. Thus, this study ascertains the employment after paraplegia in five cases who are residing in Thiruvananthapuram, Kerala.

3. Methodology

The study is qualitative in nature. It was carried with five members of All Kerala Wheelchair Rights Federation (AKWRF). AKWRF is a community formed by wheel chair users to achieve the needs and rights of bedridden and wheelchair users. The Five members selected for this study are paraplegic

SCI persons who are employed in Thiruvananthapuram district. A semi structured interview guide was prepared and the participants were subjected to in-depth interview to elicit stories regarding their journey of empowerment.

4. Case Presentation

Cases (Spinal cord injured employee)	Age	Sex	Marital Status	Education	Occupation	Monthly Income in Rupees	Duration of being SCI
Case 1	38yrs	Male	Married	12 th Standard	Catering Business	30000 - 50000	15yrs
Case 2	37yrs	Male	Engaged	BA Literature	Travel agency Business	5000 – 25,000	16yrs
Case 3	40yrs	Female	Unmarried	SSLC	Handmade Jewellery Maker	3000 - 5000	26yrs
Case 4	39yrs	Female	Unmarried	Master of Computer application	IT Professional and Volunteer in NGO	30,000	11yrs
Case 5	37yrs	Male	Unmarried	SSLC	Poultry Farm	3000- 5000	17yrs

5. Discussion and Findings

The profile of the cases gives an idea about the individuals who are affected with spinal cord injury and are working. Each case has different employment and economic status. Factors like age of injury, education, family background etc. plays major roles.

5.1 Return to Work after the Injury

The ability to return to work after injury not only depends on the physical and emotional well-being but also on non-health related factors such as age, education, previous work experiences and support from close friends and

family (Kemp, B. J., and Vash, C. L., 1971). Out of the five participants only one participant returned to her former employment. Other four participants developed a new career according to their situations. The spinal cord injured persons have to pay high cost for their treatments. The treatment cost will lead to high debts in their family. Hence, they are required to find some ways of income to deal with the debts and financial needs. That plays a push factor to find creative and alternative options to find a job that can be done within their parameters. Also, employment is considered as a mark of self-respect and confidence being financially independent.

All the participants were middle aged adults. They have old aged parents and a family to support. The loss of income among people who do not return to work after a disability is a significant stress factor to the economic well-being of individuals and their families. (Krause, J. S., and Anson, C. A., 1997). They feel responsible to support their family as any able-bodied persons. Hence the responsibility to support family is a major factor to return to work.

Peer motivation and family support plays a prominent role in return to work after the injury. Connecting with new people and maintaining contacts is considered as a good motivation and development of their respective jobs. Case 3 stated *“At my difficult times my friends motivated me a lot. They scolded me for sitting idle.”* Case 2 says *“Society and family have a major role in my career. In my situation, it would be very difficult to do my business without the support of my family and friends”*. All the participants accept that family is the major supporting system in their life. All of the participants are living with their parents.

Rehabilitation is a major important part in a patient to get back into a better life after the injury. Rehabilitation helps them physically, mentally, socially and economically. All of the patients have received halfway home rehabilitation where the physical, functional, psycho-social, sexual and spiritual rehabilitation of these patients will be done. That includes psychotherapy, vocational rehabilitation, bowel and bladder control trainings etc. Here the patients will be trained so as to help them lead improved quality of life, with very less dependence on family and community (Pallium India, 2020). Case 4 said *“Rehabilitation Centre helped me a lot in gaining motivation and confidence.”*

During the rehabilitation process they talk with other persons who are suffering from SCI and they are getting more accepted into the reality. All the participants agree that rehabilitation did remarkable positive changes in them. It gave them confidence to work thus improving their quality of life. The earlier the SCI persons receive the rehabilitation, the earlier they can start building their career.

5.2 Perceived Advantages of Working after Paraplegia

Work is a core element of our physical, social, and psychological survival. It is especially important for them to attain satisfactory employment status, because their basic living costs are increased and because self-esteem and life-satisfaction may already be significantly lowered by other factors such as a negatively altered body image, a lack of mobility to perform routine tasks, and alienation from family and friends. Employment after disability marks a return to a productive rewarding lifestyle (Masry, A.T. Al-Khodairy and W.S. El, 2006). One of the participants took 18 years to get back into employment after the injury. All the participants agree that there are remarkable positive changes reflected in their lives after starting to work.

Employment results in improved quality of life. Quality-of-life is associated with meeting individual needs, controlling one's environment, and having opportunities to make choices. Employment had strong association with quality-of-life post-injury (Yasuda, S., Wehman, P., Targett, P., Cifu, D. X., and West, M., 2002). Case 2 said *"I strongly believe that the job gained me better acceptance in society and because of it I am confident to run a family of my own."* The job gave them confidence to take better decisions for themselves. All participants shared that they feel happy while working and identifying themselves as employed. They associated work with independence and saw work and the income it produced as enabling them to develop better lifestyle and support their family. Through the work the participant states that they have less economic dependency on others and are able to meet their own needs through employment.

5.3 Challenges Faced by SCI Persons in Employment

Mobility is one of the most fundamental and important characteristics of human activities as it satisfies the basic need of going from one location to the other. All of the cases reported that transportation is the one major challenge they face. Only one participant had his own private vehicle and all

the others had to depend on rented vehicle or public transportation for travelling.

Case 2 mentioned *“Trains are very difficult to travel for wheel chair persons. Flights are wheel chair friendly, but not always affordable. While travelling in train, even in AC compartments, the pathway is very narrowed and it’s very difficult to move between them. And it requires high man power to enter and exit out of the train. This makes persons in wheel chair very difficult to travel even with support of other people. In case of bus, low floored busses are available these days, but in Kerala, the number of buses is very less and are not always dependable.”*

Public transportation facilities in Kerala are mostly not wheel chair friendly. They need other’s support to travel. This is affecting their freedom to move freely without the support of other people. Travelling alone is a very difficult task for SCI in this scenario.

Case 3 added *“Here the services of low floor buses are very limited. Hence, we cannot always depend on public transportation system. Hence every time I want to hire an auto. Majority of my earnings are now spending for transportation”*. Case 1 stated *“If public transportation and accessibility is made easier in public places, people like us can be more independent.”*

Also, there is lack of ramp facilities in public areas. Case 2 said *“In many of the buildings, the ramp facilities are just shown in initial phases just to get their sanction of license. But after sometime, they are simply removed. Hence the law system must be tightened regarding this issue”*. Case 5 added *“I wish the shops had ramps so that I could go inside the shop to select necessary materials. Now mostly I am standing out of the shop to buy materials.”*

Successful reintegration, which includes return to work, is influenced by the ability of the individual to exercise control of their environment and make personal choices. Participation in community events and activities decreased post-injury, due to lack of support and assistance with transportation, finances and overcoming architectural barriers. As a result of decreased mobility and independence, social integration was negatively affected (Wehman, P., Wilson, K., Targett, P., West, M., Bricout, J., and McKinley, W., 1999).

Irrespective of qualification or company size, being disabled is a major obstacle to passing the first hurdle in being employed: i.e. selection on the basis of one's resume (Ravaljd, Madiot, and Isabelle, 1992). This study support this finding when case 4 told *“while conducting telephonic interviews, employers will be happy with our performance because it mainly evaluates about our knowledge. But while they know that we are facing some disability they tend to feel less confident in recruiting.”* This difficulty is faced when SCI job seekers go for a fresh start in new organization. Hence four of the participants chose self-earned jobs rather than working under any organization.

In many of the companies, fresher face high difficulty in convincing their employers that they are capable of their work even in Information technology field where software skills are the major job requirement. Case 1 also reported that *“At the initial period of my catering business people were doubtful if I can complete the work according to their expectations. While the conversation in telephone, they were fine to give the order. But when they find I am a wheel chair person, they were very less confident to give the work. Some of the orders were even cancelled.”*

Out of the five participants only one returned to her former job and others are self-employed. Being self-employed, the outcome varies and the income is not always stable. Case 3 reported *“the monthly income varies within Rs 3,000 to Rs 5,000 a month and sometimes there will be no income”*. There is a very high likelihood that persons with SCI are being disadvantaged at competitive paid employment, possibly leaving no option but to be self-employed with unsatisfactory income levels (Ramakrishnan, K., Loh, S. Y., and Omar, Z., 2011).

5.4 Insecurities as a SCI Woman

Both the women participants agreed that disability in women is more difficult while comparing to disability in man in the contest of societal interaction.

Case 4 added *“Being differently abled is always difficult as a woman. When we want to go out for any of our personal reason, we have to ask permission and support from others.”* This shows that dependency is more for women than men with SCI. She added that *“Even though I am financially independent I cannot make decisions of my own”*.

Due to unavailability of ramp facility and non-wheel chair friendly places, they are often required to lift and move. *“Sometimes it’s very awkward and feel insecure when strange men come and lift us. For men it may not be a problem for someone to lift and help, but for a woman it is very difficult.”*- Case 3

Back pain and other physical challenges affect their work on daily basis. Case 4 is an IT Professional. Her shift may last from 6 to 8 hours. She told *“I develop body pain while using laptop for long hours. I have to lay down occasionally hence I take breaks. For moving from chair to bed and other needs I take help from others.”* Case 3 said *“While sitting for long hours for any work, we usually develop back pain.”*

5.6 Working after Spinal Cord Injury

Only two of the participants received vocational rehabilitation after the injury. The vocational rehabilitation services used by the employed include home modification, sales opportunities, initial investment financial support, etc. Vocational counsellors involve the SCI treatment team in providing employment supports including activities such as worksite evaluations and accommodations (Ottomanelli, L., Barnett, S. D., Goetz, L. L., and Toscano, R., 2015). Hence the treatment centre has a large role in facilitating employment to the patient. Even better outcomes might be achieved with Vocational rehabilitation if it were offered sooner after injury, before social disenfranchisement and reliance on disability benefits become more ingrained.

Individual level of education has been identified previously as prognostic factor for successful RTW after SCI (Ramakrishnan, K., Mazlan, M., Julia, P. E., and Abdul Latif, L., 2011). Out of the five participants only one participant had completed education till post-graduation at the time of injury. Case 4 who is an IT employee who completed Master of Computer application said *“I strongly believe that I got to continue my job mainly because it’s a computer-based work and my education was completed. Hence education and work experience are the main positive factors for me to get back to work and for having a stable income in life.”*

This finding corresponds with previous investigations. Education is significantly related to both obtaining and sustaining employment. The high is the educational level, the more likely that individuals obtained employment, and

having secured employment they were more likely to continue working (Ghatit, A.Z., and Hanson, R.W., 1978).

Case 4 said” *I got back my job easily because I had experience for four years in the same company which I am working now. Without that experience, it must have been difficult to get a new job after the injury*”. Work experience is an important factor to have a better job after the injury. Returning to former employment is easier than seeking a new job. Experience in employment is an advantage to find job after the injury. Those participants who did not had working experience took longer years to return back to employment.

All of the participants were injured in their age between 20 and 30. Injury at their early period of life made them easier to plan their career adapting to their injury. Older age at injury is negatively correlated with post-injury employment with the 16-30 age group having the highest employment rate and the 51 to 60-year group having the lowest (Masry, 2006).

Technical knowledge and proper use of social media is helping them to find more opportunities in their work. Case 1 said *“The Facebook page and WhatsApp status provide lot of reach to my small business”*. Case 2 added, *“I can manage work independently since everything is available through internet facilities.”* Internet payment facility and online customer interaction helps them in managing most of their works independently. Knowledge of software skills and the use of social media in marketing plays a major role in career advancement.

Those living in Urban areas found it easier to do their work rather than those living in rural areas. Case 3 added that her area of residence is in a rural location and the transportation is very difficult. Case 2 is living in the middle of Thiruvananthapuram city and vehicles can reach his home without any difficulty. He considers living in city as an added advantage for the ease of his profession to reach out to his customers.

6. Suggestions

There is a need to have a barrier free environment with better public transportation facilities and ramp facilities for wheel chair persons in the state of Kerala. Strict norms and checkups need to be made for public accessed building for ramp facilities. Government should expand outreach

services for the poor and less educated SCI persons. There is a need to take measures to reduce traffic related accidents, falls and monitor safety norms in work place. Increased awareness among public regarding the first aid and emergency action to be followed soon after the accident causing the SCI. So that the effect of the injury can be reduced. Better skill training and educational programs needs to be designed and must be made easily accessible to SCI persons. In vocational rehabilitation programs and while a person tries to seek job after the injury, more emphasis can be given to community reintegration and economic self-sufficiency of the individual. Rehabilitation professionals need to find creative and practical means to remove barriers to employment considering their self-determination. There is a need to raise awareness, among employers, the public and disabled people alike, of the services and rights available to the disabled. The individual's sensory abilities and verbal interaction skill, in addition to the individual's physical abilities, can be properly utilized to identifying suitable jobs after SCI. More intervention-based studies may be undertaken to understand various interventions that can be effectively used to bring down the problems faced by SCI persons in the scenario of Kerala state.

7. Conclusion

The study explored the experience of employment in paraplegic persons. Various positive and negative experiences are explored in the study and it gives a broader and deeper knowledge about various perspectives of challenges and advantages that are experienced by employed paraplegic persons. The study concludes that employment has high impact on building self-confidence and dignity in them. It improves the social interaction and quality of lives of SCI persons. Still, they face various challenges like discrimination in work and barriers including transportation difficulties and lack of wheel chair friendly public places. The perception of society towards employment and independence for SCI persons need to be inclusive and motivating. To ensure better employment opportunities better ideas and policies need to be developed. Vocational rehabilitation facilities and its reach need to be improved in the state. Their individual interests and talents must be appreciated and supported. Building the confidence and integrating back into society must be made easier with good community participation.

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