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The perception of people with spinal cord injury on modified home environment

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Abstract

SCI is a life-threatening condition that creates so many dysfunctions in an individual's life such as unique personal, family, and community challenges in activities of daily living return to previous work, and modification of home and vicinity. An accessible home and environmental modification allow for free and safe movement, function, and access for SCI. The study followed the interactive approach of qualitative design to search for the Impact of the modified home environment. 10 (ten) participants (5 were male and 5 were female) were selected for in-depth interviews. The objective of the study to identify the client's view on home environment modification is important to ensure better health and an accessible home environment. In this research, The mean age of participants was 35 years, and Std. Deviation ± 14 whereas the male and female ratio was 1:1. According to selected inclusion and exclusion criteria. Especially, 50% removed barriers from in front of the kitchen, 60% leveled uneven in-front yard 40% of the participant had accessible job settings. A modified home environment allows free mobility for individuals with SCI, 80% of participants had a positive perception on reduce independency, 70% of participants got self-independence in functional tasks, and had improved social relationships. Overall more than 70% of participants reported that a modified home environment has a vital role to lead a quality and meaningful life. An accessible home environment initiative for the individual with SCI can enhance the functional status of the community. In Bangladesh, both Government and Non-Government Organizations could ahead to take effective measures for further action in all aspects of SCI rehabilitation in the community.

Keywords: Perception; Spinal Cord Injury; Home Environment; Modification

1. Introduction

Spinal cord injury (SCI) is a major burning issue in the concern of health sector. Gradually the burden of SCI is going to increase and the vulnerable impacts are focused on the family and social life of an individual. SCI is a life-threatening condition that creates so many dysfunctions in an individual's life. There is a diversity of issues faced by people with SCI associated with unique personal, family, and community challenges in activities of daily living, return to previous work, and modification of their home and vicinity [1]. Most of the cases are shows dependency on social people and an accessible environment. Moreover, an inaccessible environment makes to create limited movements which disallow communication intra and inter-environment. Literature has shown that accessible home and environmental modification allows for free and safe movement, function, and access for SCI regardless of age, sex, or condition making access by all [2]. Home modifications are adaptations to living environments intended to increase usage, safety, security,

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and independence for the SCI. However, in developing countries like Bangladesh individuals with SCI are facing difficulties regarding modification where life is also difficult for able bodies, the people with disabilities have experienced a great magnitude of the problem [1].

In the recent context, people with disabilities need appropriate modification of their home and environment which ensures they lead a quality of life in society. It has been counted by research that disabled people are among the poorest of the poor in Bangladesh [3]. As there are no social security benefits for disabled people, and no financial help to compensate for the additional costs of living with impairments as required to home modification, treatment costs, and daily living expenses adjustment [1]. But things are changing as disability activists have pushed to open up access to all people, including those with spinal cord injury, paralysis, or mobility problems [4]. In our country, it is not easy to promote an accessible society for people with SCI where still today we could not make uniform rights for people with disabilities. It assumes that this research helped to identify the importance and impacts of the modified home environment for individuals with SCI.

2. Material and Methods

The study followed the interactive approach of qualitative design to identify the client's view on home environment modification is important to ensure better health and an accessible home environment for exploring the client on own views, and expectations of the modified home environment. The data were collected from 10 community areas of Bangladesh such as Ashulia, Lakshipur, Savar, Magura Sadar, Gazipur Sadar, etc. The inclusion criteria were both males and females with Spinal cord injury patients with home modification and who were living in the community and urban area. The exclusion criteria were Spinal cord injury patients who had no home modification. 10 participants participated in this study. Following the individual having phone calls and informed consent the participant interview was conducted. In-depth interviews were undertaken by using an open-ended questionnaire as well as a checklist for the study. The majority of interviews occurred in the participants' homes (some occasions needed in respective workplaces). Every participant was informed and explained about the study's purpose and its benefits and written consent was taken with the undersigned by the participants. Ethical clearance and permission were taken from the Institutional Review Board (IRB), BHPI, and Centre for the Rehabilitation of the Paralysed (CRP) according to the ethical committee guidelines before conducting this research. Initially, raw data had screened by the researcher with cross-checked for measuring the validity of the data. The collected information continued analyzed, edited, summarized, and sorted. Finally, content analysis and thematic discussion were used to present the data.

3. Results

The result and discussion of this study were carried out at the same time and presented together. In this research, 10 (ten) participants (5 were male and 5 were female) were selected for an in-depth interview. The mean age of participants was 35 years and Std. Deviation ± 14 whereas the male and female ratio was 1:1. According to selected inclusion and exclusion criteria, most samples (seven out of ten) were recruited from different villages, and less than one-third of samples were from urban. Based on multiple responses, all ten participants modified their living room, toilet, bathroom, and kitchen. Especially, half of the ten participants (five) removed the barriers from the kitchen; more than half (six participants) leveled uneven yards and more than one-third (four participants) had accessible job settings. Data were screened several times from in-depth interviews and transcripts. Finally, the following four themes were come out from data coding.

3.1. Themes

- Quality functions were performed by SCI patients due to proper home modification
- The positive impact regarding social relationship and functional capabilities were developed after the home modification
- The disadvantages of home modifications were overcome by family members and relatives due to the good advantages
- Home modification played a vital role in SCI patients incorporating into a social rehabilitation

3.2. Quality functions were performed by SCI patients due to proper home modification.

Quality depends on the quality of work. Similarly, home modification is one of the quality works for Spinal Cord Injury patients to restore function as well as self-independent. A high level of self-confidence was grown among participants as normal during involvement with functional activities. All participants had multiple responses.

Table 1 Quality functional care

| Categories of modifications | Frequency (n) | Percentages (%) |
|--|---------------|-----------------|
| Reduce dependency | 8 | 80 |
| Improvement of functional capabilities | 7 | 70 |
| Enhance domestic functions | 6 | 60 |
| Re-establishment of job | 4 | 40 |

Above mentioned table described the importance of home modification by 10 participants to SCI patients. Among the respondents, a maximum of participants (eight out of ten) had given their heartiest opinion that home modification reduced their dependency on functional care, and most (seven out of ten) also emphasized on improvement of functional capabilities, and just above one-third participants were entitled to re-establishment of job.

One participant told that *"It is not easy to always get a caregiver beside you as everyone has their work and interest, so as an individual with SCI I think the modified home environment is very much important for me as it allows me to lead an independent life and now, I can manage my functional self-care"*.

One participant told that *"Now I am very pleased that I was able to modify my home environment, after these modifications I can manage my daily functional task and personal hygiene, and even with a wheelchair independently I can go to the bathroom as well"*

People with disabilities have lived experiences of particular impairment or sickness also shaped by their environment and society around them. Disability is not merely a health condition itself but is a constraint regarded in the context of the community and societies to which the people with disabilities belong. So, home environment modification is a key issue to make them functionally independent and self-reliant.

3.3. The positive impact regarding social relationship and functional capabilities were developed after the home modification

Most of cases, modification depends on the severity of the condition. In this regard, this study found significant information from respondents about the importance of home modification as well as empowerment of life sustainability. So, an accessible home environment is a fundamental part though it varies from place to place which deals with important aspects of community re-integration of SCI. All participants had multiple responses.

Table 2 Positive impact of home modification

| Categories of modifications | Frequency (n) | Percentages (%) |
|---|---------------|-----------------|
| Self-independence in functional tasks | 8 | 80 |
| Improve social relationship | 6 | 60 |
| Improve mobility | 7 | 70 |
| Roaming around reduces boringness in daily life | 7 | 70 |
| Improve daily domestic activities capabilities | 7 | 70 |

In this table, the participants expressed the positive impact of home modification. Among the respondent, the maximum number of participants (eight) gave their opinion that they are now self-independent in the functional task and emphasized that a modified home also allowed them to improve their social relationships among the community people. Among the 10 (ten) participants most participants (seven persons) also reported that a modified home has importance for the individual with SCI to improve daily domestic activities capabilities.

A total of half of the participants (5 persons) said that now they could enjoy roaming there in the house and whenever they wish to do, they can roam around the home vicinity to get rid of their boredom relief.

One participant told that *"Following treatment of my accident I have changed my home environment for improving my self-independence which helps to do functional activities and now I can able to manage my mobility to all community areas to have and maintain my social relationships again"*.

Another participant said that *"After leveling my yard cut-off threshold and arrangement of toilet and kitchen then I felt these very important too because it makes me functional for domestic activities and it was very pleased that I can go outside with physical limitation"*. Regarding leisure point view one participant mentioned that *'before modification, I could only sit on my w/c and bed but changing after living room and made a ramp in front of my room that ease my come from room and roaming outside whenever I wish this helps me relieving stress"*

To enable persons with SCI to live independently and participate fully in all aspects of life the appropriate home environment can ensure access to persons with SCI, on an equal basis with others, to the physical environment, to transportation, and including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. The above-mentioned data tells that the clients are being beneficial in such a way that they can roam around, get from place to place, and above all, their self-independency is increased.

3.4. The disadvantages of home modifications were overcome by family members and relatives due to good advantages

People with SCI are mostly dependent on assistive devices, caregiver support, function-based activity analysis, reliable safe environment which free from hazards. So, it could be assumed that an accessible environment plays a vital role to make them independent. Barriers to home modification deal with decreased self-esteem, capabilities, level of performance and social communication, etc. From this point of view, this study found some advantages, and disadvantages, and overcoming patterns from the community by utilizing their local resources. All participants had multiple responses.

Table 3 Advantages, disadvantages of modification, and overcoming the pattern

| Category | Finding of discussion | Frequency (n) | Percentage (%) |
|---------------|---|---------------|----------------|
| Advantages | Allow free mobility to community areas | 10 | 100 |
| | Independence in the functional care | 8 | 80 |
| | Able to manage domestic activities | 7 | 70 |
| | Re-establishment of job | 4 | 40 |
| | Allow to Involve in Social events | 6 | 60 |
| Disadvantages | Disagree and negative attitudes from family members | 6 | 60 |
| | Interim economic hardship | 5 | 50 |
| | Difficulties to make understand the mason for new installations in the home and less availability of materials/resources | 6 | 60 |
| | Lack of enough space in the home | 7 | 70 |
| Overcoming | Able to convince family members | 7 | 70 |
| | Manage money by borrowing from family /relatives | 5 | 50 |
| | Able to make sense to Mason regarding their desire for home modification and got the materials/resources through a referral | 4 | 40 |
| | Change the living room and Rearrange/shifted furniture | 4 | 40 |

This table displays the advantage and disadvantages of a modified home environment for SCI patients and its overcoming pattern by SCI patients. In the above table, all the participants (ten persons) gave their heartiest opinion

that the modified home environment gave them free mobility into their respective community and a maximum of participants (eight) also emphasized has on its advantages for independence in functional care.

Among the ten (10) participants one participant said that *“a modified home environment gives me a tremendous advantage to do my own mobility and personal care which makes me independent in doing my activities of daily living. From the view of advantage modified home environment, one participant said that “Now, I don’t need anyone’s helps to go inside the house or to come out of the house; I can do these all by my own and can go to neighbors and relatives”*

In this study’s findings, most of the participants (six persons) had faced disagreement and negative attitudes from a family member and half of the participants had faced economical disadvantages during their home environment modification and more than half of the participants reported that they faced difficulties to made understood to a mason what the home modifications would look alike.

One participant said that *“After discharge from hospital to my home I have faced difficulties and negative attitudes and financial hardship from few family members to make them understand the importance of the modified home environment to adapt myself to own home as the injury event falls me in a new situation”*.

This table also displays that most of the participants (seven persons) had overcome the disagreement and negative attitudes and financial hardship from family members and neighbors by explaining the benefits of home modification to SCI patients as well as convincing them to do home environment modification. All five participants have managed their economical disadvantages during their home environment modification by borrowing money from his /her family members and relatives. More than one-third of participants reported that they managed to orientate the mason on what the home modifications look like and got the required material for appropriate materials through a referral.

One participant told *“After convincing my family about my desire home, I came to know that there was a money problem for me to arrange longing home modification as following the accident I couldn’t do anything to earn money and that makes me request to the relatives and family member to loan money for my required home change”. Though it was quite hard to lend money for relatives as home change itself a new issue for them”*.

One of the respondents mentioned that *“when I was admitted in CRP my mother and sister were along with me for around six months and during my discharge, the doctors and therapist were given much information on home change and its benefits to me. After discharge when other members disagreed to make changes at home for me but mother and sister have able to overcome this disagreement and negative attitude from family members by explaining the benefit of home modification to me as well as convincing them to do home environment modification”*

So, it seems that an accessible environment plays a vital role to make people with SCI independent. Barriers-free home modification could be allotted with increased self-esteem, capabilities, level of performance and social communication so on.

3.5. Home modifications played a vital role for SCI patients incorporating social reintegration

Home modification has a great impact on social rehabilitation though it may consider as a small part due to depending on the severity and requirements of spinal cord injury patients. Home modification allows the respondents to access social participation, empowerment, and sustainability of the quality of life (partially depending on income-generative activities).

Table 4 Impact on Social Reintegration

| Categories of home modification incorporating social reintegration | Frequency (n) | Percentage (%) |
|--|---------------|----------------|
| Improved social communication | 7 | 70 |
| Meaningful life | 7 | 70 |
| Improved social network | 6 | 60 |
| Increased income-generating activities | 7 | 70 |

In this table, all of the participants emphasized modified home on social communication, meaningful life, and social network and income-generating activities respectively. Among ten participants one participant told that *“After making*

my home modification, I can roam inside and outside of my house environment whenever I wish. If it wasn't there, I wouldn't be able to go this as I am doing now; and can go to neighbors' and relatives' homes to do maintain my social relationship"

Another participant told that "After being discharged from CRP as an individual with disabilities I became an executive member of a local disabled people organization (DPO) and then I have been involved with social work to the establishment of rights of people with disabilities into a community for that frequently I need to go local administration office and Upazila administration and social services offices. This will not possible except having a modified home environment for me"

One participant said that "After this drastic event to me and following all treatment I moved into a new house and I care I have done my house modify to meet my needs. Several home dimensions positively improved, such as my home as a place of privacy, a place of significant relationships, and a place of belonging and rootedness. It has benefit to my life". One participant said, "It gives me the most privilege that now I can go to any social gathering like any festival, marriage ceremony and I can go my groceries shop in the local bazaar."

Societal accommodation is an important issue for people with disabilities to fullest community re-integration as a part of their rehabilitation. Therefore, it is a foremost and requisite issue for primary rehabilitation aspects for community reintegration for people with disabilities.

4. Discussion

Home modification is one of the quality works for people with spinal cord injuries to restore function as well as self-independent. It seemed that the high level of self-confidence is grown among participants as normal during involvement with increased functional activities. Among the 10 (ten) respondents, 80% of the participants said that they have got a positive impact after getting a modified home because it reduced dependency on functional care to others and 70% of them emphasized on improvement of functional capabilities. Literature mentioned that maximum independence in self-care is important because none of us have the desire to be dependent upon others for personal care. 'If the patient is independent in self-care activities which are important for them, they are encouraged to greater efforts in life [5].

In this study among the 10 participants 70% emphasized that it has a better impact to allow them to improve the social relationship among the community people and 70% of them said that now they can enjoy roaming around whenever they wish to do so they can roam around for their boredom relieve. Literature mentioned that the modified home environment facilitates the client's community participation which also influences the well-being of the client as part of society. It is also said that unsuccessful community reintegration leads to developing secondary complications and causing secondary injury [6]. Accessibility for spinal cord injury patients is a vital aspect of their social rehabilitation as free mobility allows them more confidence to lead their life in the community. All the participants (10) had given their heartiest opinion that the modified home environment gave them free mobility into their community though have physical limitations Literature shows that mobility is one of the most important areas for the individual with SCI [7].

Barriers to home modification deal with decreased self-esteem, capabilities, level of performance and social communication, etc. From this point of view, this study found some disadvantages and their overcoming pattern from the community by utilizing their local resources. In this study finding, 60% of participants had faced disagreement and negative attitudes from family members. Among 10 participants 50% of respondents had faced economical disadvantages during their home environment modification. Economic barriers are related to the inability to purchase needed equipment, supplies, and services. Economic barriers may restrict the possible solution to both environmental and personal barriers [8]. Home modification ensured the participant's locus of privacy, security, control, freedom, belonging, and rootedness. In this study, 70 % of participants reported that a modified home environment has the impact of improving social communication and leading a meaningful life. The accessible home environment is crucial both to enable the implementation of community care and to assist in giving people with a disability equal rights to independent living [4]. The accessibility in the home or home modification makes the person better functioning in their performance areas.

Literature has shown that the accessible home and environmental modification allows for free and safe movement, function, and access for SCI regardless of age, sex, or condition making access by all, without obstacles, with dignity, and with as much autonomy as possible [2]. Almost one-third of the respondents had shown their need for follow-up service after every 6 months due to their necessity (such as rapidly repairing the toilet, bathroom, and kitchen). Among them, 40% explored their needs for follow-up after every 12 months of modification. From the participant's point of view, a home visit or follow was strongly recommended on a need basis. Literature suggested that the purpose of a home visit is to see how SCI patients cope with their community environment and to identify if there are any problems have arisen after their discharge [9]. Another study conducted in South Africa by the Occupational Therapy Association revealed

that a home visit is necessary particularly if the patient's physical condition is permanent. After hospitalization and rehabilitation, individuals with SCI face problems in uneven terrain and inaccessible homes and communities [10]. So the importance of follow-up visits is high in that case the practitioners would try to solve the modification problems as the client can get in and out and around of home.

It is said that planning an effective home modification requires a thorough knowledge of the needs of the people who live in the home [11]. The accessible home modification enabled the respondents to focus on home activities as well as to catch up the equal rights as normal. According to Trombly [2], an accessible home environment allows for free and safe movement, function, and access for all, regardless of age, sex, or condition. It is a space or a set of services that can be accessed by all, without obstacles, with dignity, and with as much autonomy as possible. According to North [12], Social support is frequently described as having an important positive effort in psychological distress following stress full life events such as spinal cord injury social support is vitally important for an individual with SCI to reintegrate into the community to lead a meaningful life. Everyone with SCI patients needs access to society, medical facilities, and income-generating activities, to visit neighbors, to use the toilet and water point.

5. Conclusion

The comprehensiveness of modification depends highly on people with SCI wishes, family intentions, and necessary resources. But modified home environment promotes the positive impact of community reintegration and the goal of rehabilitation of people with SCI. It is important to understand the value of environmental modifications in achieving goals in meaningful occupation and to be aware that people with disability frequently have many barriers in their physical environment. Consequently, the activity or occupation that an environmental modification aims to support should be the driver of modifications: a person only interacts with their environment through activity. The modification and designs may be the responsibility of the individual, a service provider, or the government, amongst others. For instance, one local government regarding modifications to the home, governments, organizations, and the individual should be aware that the majority of our existing housing stock is likely to require renovation and modification to meet the changing requirements of the people with disabilities who live there over their lifespan. When the existing home design becomes overly problematic, relocating to a new home with a more appropriate design may be the simplest and most economical option.

Compliance with ethical standards

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Disclosure of Conflict of Interest

The authors declare that there is no conflict of interest.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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