

Research Article

Perspectives of Parents and Professionals on Assistive Devices Utilised by Persons with Cerebral Palsy

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A B S T R A C T

Introduction: The 2011 Census estimated that 2.7 crore people have any form of disability in India. Cerebral palsy (CP) is one of the disabilities recognised by major acts in India. Assistive technology plays an important role in improving the functional independence of people with CP. The feedback from the parents and other stakeholders on handling persons with CP is helpful in identifying their unmet needs and helping to develop new devices and upgrade their features. The present study aims to gather the perspectives of parents and professionals on assistive devices utilised by persons with CP.

Methods: The data was collected from 67 parents and 57 professionals, totaling 124 people. The snowball sampling method was used to select the participants. Two semi-structured interview schedules were used to collect the data. Four individual interviews and fourteen group interviews were conducted. The recorded data was transcribed and thematically analysed using qualitative research methods and predetermined themes.

Results: The study results explain the need for developing new assistive devices and the list of modifications required in the existing devices used by persons with CP. The themes explain the mobility aids, like single-arm or lever-operated wheelchairs, motorised wheelchairs in foldable models, menstrual hygiene products suitable for sustained duration, patient transfer systems (e.g., manual/ electric patient lift transfer chairs), computer-assisted orthotic devices for precise measurement and health insurance reimbursement for assistive devices.

Conclusions: Participants expressed their needs and provided suggestions for improving the device's utility and service delivery. Detailed research is to be carried out in these aspects to identify the suitability of its use in persons with CP.

Keywords: Cerebral Palsy, Assistive Technology, Mobility Aids, Caregiver Feedback, Rehabilitation Equipment, Qualitative Research, Patient Transfer Devices, Menstrual Hygiene Products, Orthotic Devices, Health Insurance Reimbursement

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 recognised in the Rights of Persons with Disabilities Act, 2016 in India.² The prevalence of persons 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 Assistive technology plays an important role in improving the functional independence of people with CP. Various assistive technologies are used to enhance the mobility, self-care and proper positioning of the person with CP. Most of the assistive technologies fulfil the needs of persons with locomotor disabilities, but the divergence in clinical impairments in persons with cerebral palsy creates an additional need for adaptations and modifications to the existing devices. Along with that, a few new devices are also to be designed to meet their unmet needs.

Most of the literature focuses on advancing the technical features of the devices. Only a small number of these studies concentrate on the widely used basic assistive technologies. This study focuses on gathering feedback from stakeholders on the commonly used assistive technologies for persons with CP. Stakeholder feedback is considered an important source for not only upgrading the utility of the device but also improving its service delivery. This study also attempts to gather the unmet needs of persons with CP and suggestions for developing new assistive technologies.

Participants and Methods

The objective of the study was to gather the perspectives of parents and professionals on assistive devices utilised by persons with CP. Based on this objective, the following research questions were framed:

1. What new devices are to be designed to meet the unmet needs of persons with CP?
2. What are your suggestions for upgrading the device's features?
3. What are your perspectives on assistive device service delivery?

Approval was obtained from the Institutional Review Board (IRB) of the institute to conduct the study. The study participants were identified through the snowball sampling method, resulting in a sample of 67 parents and 57 professionals, totalling 124 people for this study. The sample was based on data saturation to ensure no new information was gathered from new participants. A majority of the participants were from the Spastic

Society of Tiruchirappalli and the National Institute for the Empowerment of Persons with Multiple Disabilities (Divyangjan), Chennai. The study was conducted between April 2023 and July 2023.

The study included parents and caregivers of individuals with cerebral palsy, as well as professionals with at least two years of experience working with cerebral palsy. It excluded professionals with less than two years of relevant experience and parents whose children with cerebral palsy were not using assistive devices. This study employed a qualitative research design. Based on the literature review, two semi-structured interview guides were prepared. One semi-structured interview guide was for parents and the other was for professionals. The semi-structured interview guides were reviewed by five subject matter experts, whose opinions were incorporated. The semi-structured interview guides were further piloted with three parents and three professionals. Both the semi-structured interview guides for professionals and parents included questions aimed at eliciting responses regarding the need for new assistive technology products and the modifications required in existing ones. Additionally, the interview guide for professionals featured questions designed to explore potential solutions to address concerns related to assistive technology products used by persons with disabilities. 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 individuals with CP, conducted semi-structured interviews with the participants. The researcher conducted four individual interviews and fourteen group interviews. The group interviews consisted of 7–10 participants. The duration of the interview ranged from 50 to 70 minutes. Based on the participants' responses, relevant and 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 analysed using predetermined themes. The source triangulation method was used to ensure the trustworthiness of the data.

Results and Discussion

The data was collected from multiple professionals with the intention of gathering the different dimensions of the study subject as well as ensuring the trustworthiness of the data. The details of parents and caregivers who participated in the study were presented in table 1, while the details of professionals who participated were provided in table 2. The analysis of the interview data, presented in table 3, developed the following themes and sub-themes.

Table 1.Details of Parents/ Caregivers Who Participated in the Study

S. No.	Category of Participants	n	%
1	Parents of persons with cerebral palsy	58	86.57
2	Caregivers	9	13.43
	Total	67	100.00

Table 2.Details of Professionals Who Participated in the Study

S. No.	Category of Participants	n	%
1	Physical therapists	8	14.04
2	Audiologists & speech-language pathologists	7	12.28
3	Occupational therapists	3	5.26
4	Prosthetists and orthotists	8	14.04
5	Administrators	2	3.51
6	Social workers	1	1.75
7	Special education teachers	28	49.12
	Total	57	100

Table 3.Summary of Themes and Sub-Themes

Major Themes	Sub-Themes
Modifications required for the existing assistive devices	Single-arm or lever-operated wheelchair
	Motorised wheelchair in a foldable model
Requirements for new assistive devices	Menstrual hygiene products suitable for a sustained duration
	Manual/ electric patient lift transfer chair
Assistive device services	Computerised measurement devices for orthosis
	Health insurance coverage for assistive devices

Theme 1: Modifications Required for the Existing Assistive Devices

Single-Arm or Lever-Operated Wheelchair

The persons with CP use the wheelchair for their mobility assistance. It is a commonly used assistive device for them. The presence of contractures, deformities, spasticity, dystonia and incoordination in these individuals requires additional support systems and adaptations in a wheelchair. Conditions like hemiplegia, triplegia or quadriplegia make it difficult to propel the wheelchair with both hands. A professional expressed the difficulty faced by persons with CP in propelling the wheelchair, which is mentioned below:

“Few persons with cerebral palsy have trouble pushing their wheelchairs forward while holding the rim, which is positioned on their sides and a bit back from their body. Some individuals with cerebral palsy may experience difficulties with their upper limbs, which can make it challenging for them to grasp and propel a wheelchair.” ... participant 58.

As stated by the professional, contractures in the hand and weak muscles make it difficult to grasp the wheelchair rims and propel it forward. Literature suggests modified versions of propelling wheelchairs. One-arm drive wheelchairs are available on the market, in which a person propels the wheelchair by using the flexion and extension movements of

one arm.⁵ Another piece of literature suggests a detachable two-front-lever wheelchair for persons with locomotor disabilities.⁶ There are many alternative propelling model wheelchairs available on the market. Detailed research is to be carried out to find a suitable model for persons with CP who have different hand function abilities.

Motorised Wheelchair in a Foldable Model

A motorised wheelchair is useful for the transportation of persons with severe physical disabilities. It enables people with CP to move easily and reduces dependency. So, they feel independent enough to meet their mobility needs. The control interfaces used in the motorised wheelchair are simple and easy to use, even with severe hand function impairments. Persons with severe impairments often prefer these devices due to their various advantages. Parents of persons with CP are expressing a few concerns about the device. They are:

"The cost of the motorised wheelchair is high and it may not be affordable to many persons with CP." ... participant 6. Another parent states that "it is difficult to carry the motorised wheelchair from one place to another." ... participant 27.

Most of the professionals supported the statements of the parents and expressed that the high cost and transportation challenges limit the utility of the motorised wheelchair. A professional suggested that "there is a need to develop a foldable model of the motorised wheelchair at a lower cost suitable for the Indian environment" ... participant 52.

Foldable wheelchairs allow persons with CP and their family members to easily transport and use them in various environments. We need to conduct detailed research studies to lower the device's cost and enhance its designs to accommodate various environmental conditions.

Theme 2: Requirements for New Assistive Devices **Menstrual Hygiene Products Suitable for a Sustained Duration**

A working parent of a woman with CP expressed her concern about the use of menstrual hygiene products for her female adult with CP.

"I have an adult girl with cerebral palsy. I am a working woman. During the menstrual cycle of my daughter, there is a requirement to change the napkin every 3–4 hours. My workplace is far away from my home. It's also difficult to get help from others for this purpose. My child felt restless when she used the same pad for a prolonged period of time. If a suitable menstrual pad is long-lasting, it will be very helpful" ... participant 29.

A study conducted on women with developmental disabilities states that female adults with developmental disabilities refuse to wear napkins and resist their mothers when they are attempting to use them for them.⁷ As stated by the parent, many girls with CP are facing similar issues in their day-to-day lives. Detailed research is to be carried out to find the solution to the problem and napkins usable for sustained duration may be developed.

Manual/ Electric Patient Lift Transfer Chair

The parents of persons with CP have difficulties lifting and transferring their children to various activities. A parent expressed the following:

"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.

Healthcare professionals supported the statements of the parents and emphasised the need to develop a new device for easy lifting and transfer. There are a few models of manual or electronic patient lifting and transferring chairs available on the market for hospital patients.⁸ These types of chairs may be used for people with cerebral palsy. Research may be conducted to reduce the cost of these devices and ensure their availability, which is helpful for persons with cerebral palsy and their family members.

Theme 3: Assistive Device Services

Computerised Measurement Devices for Orthosis

Most people with CP use ankle-foot orthosis (AFO). While taking the measurements and using the devices, people are facing some difficulties. A parent stated, *"The ankle-foot orthosis given to my child was not properly fitting. If there is a computerised measurement procedure, it will be much more helpful for providing the appropriate orthosis."* ... participant 19.

Another 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.

At present, manual measurement methods are used for orthosis fabrication. When taking measurements for many persons with disabilities during the camps, it consumes lots of time. Along with this, considerable time was taken to fabricate each orthosis. These factors resulted in a prolonged delay between the assessment and distribution. This time delay sometimes goes up to 3–4 months. The

orthosis may lead to inappropriate size due to the growth of the child with a disability during this period. The introduction of computerised measurement systems of orthosis by using 3D printing technology may help reduce the time needed for assessment and fabrication. A computerised 3D technology system helps to readily access and modify the measurements quickly. This helps to speed up the production of the orthosis, which considerably reduces the time delay. Since the 3D printing technology of orthosis is an emerging area, continuous research and development are required to improve its effectiveness.

Health Insurance Coverage for Assistive Devices

Through the Niramaya Health Insurance Scheme, the Government of India provides health insurance to people with disabilities who are covered under the National Trust Act. This scheme provides coverage up to 1 lakh rupees.⁹ Apart from this scheme, the general insurance companies are not ready to provide health insurance to persons with disabilities and their families. The expenses incurred for the purchase of assistive devices are not covered by any health insurance plans. Similarly, life insurance is also denied to persons with disabilities. Instead of providing death benefits, the insurance companies may focus on survival benefits through the insurance. The government should take appropriate action to ensure all insurance companies are introducing health insurance and other insurance schemes for persons with disabilities, including coverage of assistive technology.

Recommendations

1. Single-arm or lever-operated wheelchairs should be sensitised among users and their suitability for persons with CP needs further exploration.
2. Research should focus on reducing the cost of motorised wheelchairs and making them foldable for easy transportation.
3. Difficulties faced by parents regarding the use of menstrual napkins for girls with CP need attention and suitable, long-lasting menstrual napkins should be designed. Detailed research is required to explore the implications of using the same napkin for prolonged durations.
4. To address the challenges faced by the parents in transferring persons with CP for indoor activities, devices such as patient lift transfer chairs and others should be developed to meet their needs.
5. Computerised measurement and manufacturing of orthotic devices should be promoted and research should aim to reduce their cost.
6. The government should consider developing regulations requiring insurance companies to provide health

insurance for persons with disabilities and include the cost of assistive devices in these plans.

7. A combined effort by parents, professionals, device manufacturers and policymakers is necessary to enhance the lives of persons with disabilities.

Conclusion

The study aimed to gather the perspectives of parents and professionals on assistive devices utilised by persons with cerebral palsy (CP). Data was collected from parents and various rehabilitation professionals. Participants expressed their needs and provided valuable suggestions for improving the utility of assistive devices and enhancing service delivery.

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