

Perspective of SCI Patient on Half Way Hostel as Training for Community Integration at CRP

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Abstract:

Purpose of the study: The purpose of the study to explore the perspective of SCL patient on half way hostel as training for community integration at CRP. **Specific objective of the study:** To explore patients view about community integration, know their needs for successful community integration from their point of view, explore their view about half way hostel does it help them or not to integrate the community, explore the good side and the bad side of half way hostel from their point of view, explore any recommendations from them to make it an important part for community integration. **Methodology:** A qualitative study was selected to explore different perspective of SCL patient about the training of half way hostel. A semi-structured face to face interview was conducted to collect the data. **Samples:** Convenience sampling method was choose to select the samples. Six participants were allowed to include in this study considering specific criteria of the sample. Five of them were male and one was female. **Setting:** participants own home (Naturalistic setting). **Result:** After analyzing and coding of data, five main themes were identified. These were: Positive attitudes of others contribute to client satisfaction, Functional independence depends upon training in simulated situation, Physical capability affects better integration, Recreation ensure better participation, Patient will get benefit from well-arranged environment of half way hostel.

Key words: Perspective, SCL, Half way Hostel, CRP, Community integration.

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Introduction:

Bangladesh is a South Asian country and is considered to be one of the least developed countries in the world. According to world health organization (WHO) statistics, 10% of the total populations of developing countries are disabled and Bangladesh appears to be no exception. Among this 10%, 4.6% are spinal cord injuries (Board of Bangladesh statistics, 1996). People with disabilities in Bangladesh are among the most vulnerable, neglected and deprived segments of the population, as those are in the other developing countries. For this reasons community integration is very important in Bangladesh. Whether or not we have a disability, we will never fully achieve our goals until we establish a culture that focuses the full force of science and democracy on he systematic empowerment of every one to live to his or her full potential (Dart, J.2001).

The centre for the rehabilitation of the paralyzed (CRP) is a non-government organization (NGO), which treats and Rehabilitate paralyzed people through improving the quality of life of disabled people in Bangladesh. Training at the half way hostel is a part of the rehabilitation program of centre for the rehabilitation of the paralyzed. The half way hostel was developed to replicate a rural environment in order to facilitate reintegration into own family and community life post discharge (Thomas, et al. 1999).

The main aim of the rehabilitations program at CRP is to ensure that a person with a disability is integrated

successfully into their own community (whybroe and salam.2001).

The purpose of this study is to explore spinal cord lesion patient's perspectives on how the half way hostel prepared them for the community.

Through spinal cord lesion is one of the major catastrophic health problem in Bangladesh with the high rates of morbidity and mortality, no survey was conducted by any organization to find out the number of spinal cord lesion patient in Bangladesh. Therefore no data was found to accurately identify this number.

Most of SCL patient are from very poor socio-economic status and sometimes they are the only earning members of their family. Results of SCL have a major economic and social impact both on the patient's life including physical, behavioral, psychological and social functioning (Unalan et al, 2001). A study commissioned by DFID- Bangladesh in 1999 about the impact evaluation of the centre for the Rehabilitation of the Paralyzed (CRP) revealed that 75% of CRP client were from poor socioeconomic condition (Thomas et al, 1999). But they are not getting proper treatment and Rehab facilities for integration, which makes them a burden for society.

An epidemiological study conducted by Hoque, et al., (1999) showed that the most common traumatic and non-traumatic cause in Bangladesh are fall from height 43%, Falling while carrying a heavy load on head 20% Road traffic accident 18% and Stab, Sport and bullet injury is

6%. Similarly non traumatic cause included Potts Disease 28%, spinal Tumor 21%, Transverse Myelitis 10% and GBS 6%.

The male and female ratio is 7.5:1.0 and common age group between 10-40 which is similar to that reported from Jordan and Thailand (Hoque, et al., 1999). In developed countries the major cause are motor accidents (over 38%), accident that occur during sports or physical activities, fall and trauma during violent crimes (Apple D.F & M.D. Jr, 1996). However virus and viral infections (Such as transverse Myelitis), Cysts and tumor on or near the spinal cord can cause permanent damage of the cord leading to progressive paralysis (Gatehouse M, 1995). In Japan fall from height is the most common cause of traumatic SCL, 43% of them are fall from height, 18% RTA. In India fall from height 55%, 13% RTA (Hoque, et al, 1999).

When a person with spinal cord lesion is referred to CRP the centers approach is to provide treatment and rehabilitation to the whole person. Its focus is a person's whole life from the day they enter the centre to the last day of that person's life. A person with spinal cord lesion stays, on average four month at the hospital under the facilitation of a multidisciplinary team (Momin, 2001).

Half Way Hostel

In the reintegration stage the person stays in the half way hostel for one or two months (Kulsum, 2001). The half way hostel is a model on a traditional Bangladeshi village.

The purpose of the half way Hostel:

The purpose of the half way hostel is to build the confidence of the SCL person and their family member so that when they are home then they can manage themselves without the support of professionals.

Aims and philosophy of the hostel setup:

- To create an environmental similar to the client's home situation.
- To encourage independence in all activities of daily living (ADL).
- To encourage the family to be involved in the final stage or rehabilitation including the client's return home.
- To offer ongoing support to clients and their families.
- To look closely at how the client and his/her family will manage in the home environment.
- To identify any problem for the client and his/her family.
- To identify the need for equipment and/or adaptations to the home and/or work environment.
- To enable successful integration back into the client's original environment by offering continuing support. (Azad, 2001).

Perspective can be defined from different view. From position view perspective is a way regarding situation topics etc. consider what follows from the positivist

views and perspective from liner views "the appearance of things relative to one another as determine by their distance from the viewer (Internet).

According to wehmeier, (1997) "perspective is the way that you think about your point of view" It can also be defined as "ability to see, hear, or understand, quality of understanding, way of seeing or understanding (Oxford advanced learner dictionary, 1994)". The word perspective has a depth meaning and the participant would express their perception about half way hostel and integration. In this research the participant will express their perspective about training of half way hostel.

The importance of knowing the patient perspective:

The researcher wants to explore the perspective of SCL patient towards the community integration and training that they have done at half way hostel because the people with SCL have had very limited opportunity to share their views as research questions were invariably structured, and a quantitative research approach was frequently adopted (Thomas, et al, 1999).

There is the current focus upon client centered practice: collaborative and partnership approaches to practice that encourage client autonomy, choice, and control, and that respect clients abilities and supports their rights to enact those choices (Canadian Association o Occupational Therapists, 1997, Cited in Hammell,1991). Chowdhury and Rahman, (2001) mentioned that much of the success in the rehabilitation program lies in patient's relationship with their physicians, nurses, physiotherapists, Occupational therapists etc. So the patient is a very important part of the rehabilitation process. They have the authority to make choice in treatment. Patients are not passive consumer but active agents on their own behalf in fact. According to Sen Amartyas (1995) cited in Tareque (2002) "to see them as patient rather than agents can undermine the exercise, not to focus on the fact that they think, choose, act and respond, is to miss some thing terribly crucial.

It is very important to know the client perspective towards community integration because in Bangladesh there is a belief that disable people are invalid, inactive and useless. He/she loses her working ability and productivity. As a consequence of this he/she is pushed aside from mainstream activities and economically excluded. This exclusion is not only a problem for an individual, but for the whole families of a disabled person as they suffer as well as the community (Momin, 2001).

Also they are random selected for political offices and are in general, excluded from planning and decision making in their society (Abang, 1998). It is very important to include them in every aspect of society and also give them the authority to take decisions about their own life. According to Rahaman, (2001) community based rehabilitation will not be successful if all the communities and disabled people themselves are fully involved in the program design and implementation. So

the patient's perspective is important to set up an effective rehabilitation program to integrate them successfully in the community.

So community integration means bringing someone to their own community where they were in the past and where they can work/function harmoniously.

Gordon and Brown (2003) stated "Community integration refers exclusively to non-institutional living, so that the focus is solely on people with SCL who are living in non-medical, non-custodial setting". Community integration encompasses the basic of life "where one lives and what one does within the social-physical context of living defining characteristics. Integration into the community, at the very least, requires living in a residence that supports and hopefully, encourages and individual to interact fully with the community (Gordon and Brown, 2003).

Methodology:

The aim of the study was to explore the spinal cord lesion patient's perspective on how the halfway hostel prepares them for the community. A qualitative approach and semi-structured face-to-face interview was appropriate to explore the client's perspective. Qualitative methods are appropriate where the research question requires patients to understand or describe a phenomenon about which little is known, when seeking to know the point of view of the study participant (Bogdan & Biklen, 1998 cited in Hammell, et al. 2000).

In qualitative research the researcher selects people who were likely to increase understanding of the research topic (Hammell, et al. 2000). Participant for the study was selected by using convenient sampling method. All the participants were selected from the ex-patients of CRP and who had completed rehabilitation program (Integration training at halfway hostel) at CRP. So they could express their opinions, feelings and experiences about the training at halfway hostel. The participant number was six. A qualitative methodology is also appropriate when there are only a small number of potential study participants (Krefting, 1989 cited in Hammell, et al. 2000).

Data collection method:

A tape recorder was used to record the conversation and discussion of the participant and interviewer. Pen and papers were used simultaneously to accumulate field notes.

"Tape recorder had used for full transcript of interview and accessibility of independent analysis" (Polgar, S. & Thomas, S. A. 1991). If the participant did not allow the use of tape recorder, or feels any discomfort then the tape recorder would stop being used.

Data was collected using semi-structure face to face interview. The aim of the study was to explore the individual patient's perspective and experience, so it was

appropriate to use semi-structured interview. Semi-structured interviews it easier to guide the interview, without fixed ordering of the questions (Minichiello, et al. 1997). As it was face to face it also allows the observation of body language and makes qualitative research so valuable (Morse & Field, 1995). The researcher with her colleague went the participants own home to take the interview. Before went home they was informed about the interview and was asked for a suitable time for an interview. Prior to the interview the participant was given a consent form and took signature on that form. The participant was informed clearly that their speech might be published but their personal identity was kept confidential. The researcher was assured the participants that the study wouldn't be harmful for them to participate in the interview.

After transcribing the entire interview the data was organized according to the interview questions. The entire transcript was read several times by the researcher to get inside the data, to find out what the participants actually wanted to say and to discover recurring themes, which stand out. Once the data was completely familiar than the data analysis was commenced. Data analysis is the process of systematically arranging and presenting information in order to research for ideas (Minichiello, V. et al, 1997). In the second step of analysis general themes were discovered through interpretation of the findings.

Results and Discussion:

1. Positive attitude of others contributes to client satisfaction

All the participant was satisfied with the behavior of therapists and doctors. If a person gets a SCL usually he/she is very depressed and it is difficult to cope with the impairment. So when the person experiences a positive approach from others especially the medical personnel, which make them inspite to work within the ability that they have. One participant "*when I went to CRP I was very depressed but after talking with therapists, doctors and other personnel I got inspiration to live*". As this participant experience positive attitude and care he was satisfied in spine of his impairment. Literature support that negative attitudes had significant adverse effect on the mental and emotional status of the disabled people (Zaman, et al, 2001).

Supportive environment

The environment of CRP was accessible and staffs were helpful to them. They also came in contact with people in a similar situation, which reduced their depression help to cope with their impairment. When they were in a group they felt encouragement to think that it was possible to do something by them.

Family and social support: Family and social support is very important for every person with impairment. When they return home most of them have some physical impairment. So they need family support to work with

their impairment. Those participants got proper family support they are more independent and satisfied in spite of impairment.

2. Functional independence depends upon training in simulated situations.

They need some training and guidelines, which makes them independent according to their ability. The training will be effective if the nature and environment of the training is similar to their home. One participant said *"as I have to spend rest of my life at my own home not at hospital, they trained me how to compensate within home environment and for this reason I am satisfied"*. At the half way hostel they got simulated situation to their home environment so that they learn to cope with their own environment and became independent as much as possible.

Simulated situation motivates them to train properly

This simulated situation makes them motivated about the training. Most of the participants were from village and they needed to know how to walk or move on rough surface. So when they were proposed to practice walking on rough surface then they could understand its importance which made them motivated to take training which help to cope with home environment and made them independent.

Once research has done in Thailand by Pisak, et al (2003) they found that better functional performance at hospital than at home, this could be explained by the different environment between these two places.

3. Physical capability affects better integration

Successful integration, depends on different things, physical ability is major one. Most of the participants have shown priority on physical capability to integrate at the community. As usual the family people through that they have no ability to work. So they need to show that they have the ability and to prove it they need physical ability.

4. Recreation ensures better participation

Recreation is an important and essential aspect of life. Whether the person is able or disable. It plays an important role in people with disabilities or impairment. Usually a person becomes depressed after impairment. They may always in depress mood and don't want to talk with others. Any kind of recreational activities can play an important role addressing this situation. All the participants of this study, shown importance of recreational activities on their life. At half way hostel all has gotten equal change to involve any recreation activities, which make them inspired to work. When they worked with recreation, they didn't get the time to feel alone.

5. Patient will get more benefit from well-arranged environment of half way hostel

Most of the participant though that they would get more benefit if some changes occur at half way hostel. All the

participants were shown satisfaction towards the environment of half way hostel but some of them reported some bad experiences. One of them could not move around the tube well as that place was slippery. One participant recommended about neat and cleanness. He said, *"Half way hostel has done its best for us but some place was slippery so that I could not walk"*.

The aim of half way hostel is to produce simulated situation to the participant to make them prepare about home environment. The facilities of half way hostel meet the demand of patient who was from rural area rather than from town or higher-class status.

Limitation and barriers:

- The study topic was new; therefore it was difficult to find appropriate information and literature on this.

It was the first attempt for the researcher doing a research.

- Convenient samplings were used as it was easy for the Researcher.
- The research paper is written in English but the researcher and the participant's mother language was Bengali so it was difficult to express some of the point accurately in English.
- The Researcher didn't do the pilot study.

Recommendation:

- The training provider or professionals should give priority to physical integration.
- Should continue the recreational activities, which affect very positively on the trainees.
- Should think about some higher facilities, which will improve acceptance of training for those from higher-class status.
- More work is required to change the existing attitude of family and society towards disabled.
- Appropriate steps should be taken for keeping the environment clean, especially from mosquitoes and accessible for all i.e. floors are dry not slippery.
- Further research should be done with a large number of samples and also with the female participants to explore that whether this hostel is appropriate for them or not.

Conclusion:

CRP has arranged a residential procedure of half way hostel for community integration so people with SCL got the change to get preparation for their home environment. Clients are satisfied with the training as this training made them independence according to their capability. Family support is very important things for integration. The professional should give more attention on physical integration, which will help to integrate at the community. They were also pleased with the care and attitude of the medical person. From this study some

important information has emerged which should analyzed by the authority and medical personnel to make it more effective for clients.

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