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PARENTS' PERSPECTIVES ON THE SERVICE DELIVERY SYSTEM OF ASSISTIVE DEVICES FOR PERSONS WITH CEREBRAL PALSY

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ABSTRACT

The 2011 Census estimated that 2.7 crore people have any form of disability in India. Cerebral Palsy (CP) is one of the disabilities recognized by major acts in India. Cerebral palsy is a neurological condition affecting movement and muscle coordination. Assistive devices play an important role in improving the functionality of people with CP. The parents of persons with CP are facing many difficulties with the services pertaining to assistive devices. The present study aims to gather feedback from parents about the service delivery system for assistive devices for persons with CP. Data was collected from 67 parents of persons with CP. The snowball sampling method was used to select the samples. A semi-structured interview schedule was used to collect the data. Three individual interviews and six group interviews were conducted. The recorded data was transcribed and thematically analysed using the predetermined themes. The study's findings explain the themes related to the parent's perception of the procurement of assistive devices', customization, cost, repairing facilities, training, etc. The feedback from the parents of persons with CP may assist in improving assistive device distribution, maintenance and services.

Keywords: cerebral palsy, assistive devices, parental perspectives, service delivery

INTRODUCTION

According to the 2011 Census, in India, 2.7 crore people have disabilities, which constitutes 2.21% of India's total population [1]. Cerebral Palsy (CP) is one of the disabilities recognized in the Rights of Persons with Disabilities Act, 2016 [2]. Cerebral palsy is a neurological condition characterized by muscular tightness, involuntary movements or muscular weakness that results in impaired motor function, incoordination, delayed developmental milestones, difficulties in hand function, self-care activities, mobility, etc. The clinical manifestations differ from person to person based on the extent of the brain injury. Many persons with CP have the associated problems of intellectual impairment, epilepsy, etc. The prevalence of persons with CP in India is estimated at 2.95 per 1000 children [3]. The Gross Motor Function Classification System (GMFCS) classifies individuals with CP from level 1 to level 5 based on their functional abilities [4]. Level 1 indicates minor functional limitation and level 5 indicates severe functional impairment.

Assistive devices play an important role in improving the functionality of people with CP. Various assistive devices are used to enhance the mobility, communication, education, self-care and proper positioning of the person with CP. Parents or caretakers of persons with CP encounter many

difficulties in procuring, customizing and repairing assistive devices. Gathering feedback from them will be helpful in enhancing service delivery. Considering these factors, this study attempted to gather feedback from them.

PARTICIPANTS AND METHODS

The objective of this study was to gather parents' perspectives on the service delivery system of assistive devices for persons with cerebral palsy. Based on this objective, the following research questions were framed:

1. What are the difficulties that parents of persons with CP face in procuring assistive devices?
2. What are the difficulties that parents of persons with CP face in customizing the assistive devices?
3. What are the difficulties that parents of persons with CP face in repairing the assistive devices?
4. What are the parents' suggestions for improving the service delivery of assistive devices used by persons with CP?

The institute's ethical committee approved to conduct the study. Parents of persons with CP were identified through the snowball sampling technique, resulting in a sample of 67 parents for this study. The sample was based on data saturation to ensure no further new information was gathered from new participants. A majority of participants were

from the Spastic Society of Tiruchirappalli and the National Institute for the Empowerment of Persons with Multiple Disabilities (Divyangjan), Chennai.

This study employed a qualitative approach. Based on the literature review, a semi-structured interview schedule was prepared and reviewed by five field experts, whose opinions were incorporated. The semi-structured interview schedule was further piloted with three parents. The purpose of the study was communicated to the participants and informed consent was obtained from them. One of the researchers, who is an experienced male physiotherapist working with persons with CP, conducted semi-structured interviews with the participants. The researcher conducted three

individual interviews and six group interviews. The group interviews consisted of 3–6 participants. The duration of the interview ranged from 45 to 60 minutes. Based on the participants' responses, relevant, in-depth questions were further posed to generate richer information. All interviews were audio-recorded. The recorded data was transcribed by both researchers and thematically analyzed using the predetermined themes.

RESULTS AND DISCUSSION

The expectations and suggestions of the parents are based on the nature and characteristics of the impairment of their children or adults with CP. Hence, the demographic characteristics of persons with CP are given below:

Table 1: Demographic details of persons with CP (N = 67)

Sr. no	Details of the participants	numbers	%
1	Gender		
	Male	40	59.70%
	Female	27	40.30%
2	Age in years		
	Below 5	9	13.43%
	6-10	23	34.33%
	11-15	14	20.90%
	16-20	14	20.90%
	Above 20	7	10.45%
3	GMFCS Level		
	Level-III	29	43.28%
	Level-IV	20	29.85%
	Level-V	18	26.87%
4	Place of residence		
	Rural	28	41.79%
	Urban	39	58.21%

Persons with cerebral palsy belonging to GMFCS levels III, IV and V have a moderate to severe level of impairment and use assistive devices to enhance their performance. The data were collected both

in urban and rural areas to describe the different dimensions of the issues faced by them. The analysis of the interview data developed the following themes and sub-themes:

Table 2: Summary of Themes

Major themes	Sub-themes
Assistive device procurement	Availability of the devices Cost of the devices Customization of the devices
Assistive device services	Repairing the device Training to use the devices

Theme 1: Device procurement

Availability of the devices

A few parents of persons with CP are unaware of the places to purchase assistive devices. They have issues identifying the shops selling the devices. In the rarely located shops, there is a shortage of devices to purchase. A parent expressed concern about the availability of assistive devices:

“At the gross root level, the majority of people with CP and their family members are not aware of the places where the devices are available for procurement. In urban areas, due to the presence of special schools and disability-oriented organisations, awareness levels are higher as compared to rural areas” ...participant 1.

Another parent stated that *“most of the assistive devices used by persons with CP are not available on the open market. Few hospital-based assistive devices, like wheelchairs, crutches and walkers, are available on the open market. It is difficult to get adapted or customized materials from the open market.”* ...participant 57.

The arguments of the parents are supported by a study conducted by Visagie *et al.*, who state that the users of assistive devices in rural areas encounter numerous challenges

due to a lack of information about assistive devices [5]. There is a need to raise awareness among parents about the availability of materials, particularly in rural areas. The government may consider establishing a sale counter for aids and appliances for persons with disabilities at the district level. The government may consider establishing an assistive device portal to cater to the needs of people with disabilities. The portal may contain information such as the device's description, the features of different models, pricing, retail locations, service facilities for repairs and comparisons with related devices. This could aid in expediting the acquisition of devices by the users.

Cost of the devices

Poverty and disability have a significant two-way relationship. Disability is sometimes stated to be "both a cause and a result of poverty," with poverty and disability "reinforcing each other, contributing to increased vulnerability and exclusion." The lower economic status of many families makes it less affordable for them to purchase assistive devices. In the present study, 75 percent of the respondents (50 participants) stated that the high cost of

certain devices makes them less affordable to acquire. A study conducted to identify the perceptions of parents of children with disabilities clarified that poverty is the main factor hindering parents from purchasing assistive devices for their children [6].

The government of India provides subsidies to persons with disabilities to purchase assistive devices through the “Scheme of Assistance to Persons with Disabilities for Purchase/Fitting of Aids /Appliances” (ADIP scheme). The scheme mainly targets people with low economic status and provides subsidies. This helps reduce the cost of the devices. The parents suggested a few modalities to reduce the cost of the devices.

“Using recyclable materials wherever possible without compromising the functionality of the assistive devices may help reduce the cost of the assistive devices.” ... participant 15.

Another parent stated that *“foreign nations design the majority of the materials used in assistive devices. Adapting the design of these devices to suit the Indian context and producing them domestically helps in cost reduction.” ... participant 46.*

As stated by the parent, the Indian Institute of Technology, Chennai, developed an “Arise standing wheelchair.” This wheelchair is a multipurpose device utilized by persons with locomotor disabilities to do various activities in sitting as well as in

standing positions. The cost of the device was very high when it was imported from foreign agencies. The cost was drastically reduced when produced in India [7].

Customization of the devices

The clinical manifestations of persons with CP differ from person to person. Individuals with CP require customized assistive devices based on their specific impairments. The majority of the devices available on the market are in some prescribed sizes and it is difficult to get customized devices. A few devices like Ankle Foot Orthoses (AFO) and a few orthoses are customized according to the person's needs, but other devices like wheelchairs, adapted spoons, adapted furniture and adapted toilet fixtures are not customized. Even in getting the customized devices, parents have some difficulties. A parent expressed that,

“There is a time delay between the assessment and distribution of the assistive devices, sometimes up to 3–4 months. Due to the growth of the child, the device becomes an inappropriate size at the time of fitment.” ... participant 60.

There is a scarcity of prosthetic and orthotic manufacturing professionals. The number of workshops is also limited. Increasing the workforce and expanding the number of production facilities could potentially decrease the time lag between the evaluation and delivery of assistive equipment. Lack of customization of assistive devices is

considered one of the important factors in device abandonment. The rehabilitation professionals strongly insisted on customized devices for persons with disabilities to reduce the rate of device abandonment [8]. Efforts may be made to provide customized devices for persons with CP.

Assistive device services

Repairing the device

The parents of persons with CP have difficulties repairing the devices. The availability of repair centres and professional staff to do the repairs is low. People in rural areas face more difficulties than in urban areas. For assistive devices, spare parts are less available. Due to these factors, many devices are discarded rather than serviced. A statement by a parent indicates that *“the post-procurement support for many devices is highly inadequate.”* ... participant 42.

Another parent expressed that *“the service of the assistive devices takes an excessively long period. Users may wait anything from a few days to several months for device repairs.”* ... participant 40. As stated by the parent, the after-sale services are not adequate. The lack of professionals for repair services is one of the reasons for the huge delay in providing repair services.

Another parent suggested that *“offering basic repair training for assistive devices to staff working in non-governmental*

organizations and other institutions will facilitate the timely carrying out of minor repair services.” ... participant 17. The parent's suggestion could be beneficial for servicing a few low-tech devices that don't require much technical expertise. We need to conduct further research to determine the feasibility of implementing the parent's suggestion.

Training to use the devices

Training in using assistive devices is essential for ensuring the device's smooth operation. Providing training to the end user helps to improve safety, maximize device utilization and prevent secondary complications. The study participants provided the following information regarding their training in using assistive devices:

“Providing training to use the assistive devices will facilitate the safe usage of the devices and reduce injuries. Parents and users of assistive devices should be informed on the proper techniques for donning and removing the devices, cleaning them, maintaining them, and knowing when to seek assistance from rehabilitation professionals.” ... participant 25.

Another participant stated that *“one of the causes of device repairs is a lack of training and information regarding how to utilize the equipment. Providing training to end users, parents and their caregivers may reduce the rate of repairs.”* ... participant 32.

A study conducted by Visagie *et al.* supports the arguments of the parents. The study asserts that users receive insufficient training on operating assistive devices. Only a few devices come with a user manual. Due to a lack of user training, improper utilization of assistive devices may lead to frequent repairs [5]. Providing proper training about the use of the devices will help to improve their performance and reduce repairs.

CONCLUSION

The present study aims to gather feedback from parents about the service delivery system for assistive devices for persons with CP. Data were collected from the two different institutions located in different parts of Tamil Nadu. The parents provided their feedback related to devices, such as difficulties faced in device availability and procurement, difficulties in customizing them, and difficulties in repairing them, and emphasized the need for providing training. The device manufacturers and government agencies may consider establishing a greater number of sale counters to ensure the availability of the device. Promoting research and development in assistive device designs by Indian manufacturers may help reduce the cost of the devices. A greater number of professionals are to be trained to prepare customized devices for persons with CP. Establishing a greater number of repair centres and providing training to end users

about the proper usage of the devices helps improve the utility of the devices used by persons with CP.

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