



“CLIENT BASED BARRIER FREE ENVIRONMENT AT HOME FOR A WOMAN WITH SPINAL CORD INJURY”: AN OCCUPATIONAL THERAPIST'S PERSPECTIVE: A SINGLE CASE STUDY

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ABSTRACT Woman empowerment is of the utmost importance to eradicate the social stigma associated with disabled women. It can be acquired through awareness about the physical as well as emotional challenges and promoting inclusive, barrier free and equitable society for women with disability. A woman's journey starts from home. As long as a woman with disability will be dependent on family, she will be considered as disabled not only in the society but also at home. To empower a disabled woman in a family and in the society, a barrier free environment should be created first at home before promoting inclusive, barrier free and equitable society for them. A woman will be no longer dependent and burden for family members if she gets a barrier free environment and easy access at home to complete activity performance in her daily life. In relation to this issue, a woman with Spinal Cord Injury was interviewed. She was diagnosed as complete paraplegic post SCI. This woman was interviewed and discussed about the difficulties with her daily routine work because of her disability and the environmental barrier at home. A simple questionnaire was prepared to find out the obstacles in daily life because of environmental barriers at home. Based on priorities of problems, simple home modification was suggested and the woman was taught certain techniques and exercises to be independent at home.

KEYWORDS : Disability, Woman Empowerment, Barrier Free Environment

INTRODUCTION

Disability is an impairment that may be cognitive, developmental, intellectual, mental, physical, sensory, or some combination of these. It substantially affects a person's life activities and may be present from birth or occur during a person's lifetime. It is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Some Theorists argue that disability is a form of social oppression and that disabled people experience considerable inequality in all areas of social life, including: education, health care, employment, housing, and transport. Evidence also suggests that there is inequality in education produced by the 'disabling barriers' within contemporary societies which prevent or hinder disabled people from full participation within society. **Bowe (1978)** has suggested six principal barriers: architectural, attitudinal, educational, occupational, legal and personal.^{2,3}

An estimated one in five women lives with disabilities and the prevalence of disabilities are actually higher among women than men (19.2 versus 12 per cent). Contributing factors include the lower economic and social status of women and girls, gender-based violence and harmful or gender-discriminatory practices.⁴

People with disabilities face exclusion and widespread stigma while women are excluded from decision-making and face pervasive violence and insecurity. Women and girls with disabilities face double discrimination. Thus, women and girls with disabilities face intersecting and interlocking forms of discrimination because they are female and they have a disability. Women and girls with disabilities are at risk of sickness, injury, negligence, maltreatment and exploitation.^{5,6,7}

Among various disabilities, Spinal cord injury (SCI) is a devastating, life-altering injury, and a challenge for clinicians to treat under ideal circumstances. Managing acute SCI, providing comprehensive rehabilitation, and ensuring adequate supports to allow community reintegration are resource-intensive endeavours. The epidemiology of SCI differs between high- and low-resource nations, the challenges associated with providing comprehensive care in low-resource environments, and the obstacles faced when disasters occur in such settings. Meeting this challenge will require a concentrated and conscious effort, incorporating creativity, and dedication, in order to adapt current approaches to the global reality.⁸

Following hospitalization and rehabilitation, individuals with SCI are often confronted with harsh terrains, and inaccessible homes and communities. This can be complicated further by societal attitudes which devalue individuals with significant disabilities. The consequences of Spinal Cord Injuries (SCI) and the disabilities that follow are of great concern not only to the medical world but also to the

person affected, the family, the employer and the society.⁹

The role of OT in spinal cord injury (SCI) rehabilitation comprises the adaptation of social, Activities of Daily Living and other kinds of environment for the disabled and to assist the client in regaining abilities and roles that are important and meaningful, whereas individual aims are specific and related to a certain patient. A major consequence of spinal injury disability is a general reduction in personal independence and social participation. Occupational therapists also play an important role in addressing the physical and psychosocial needs of an individual with spinal cord injury. They often evaluate and focus on building skills that allow the individual to function in various roles in life. Their unique training gives them a well-developed perspective on the integration of the person, environment and task. Occupational therapists offer interventions for problem solving, confidence building, social skills, communication, sexual functioning and a variety of cognitive skills.^{10,11}

A physical disability significantly reduces one's survival advantage, and a person with a disability can be seen as another mouth to feed, while not contributing to the sustenance of the family. Women with disabilities are constantly challenged to function more independently in their homes. By creating a barrier free environment at home, women can maintain independence with safety and confidence.¹²

So, this study was conducted to make a woman with SCI to regain possible physical strength, minimize her dependency in self care, functional activities, find out possible barriers at home and to make it barrier free from the perspective of occupational therapist, and to make her independent and confident as maximum as possible before reintegrating to community.

METHODOLOGY

Aims and objectives

- To maximize the woman's independency in self care and functional activities.
- To plan and implement a barrier free environment for the woman at home.
- Impact of occupational therapy and planned client based barrier free environment on patient's physical status and quality of life respectively.

Subject and setting

This study was conducted in the year 2019 in a private rehabilitation centre, Puducherry. A 35 year old woman, housewife by profession and complete paraplegia was selected for this study. She became paraplegic following RTA and was brought to the occupational therapy department after spinal surgery via reference of orthopaedic surgeon for complete rehabilitation.

MMSE was used to quantitatively measure her cognitive performance. Muscle power was checked for upper limbs and lower limbs as well. The motor part of Functional Independence Measure scale and SF-36 were administered as outcome measures to find out patient's level of

disability as well as change in patient's physical status and quality of life of the woman respectively in response to rehabilitation during admission, discharge and follow up.

Procedure

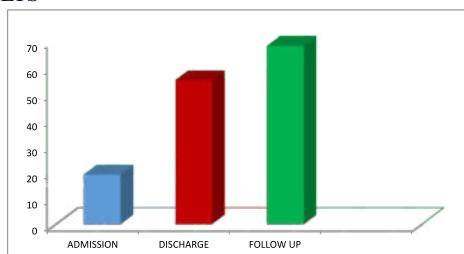
After admission in the Spinal Cord Rehabilitation Unit in that centre, the woman was interviewed and assessed. Demographical data of the subject was recorded in the assessment format. She had been diagnosed as complete paraplegic (ASIA A), level of lesion T9-T12 and was dependent on family members for self care and functional activities. A simple questionnaire was prepared in patient's language based on assessment. Then the woman was asked to fill up the questionnaire. The questionnaire consisted of details about home environment, role play and priority of work at home.

After a thorough discussion with the woman, the possible environmental barriers at home, felt needs and her interest level towards home tasks were identified. Before treatment planning and implementation, the woman and the family members were explained about the purpose of this study and informed consent was taken from them. FIM and SF-36 were administered to find out her dependency level on ADL and quality of life respectively as baseline measurement. Her cognitive status was checked by MMSE which was normal. As part of physical evaluation, the woman was thoroughly checked to find out any pressure sores, pain in the shoulder, contracture or any other complication like heterotrophic ossification.

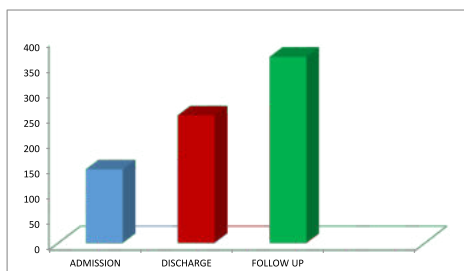
Then occupational therapy program was planned based on woman's physical as well as psychological status. The treatment included mainly Reflexes inhibiting postures, Passive range of motion of lower limbs, Mat activity, Transfer techniques, Therapeutic activities to strengthen upper limb muscles, splintage of lower limbs to prevent further contracture, Modified ADL techniques. The woman was allowed to physiotherapy sessions. The OT sessions had duration of 90 minutes and for 5 days in a week till discharge. Based on prepared questionnaire, a simple simulated kitchen, bedroom and bathroom were prepared to its possible maximum similarity at occupational therapy department. The solutions for the listed possible environmental barriers at home were explained to the family members. Ex-western toilet instead of Indian toilet or adaptive chair toilet, toilet grab bars, removal of thresholds, non skid mat, less furnitures at home to have adequate space for wheelchair manoeuvring, daily required personal as well as cooking items within available range. The woman received planned extensive occupational therapy program for two hours for five sessions in a week till discharge. Home exercise program was prepared and the family members were instructed to follow the home exercise program at home.

FIM and SF-36 were administered again during discharge and follow up to monitor changes in patient's functional status, quality of life and impact of rehabilitation.

RESULTS



Graph-1 (functional Independence Measure)



Graph-2 (SF-36)

DISCUSSION

The main aim of this single case study was to make the woman functionally independent and to find out the possible problems/obstacles or barriers for a woman with disability at home and to implement problem solving approach to resolve these problems and to create a barrier free environment for the woman by simulated training so as to make her as independent as possible at home before paving her way towards a barrier free and equitable society.

The result of this above single case study showed a significant improvement in FIM and SF-36 during admission, discharge and follow up. These findings were supported by the study done by Pillastrini, P et al. that occupational therapy in early treatment of SCI not only helps to evaluate the people's ability and level of functioning at their home but also to retrain them to perform daily living skills using adaptive techniques; to facilitate coping skills that could help a person overcome the effects of SCI; to implement exercises and routines that strengthen muscles that may have been affected and are necessary in daily activities; to determine the type of assistive devices that could help a person become more independent with daily living skills.¹²

Women face barriers to full equality and advancement because of such factors as race, age, language, ethnicity, culture, religion or disability. Persistence of certain cultural, legal and institutional barriers makes women and girls with disabilities the victims of two-fold discrimination: as women and as persons with disabilities. Those with disabilities are constantly challenged to function more independently in their homes, and caregivers are looking for better and safer means in which to care for their clients or family members.^{13,14}

So, it's very important and imperative to make the women with disability as independent as possible at home as their journey starts from home and self confidence gets built if they can accomplish their self care activities and role play at home without any guilt for being disabled. So, before reintegrating to community and being part of the equitable society, it is important to make them independent and self reliant by creating a barrier free environment for them at home.

CONCLUSION

This study concluded that if the women with disabilities will get proper rehabilitation, suggested barrier free environment at home and constant family support, it will enhance their abilities and fasten the building process of regaining confidence to reintegrate to the community.

LIMITATION

- Single case study.
- Single follow up assessment after discharge.

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