



PARENTAL PERSPECTIVES ON THE DEVELOPMENT OF NEW BIOMEDICAL DEVICES FOR PERSONS WITH CEREBRAL PALSY

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ABSTRACT

The 2011 Census estimated that 2.7 crore people have one or anyone of the form of disabilities 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 persons with CP. Since the clinical manifestations of persons with CP differ from person to person, some of the existing commonly used assistive devices need to be upgraded and a few new devices are to be invented to fulfil their needs. The present study attempts to gather feedback from the parents pertaining to their need for developing new 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 findings of the study indicate themes related to the requirements of new assistive devices in different domains like mobility, positioning, communication, self-care activities, etc. It also mentions the modifications required for the existing assistive devices used by persons with CP.

Keywords: cerebral palsy, assistive devices, parental perspectives, upgradation

INTRODUCTION

As per Census 2011, in India, 2.7 crore people have disabilities, which constitutes 2.21% of the total population of India [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 or 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 person with CP in India is estimated at 2.95 per 1000 children [3]. Based on the functional abilities of persons with CP, the Gross Motor Function Classification System (GMFCS) classifies them from level 1 to level 5 [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 persons with CP. Various assistive devices are used to enhance the mobility, communication, education, self-care and proper positioning of the person with CP. The commonly used assistive devices are useful for persons with

locomotor disabilities, but, due to divergence in the clinical manifestations, some of the assistive devices need adaptations and customizations to make them suitable for persons with CP. Most of the literature focuses on advancing the technical features of the devices. A very few of them focus on the commonly used basic assistive devices. They focus on the satisfaction level, the utility of the devices, etc. But there is a scarcity of literature to identify the need for developing new devices for persons with CP. At the grass roots level, in addition to the devices getting upgraded, there is also a need to design a few new assistive devices that can cater to the needs of individuals with CP thereby facilitating their handling by parents or caregivers. This study attempts to gather feedback from the parents of persons with CP in various dimensions to identify the need for developing new devices.

PARTICIPANTS AND METHODS

The objective of the study was to gather parental perspectives on the development of new assistive devices for persons with CP. Based on this objective, the following research questions were framed:

1. What new devices are to be designed to meet the needs of persons with CP?
2. What are the features or designs you are expecting in the new device?

3. What is your suggestion to upgrade the device's features?

The institute's ethical committee granted approval 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 from 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 the 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 ranges 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 locomotor disabilities are in need of various assistive devices to assist with rehabilitation measures. The commonly used assistive devices by persons with locomotor disabilities are designed to cater to their needs. Persons with CP use most of these devices. Due to the diverse clinical manifestations of persons with CP, a few devices are not suitable for them and do not fulfil their requirements. For example, the standardized wheelchair is not suitable

for persons who have problems with their trunk and impaired hand function. The users have the attitude that “something is better than nothing.” While interviewing the parents of children with CP, they expressed these needs in developing the new devices and the need for modifying the existing devices. The analysis of the interview data developed the following themes and sub-themes:

Table 2: Summary of Themes

Major themes	Sub-themes
Requirements for new assistive devices.	Indoor mobility devices Positioning devices Communication devices Self-care devices
Modifications required for the existing assistive devices	Mobility devices Sitting option in mobility devices. Therapeutic devices

Theme 1: Requirements for new assistive devices

The participants expressed their desires to develop new assistive devices to meet the needs of persons with CP.

Indoor mobility devices

The parents of persons with CP find difficulties handling their children’s indoor mobility in the home environment.

A parent stated that *“I find it difficult to carry my child for indoor mobility to go to the bathroom, bed, etc. Every time, lifting and lowering the child in a wheelchair is not convenient. Devices are needed to assist indoor mobility.”* ... participant 31.

They also suggested the features needed in the indoor mobility devices,

“The height of the indoor mobility devices is low enough to easily transfer a person with CP and they have wheels to easily move from one place to another. The wheels also have brake facilities to hold the device in a particular location. The device may have the feature of self-propelling or being propelled by a parent or caregiver.” ... participant 36. A study conducted by S. Ostensjo *et al.* supports the statements of the parents, who state that children with CP need a high amount of assistance for indoor transfer activities. When a person grows, the amount of assistance needed get increased and the parents have difficulties dealing with it [5].

Positioning devices

Modular CP chair for multipurpose use

Persons with CP use a specialized chair for their sitting. The trunk muscle impairments cause abnormal posture, resulting in incorrect sitting positions. These CP chairs provide additional support for the hip and trunk, helping to maintain the erect sitting position. Some adaptations are needed to use the chair for activities like reading, writing and eating and to assist the child in standing in it.

A parent expressed that *“CP chairs that can be modified according to the different needs of person with CP are not available in the market. A single unit of chair that can be converted for the purpose of standing, reading, or eating may have to be designed. This helps in reducing the need for frequent transfers for person with CP.”* ... participant 11.

By considering the importance of developing multi-use device, the Indian Institute of Technology, Chennai, developed an “Arise standing wheelchair”. This wheelchair is a multipurpose device being utilized by persons with locomotor disabilities to do various activities in sitting as well as in standing positions [6]. Similarly, a multipurpose CP chair may be developed as suggested by the parent of person with CP.

Toilet chair with trunk support

As previously mentioned, abnormal trunk posture necessitates spinal support in a variety of sitting situations. A parent emphasized the importance of designing trunk support devices to be used in toilets.

“Persons with CP who have postural instability in their trunk are finding it difficult to use the toilet chairs. Designing the toilet seats with trunk support may be helpful for these people.” ... participant 13. We need to adapt the seating chair to accommodate persons with spinal problems in various activity situations.

Communication devices

Devices to identify the voices of persons with CP

The brain injury causes partial or complete loss of vocal communication in a few persons with CP. The impact of spastic muscles around the vocal cords leads to an unclear voice from them. The alternative and augmentative communication training being given for these persons provides some remedy for their communication, but many persons are in need of a few assistive devices to enhance their communication.

A participant stated that *“many persons with CP have speech problems and the voices of these people are unclear and not understandable by other persons. Designing a device with the ability to customize the voices of persons with CP along with their meaning will be very helpful in*

understanding their words.” ... participant 57.

Parents of person with CP can understand the ambiguous and non-verbal communication of their children, but it may not be understandable by others. If there is an option to customize the speeches of these unclear speeches to understandable words, it will be very useful for others to understand these children’s communication.

Pocket-size communication devices

Another parent communicated that *“a few persons with CP use some high-tech devices for communication. But many persons with communication impairments don’t have these devices due to their cost. It is difficult to carry large communication boards, devices, etc. A simple, pocket-size, low-cost communication device is needed for these persons to meet their communication needs.”* ... participant 23.

The statement of the parent emphasized the need for developing a portable, small-sized communication device for the children. Ensuring the nominal cost of the devices and incorporating customization features may be helpful for these children to handle their communication difficulties.

Self-care devices

Devices for toilet indication

Spasticity, involuntary movements, or incoordination have an impact on the self-care activities of the majority of persons with CP. Persistent problems in eating,

dressing, bathing and toileting are present in these persons.

A parent’s statement indicates that *“my child has problems with bladder and bowel control. I have to open the diapers every time to check whether my child has urinated or not. Sometimes this causes embarrassing situations. Like me, many parents are facing similar issues. The need arises for a reusable toilet indication device. If the device senses the urinary bladder pressure and gives some audio alerts, it will be very useful.”* ... participant 42.

The institutions provide training to parents on how to manage the bowel and bladder problems of their children with CP. The parents are instructed to motivate their children to go to the toilet at frequent intervals. Persons with severe impairments have difficulties managing their bowel and bladder control. Developing the biomedical device as stated by the parent will be very beneficial to these persons.

Theme 2: Modifications required for the existing assistive devices

The assistive devices are in need of continuous upgradation according to the basic requirements of the end users. As stated earlier, many devices are designed to fulfil the needs of persons with locomotor disabilities. The divergent nature of CP requires additional support systems and adaptations in assistive devices to cope with their impairments and growing needs. The

end users suggested a few modifications to the following devices:

Mobility devices

Wheelchair with an umbrella or rain cover

Persons with CP commonly use wheelchairs for mobility. There are few wheelchairs that provide additional trunk support to these people. Based on the severity of the impairment, some persons with CP propel the wheelchair on their own and a few needs assistance from a parent or caretaker to propel it. They use the wheelchairs in both indoor and outdoor environments. While using it outdoors, a few of them faced some difficulties. A parent expressed the difficulty she faced and expected a solution for the same, which was described below:

“When I and my child go to the special school, my child uses a wheelchair. Sometimes she sweated a lot in the summer heat and sometimes get drenched in the rain. Providing an umbrella or rain cover in detachable or foldable mode with a wheelchair may be useful for her” ... participant 29.

The study was conducted in the southern part of India, where the average temperature is around 35°C to 38°C. In summer, it rises to 42°C. Similarly, low pressure in the Bay of Bengal leading to heavy downpours of rain in the rainy season is a common phenomenon. As suggested by the user, these types of attachments in wheelchairs

will be helpful to cope with the changing weather conditions during outdoor use of wheelchairs.

The sitting option in the mobility devices

Persons with CP use various devices, like walkers, rollators, tripods, quadripods, CP walkers, etc., to improve their walking. The professionals provide gait training with the assistance of these walking devices. A parent requested a seating option for a few of these devices. The statement by him is as follows:

“Due to contractures and deformities in the lower limb, children with CP easily get tired while walking. After moving a particular distance, most of them want to sit for a few minutes and then continue walking. Sometimes the parents carry the wheelchair along with other mobility devices to assist with sitting. In India, a very few mobility devices have the provision of sitting while walking. For example, few rollators have this provision. As a parent of a child with cerebral palsy, I expect to provide the sitting provisions with a few more devices, like a walker, a rollator, etc” ... participant 4.

As stated by the parent, a few persons with CP have difficulties with their endurance while walking. In the phases of initial gait training, the quantum of assistance needed is high and they need rest in between their walking spells. Adding a provision for seating facilities in the walking devices will

help to improve their performance in walking.

Therapeutic devices

Reciprocal leg movement devices with adjustable leg length

The physiotherapists and occupational therapists use a variety of therapeutic devices to normalize the muscle tone, improve muscle strength, teach movement patterns, mobility, etc. The reciprocal movement of the legs is affected in person with diplegic CP. To facilitate these reciprocal leg movements, the therapist uses cycles and a few other devices. Delays in the motor development of a few children postpone their crawling movements for a few months to a few years. A parent stated the need for an adaptation in the cycling devices.

“The reciprocal movement of the legs of children with CP is impaired due to the nature of the impairment. The small children use a baby tricycle to enhance reciprocal movements. Adult-size reciprocal leg movement devices are available. Since developmental delays are present in most of the children with CP, they are in need of these devices at different age levels. If adjustable leg length is provided, it will be useful for all age groups of persons with CP to practice it.” ... participant 46.

Most of the assistive devices are used for a particular period of time and later on discarded. Due to the growth of the child

with a disability, some devices may not be used and the parents are discarding the old ones and purchasing new ones. If devices are developed with adjustable features to accommodate the growth of the child, the discard rate of some devices may be lowered.

CONCLUSION

The present study aimed at identifying parental perspectives on the development of new assistive devices and gathering feedback on the upgrades needed in the existing assistive devices used by persons with CP. Data were collected from the two different institutions located in different parts of Tamil Nadu. It is indicative that the person with CP and their parents are in need of developing new devices. They suggested developing indoor mobility devices, modular CP chairs for multipurpose use, toilet chairs with trunk support, communication devices, toilet indication devices, etc. They also expressed their desire to upgrade a few existing assistive devices. Umbrella or rain cover in the wheelchair, seating options in the mobility devices and a few therapeutic devices suitable for different age groups.

They also suggested the modifications required in the assistive devices. The ideas suggested by them may increase the utility of the devices but there is also a chance to hamper the utility of the device. Detailed professional discussions and further

research are needed to check the feasibility of incorporating the changes or developing the devices. The agencies involved in the manufacture of aids and appliances may consider these perspectives provided by the parents and develop the devices to meet the unmet needs of persons with CP and create a conducive environment for persons with CP in utilizing the assistive devices to get the optimum benefits.

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