

Barriers for Individuals with Spinal Cord Injury during Community Reintegration: A Qualitative Study

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Abstract

Background: After completing the rehabilitation services, person with Spinal Cord Injury (SCI) return the community with learned knowledge and skills of integration the livelihood situation. Centre for the rehabilitation of the paralyzed (CRP) provides three months in-patient rehabilitation services and though to be successful in leading an integrated and enabling life. As a developing nation, person with SCI in Bangladesh again enter to the community and might confronts various types of barriers and inaccessibility in their society.

Objective: This study was aimed to find out the barriers and inaccessibility during reintegration into the community among individuals with spinal cord injury in Bangladesh.

Method: Participants, who had sustained an SCI with the ages between 26 to 45 years, responded to semi-structured written questions which were categorized as one Health-related; barriers for patients with SCI inaccessibility of community reintegration; two, Mobility aids and equipment issues as barrier of inaccessibility in the community; three, Environmental issues as a barrier of inaccessibility in community reintegration; four, Barriers to transportation in community reintegration; five, Societal barriers of inaccessibility in community reintegration; six, Employment and economic barriers inaccessibility of community reintegration. A total eleven individuals were interviewed conveniently and analysed by Qualitative Content Analysis (QCA).

Results: Content was analysed by several thematic factors that based on the utmost physical, social, economic and environmental barriers. The mean age the respondents were 35.45 (\pm 7.39) years. The most prominent categories of barrier were transportation barrier (infrastructure 100%), environmental barrier (slops and stairs 90%) and socio-economical barrier (lack of acceptance & poverty both 81.8%).

Conclusion: This study comprehends the multispectral experience of barriers & inaccessibility during community reintegration of the person with SCI. They had residual disability and confronted diversity of barriers. In addition, ascertainment of these barriers will help to give emphasize on overcoming strategy of those challenges.

Keywords: Spinal cord injury; Barriers; Inaccessibility; Community reintegration

Introduction

Spinal Cord Injury (SCI) leads to long-lasting and challenging disability which leading to temporary and permanent functional impairment. Person with SCI confronted diverse types of impairments and limitation of activities after discharge [1,2] Rehabilitation is a crucial part for person with SCI to restore full physical and psychological functioning and renovating social connection in their livelihood [3-5]. Their major goal is to integrate into the society and be able to battle life situation [5]. As an acquired disability, newly injured patient experiences various types of physical, psychological [5-7] and social limitations in the community. Perhaps it occurs due to insufficient knowledge on reintegrating towards society [8,9]. In rehabilitation, Community reintegration is the key point for enhancing

proper function and improves Quality Of Life (QOL) in the society [10,11]. After completion of rehabilitation, person with SCI return to the society and experiences several forms of restriction depending on disability or injury [6,12]. Indeed, reintegration full fills social roles and attempt to adjust with social contextual factors; moreover most of the patients undergo several domain of physical and environmental restriction [2,13]. WHO revealed, disable people has the right to be integrated into community as an active and fruitful member [5,14]. There several influencing factors to interfering the inclusion features and consequences of the injury or impairment; [11,15] such as environmental factors that varies with, physical, social, attitudinal, and cultural issues [9,16]. Recently injured people are encountered with accessibility barriers through the community like other barrier as attitudinal, organizational or systemic, Architectural or physical, information or communication, and technology or technical [5,17]. The significant barriers occurs due to limited resources in the community; Hence health services, social services, independent living

services constituting mobility, physical independence, occupation are more limited. Other barriers relates with economic status, research elicited financial crisis minimizes independence [18]. During integration, the person might also be isolated from society because of physical barriers such as chronic pain, bowel-bladder problem, and comorbid conditions [7,8]. Apart from physical issues, environmental barriers have particular significance and the factors focused by several studies. In addition, manmade environmental barriers can be enlisted as inaccessible buildings, lack of slope and ramps inaccessible toilets and public transport [19-21]. Inadequate parking for person with disabilities, narrow doorways, heavy doors without automatic opening capabilities, lack of elevators, are among the most cited structural barriers for persons with SCI [22]. Adaptively with a disability is an enormous challenge after injury where attitudinal barriers included discrimination, ignorance, inferiority, stigma etc. minimized social participation [23,24]. In developing countries, Cultivation is the main source of income where their life becomes arduous due to lack of infrastructure and lack of employment facility [11,25]. If Person with SCI is unsuccessful in achieving adjustment with community reintegration after discharge from institute based rehabilitation, there is a greater chance of experiencing psychological disturbance as depression and anxiety [5,7,26,27]. Other study reported that person with SCI were unemployed and unable to leave from poverty after discharge from rehabilitation centre. Maintain proper health condition, social and mental well-being is essential for minimizing barriers and progress quality of life [28-30]. The purpose of this study was to determine the barriers and why that person has been encountered by individuals with SCI when they attempt to reintegrate into their community.

Materials and Methods

Study design, study site and setting

The study was design by a qualitative approach. Qualitative research is exploratory in nature by which the researcher can gain insights into another person's view's, opinion, feeling and beliefs within their own natural setting [31]. The site of the study was in the community setting in several districts of Bangladesh where patients discharged from the Centre for the Rehabilitation of the Paralysed (CRP). In 1979, CRP was established and the organization emphasized on a holistic approach to Rehabilitation and Community integration for people with disabilities.

Study period

The study was accomplished from May 2017 to December 2017.

Study population

A total eleven participants with SCI were introduced by convenient sampling technique. Inclusion criteria were age between 25-45 years, SCI persons who have already completed their rehabilitation from CRP and at least 2 months resided in the community, both paraplegic and tetraplegia patient, neurological level is complete and incomplete (ASIA scale A-E), assessment ranging from C5 to L2 and both male and female patient has been chosen as participants.

Data collection tool and procedure of data collection

The data were collected by face to face interview with an open-ended questionnaire. Informed consent was taken from the participants. All question and information sheet were developed into

Bangla. The interview was conducted in Bengali language and recorded by the recorder of a mobile phone. Venue of an interview were the community where the persons with spinal cord injury deal with their family but the place of interview depended on situation and permission of regarding the authority. The data has been taken until similar assessors were obtained as a maximum response as repetition.

Data analysis

The data were evaluated by Qualitative content analysis (QCA) and 3 stages: coding, categorizing and generating theme. The researchers were arranging all the information according to the categorization. Under these categories, the researcher coded all the information from the interviewed transcript. After finishing the tabulation of coding, the researcher detected some important codes that made the themes of the study. At last, themes were identified and emerged as a process of interpretation.

Ethical consideration

The study was approved by the Institutional Review Board (IRB) of Bangladesh Health Profession Institute (BHPI). All study personnel were certified in and the study protocol confirmed to the ethical guidelines of the IRB of BHPI and followed the World Health Organization (WHO) & Bangladesh Medical Research Council (BMRC) guideline. The respondents were clearly informed about the aim and objectives of the study. After that, they were interviewed following signing the consent form and informed that they have full right to discontinue their participation anytime they wish. Also confidentiality has been maintained and assured to participants.

Results

Variables	Frequency (n)	Percentage (%)
	Age group [Mean age 35.45 (± 7.39)]	
26-30	5	50.25
31-35	3	29.5
36-40	2	15.15
41-45	1	5.1
Sex		
Male	9	81.8
Female	2	18.1
Marital status		
Married	5	45.4
Unmarried	5	45.4
Divorce	1	9.09
Family type		
Nuclear family	6	54.5
Extended family	5	45.4
Residential area		

Rural	8	72.7
Urban	3	27.2
Educational status		
Primary certificate school	5	45.4
Secondary certificate school	5	45.4
Higher certificates school	1	9.09
Occupation		
Service holder	1	9.09
Unemployment	5	45.4
Business	2	18.1
Housewife	2	18.1
Earning member		
Own	3	27.2
Husband	2	18.1
Wife	1	9.09
Others	5	45.4
Average family income		
5000-20000	8	72.7
21000-35000	2	18.1
36000-50000	1	9.09
Participant's injury-related information-Etiology		
Road traffic accident	5	45.4
Fall from height	3	27.2
Fall of overload	2	18.1
Shallow driving	1	9.09
Skeletal level of injury		
Cervical	2	18.1
Thoracic	4	36.3
Lumbar	5	45.4
Impairment according to ASIA scale		
Complete A	7	63.3
Incomplete B	2	18.1
Incomplete C	1	9.09
Incomplete D	1	9.09
Diagnosis		
Tetraplegia	3	27.2

Paraplegia	8	72.7
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Table 1: Socio-demographic and health-related in the information of the participants Frequency (n) Percentage (%).

The study population had mean age of 35.45 (\pm 7.39), and around 81.8% of the participants enrolled participants were male and 18.1% were female. Average 54.4% belonged nuclear family, 45.4% were unemployed. While in earning status, 45% depended on others. Road Traffic Accident were main leading cause for SCI constituting approximately 45%, About 63.3% showed complete A lesion, 72.2% reported paraplegic as they were the highest participants attended in this study (Table 1).

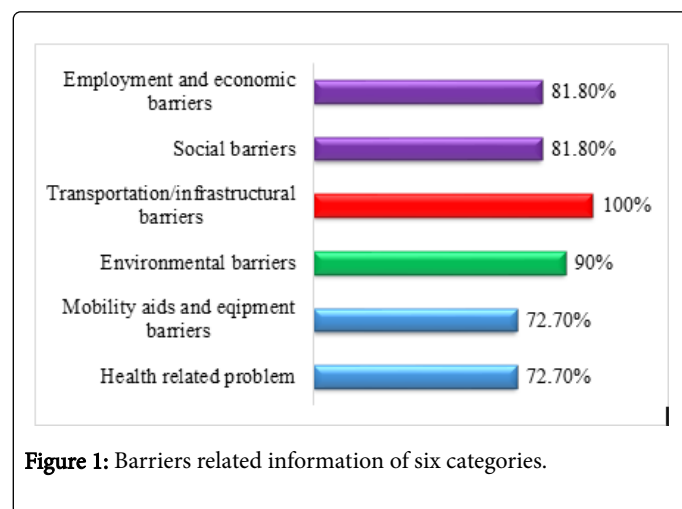


Figure 1: Barriers related information of six categories.

Categories emerged from data analysis. Each category was further divided into several subcategories specific to the single problem domain. The six major categories of barriers included Health-related barriers, Mobility aids and equipment issues, Environmental barriers, transportation barriers, social barriers, Employment and economic barriers. These are reported through Figure 1.

In Category-1, Health-related issues were reported from medical complications, pain (72.7%), bowel bladder difficulties (72.7%), spasticity (45.4%), Weakness & Balance problem (36.3%), swelling of leg (9.09%) and Depression (63.6%) were health-related barriers. Moreover, pain and bowel & bladder problem were the most common barriers. As Category-2, Mobility aids and equipment issues was certain barrier of inaccessibility in community. The category includes Lack of assistance (72.7%), crowded place (27.2%), no problem with mobility aids (18.1%), no mobility aids (9.09%), and Equipment issues (72.7%). In the community, participants couldn't properly participate in social program or daily activities because of inadequate assistance lacking and scarcity adjustable equipment as a result, both were most common barrier reported in this category. Category-3: Environmental barriers were related to uneven road (81.8%), narrow and muddy road (27.2%), Slops and stairs (90.0%). Category-4, transportation is the key factor for SCI patients. The study revealed that, all of the patients had infrastructural problem in accessibility were (100%) neglected (27.2%). Study explored in Category-5, societal barrier found to be a cause of inaccessibility. For SCI person it is hard to accept incidence and, adjust with the new environment with a wheelchair. Lack of social acceptance (81.8%) is the most related factors of barriers for inaccessibility of community reintegration. The Negative perception (18.1%) and

negligence (54.5%) was other barrier. Category-6 reveals employment and economic barriers are reasons to inaccessibility in community reintegration. In the economic aspect, poverty and unemployment were the most common barriers addressed by the respondents that were respectively 81.8% and 54.5%.

Discussion

The study focused on the findings related to barriers in a community where persons with SCI living after discharge from institute based rehabilitation. The objective of this research was to determine which physical, social, and/or emotional and environmental issues are responsible for barriers that interfering community reintegration.

Theme-1

Pain and bowel- bladder problem is the most common health-related problem experienced as barriers causing inaccessibility in community reintegration to the community.

From the transcripts, among eleven participants, eight of them reported pain, incontinence and bowel bladder were the main problems, six participants had spasticity, four participants had weakness and balance problem, one participant had swelling in the ankle that create restriction to access in the community and seven participants had depression about access in the community reintegration as residual problem [27].

One participant said that, *"I have a frequent problem with pain & incontinence, bowel bladder also a reason that's why I do not want to participate. I always fear because when I want to go to another house, where to do the toilet?"* [16].

Another one participant said that- *"There is more inflammation in my hands and legs that I cannot sit in a wheelchair more than 2 hours. Again defecation-urination also problem, I have no sensation of it for these I cannot go to the community."*

About bowel bladder incontinence one participant said that- *"when I am in a meeting and need to do defecation & catheterization, there were too many crowds and I am unable to do my catheterization as well as defecation properly then my cloth becomes a spoil, I think it is one kind of barriers in the community"*.

Literature revealed that persons with SCI describe the pain were the most critical medical condition to deal with, 71% have reported that pain interfered with daily activities [9,15,32] Another study reported that 18% of individuals did not return to work following an SCI because of pain [33]. Bowel dysfunction is a significant consequence of spinal cord injury SCI and it may impact on quality of life [34].

Seven Participants said that they are mentally depressed down & feelings discomfort after SCI, they feel no interest to participate with community people.

One participant said that- *"Yes, depression creates some barrier. I always ask myself that am I able to walk again? After that I know I cannot"* [27].

Study also reveals that depression leads to disengagement during the transition of home and that isolating themselves at home [35]. Depression is lined to poor community mobility, poor community integration, and fewer meaningful social pursuits [5,15,36].

Theme-2

Lack of assistance and equipment issues are the most encountering problem of mobility that creates barriers of inaccessibility in the community.

About seven of the participants said that lack of assistance and equipment support is the most encountering problem of mobility that creates barriers during community reintegration.

One participant said that *"I could not propel the wheelchair. If I hire assistance to propel then I could be able to participate in the community."* He also said, *"I had no assistance for using a catheter, I have a bowel-bladder problem so without using catheter I could not go to the community."* [7].

Literature explored 14.4% of individuals with SCI need assistance at home. Lack of assistance or support and accessibility have been identified as barriers for people with SCI in carry out their activities of daily living [2,8]. One participant said that *"Transport system is not well enough. I can't go alone because of I afraid if I fall down"* [20].

Another patient said that- *"I need assistance. Mobility aids creates a problem because I need another person's help. Whom I want to take with me he may have his important work to do"* [22].

Two participants also said that they cannot maintain a wheelchair in a crowded place. One of them said, *"In Durga Puja (religious matter), it has too much crowd that's why I cannot participate in my worship because wheelchair not accessible to that place"* [21].

Study revealed that- assistance is needed among most of the participants with SCI in community reintegration [12,37]. Mobility issues, which include transfers and balance, were the most commonly reported physical limitations in the study [8,38].

Theme-3

Inaccessible environmental structure/slopes and stairs are the vital factors as barrier.

In environmental barriers, 80% of the participants said that they faced barriers with slops and stairs, the problem with uneven road and few participants said their problem with the narrow and muddy road. This finding is similar to other studies of Barclay et al. *"Almost all participants described situations, where they were restricted from participation in activities as they wanted due to manmade barriers"* [35,39].

A participant said that- *"when I want to visit my neighbour's house I have faced accessibility difficulties like they use stairs but my wheelchair has not to access them"* [22].

Another participant said that- *"In the case of accessing in the house or buildings in the community, the main barriers are stairs. The wheelchair has no access on the stairs, it is better to have a ramp"*.

According to WHO, for adults with SCI, leaving the rehabilitation hospital may be difficult if their accommodation has barriers such as stairs, small bathrooms and inaccessible kitchens which in effect make them *"prisoners in their own homes"* [40].

Eight participants mentioned that the uneven road is another encountering barrier to access in the community. One participates state that *"sometimes the roads are unconstructed, that the roads are not flat. There are many jig-jack places in roads. For this reason, I can't go to the community alone"* [22].

One participant said that, *“the narrow and muddy road also a barrier to access in the community with mobility aids”*[21]. So it can be easily conclude that inaccessible environmental structure/slopes and stairs are the vital factors for barrier in the community.

Evidence shows that *“In a rural area of Asia, many persons with disability live in remote area where subsistence farming is the primary source of income, limited road access and inaccessible housing are often barriers to those using mobility devices”*[25].

Theme-4

Inaccessible public transport due to its enabling structure is one of the barriers in the community reintegration.

Eleven participants stated that they have a severe problem in access to vehicles due to its structure. Two participants said that they become negligence when they want to access to the vehicles and two participants said that they don't get opportunities to sit in the bus where have reserve seat for them. One participant said that- *“Transports is a biggest barrier. I can't go anyplace. If I need to go anywhere I need to rent a private car. Nobody give the chance to get up the bus. If I say I want to go with pay but they don't allow getting up into the bus. One participant stated that, “I was standing in bus, nobody is ready to give me the chance to sit. I would go there by rickshaw. That vehicle has opportunities of sitting but getting on it is difficult”*[20].

Literature showed that mobility and equipment issues including transportation are 23% all of the barriers in the community reintegration in people with SCI [25]. In transportation, Access with wheelchair is the most common barrier (22.54%) [8,39]. Dwyer & Mulligan stated that, *“Inaccessible housing and transportation particularly compared to the hospital or spinal unit was identified as a barrier in community reintegration”*[41].

Theme-5

Lack of social acceptance is the most related factors of barriers inaccessibility of community reintegration.

In this study, eight participants said that, they feel isolation from society after spinal cord injury that is one of the big barriers to access in the community. Again, six participants said, they become highly negligence by the persons of society, four participants become a victim of criticism and two participants report for the negative perception of the community, only three participants get supportive environment from the community.

Babamohamadi et al. stated the similar findings, there is lack of social acceptance and support was one of the most important barriers to coping with SCI” [26]. One participant said, *“I felt social isolation because people talked about me, they told me that I am a curse.”* Another participant stated that *“At once I get honour from society when I was well. But now I lost that position because I am not like them. I can't do anything like others”*[5].

This statement reflected that the lack of social acceptance is the most relevant factors of barriers in community reintegration. Where social acceptance is one of the most important variables. The scene of the literature said that the physical environment, unsupportive social attitudes and mental health issues were identified as barriers to community participation [33].

Theme-6

In an economical aspect, poverty is one of the barriers of accessibility.

An inadequate financial resource to enable in the community reintegration was identified by most of the participants. In this study eight participants reported, poverty was the barrier in community reintegration, six participants said that lack of employment opportunities was a barrier to access in the community, four participants have employment opportunities among them two are willingly unemployed. Only one participant had economical solvency. In the reflection of the question, *“Is it (financial problem) barrier in the community reintegration after disability?”* One participant said that- *“Of Course, because I have no income. I cannot found anyone who can help me with money. At present, it is about impossible for me to maintain my family expense because of this financial problem”*.

In accordance of literature, when a family is fully depending on the SCI persons and he is the main source of income then there is a serious economic hardship experienced by the family [42]. Six participants said that lack of employment opportunities is a barrier to access in the community reintegration. One participant stated that- *“When I was employed every day I could go to the roadside. But now I have no job, for this reason, I can't go anyplace”*[41].

Research reveals employment and income are two important elements which determine the standard of living for an individual. Employment can provide confidence to a person and assurance to live with dignity and independence.

Conclusion

Spinal cord injured people experience barriers in community reintegration phase this study, identifies issues confronting barriers in terms of physical, mental, mobility and equipment issues, environmental, social and economic aspects. Although SCI causes a residual disability to a person they can be reintegrated if the barriers in accessibility identified and resolution occurs on the basis of severity. So, emphasizing on overcoming strategy of these challenges can improve the level of integration towards community.

Limitation of the Study

This study does not represent the overall image of Bangladesh in respect. The number of participant was limited and the result might not be generalized.

Recommendations

It is recommended to do further research on large group of people in both qualitative and find out the solution to overcome of barriers inaccessibility faced by SCI patients in presuming their community living.

Conflicts of Interest

Authors declare there is no conflict of interest.

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