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ARTICLE

Needs of Augmentative and Alternative Communication System for Children with Cerebral Palsy: Parents Perception

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ABSTRACT

Background: Cerebral Palsy (CP) often results in significant communication challenges, impeding children's ability to express their needs and emotions effectively. Augmentative and Alternative Communication (AAC) systems have been developed to support individuals with such communication impairments, offering tools ranging from simple picture boards to advanced speech-generating devices. **Objective:** To explore the parent's perception of children with Cerebral Palsy (CP) regarding the needs of Augmentative and Alternative Communication (AAC) system. **Methodology:** This is a qualitative type of phenomenological study where 7 parents of children with CP who met the inclusion criteria assigned purposively from the outpatient unit of Centre for the Rehabilitation of the Paralysed (CRP) Savar, Dhaka. Data was collected by using standard self-inventory questionnaire that contains 10 questions. Semi-structure, face to face interviews were conducted to collect in-depth information. **Result:** Parents are highly concern to the functional communication of children with CP thus the AAC system was preferred and could be a possible recommendation. **Conclusion:** Communication difficulties were closely connected with the life of children with CP. For communication difficulties they were not able to pass a meaningful life. They faced different problems in the family, school and society. AAC system is a helpful technique for severe communication difficulties CP child, it is significant to know for the parents of children with CP. This study also helps to the SLTs to work in this area and a speech and language therapist could support children with CP to develop their expressive skills verbally or non-verbally.

Keywords: Cerebral Palsy, Augmentative and Alternative Communication, Parent Perception, Communication Difficulties, Speech and Language Therapy.

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INTRODUCTION

Cerebral Palsy (CP) is a disorder affecting movement, muscle tone, and posture, making it a primary cause of physical disability in children [1]. CP is widely recognized as a complex neurological condition with diverse clinical manifestations [2]. Children and adolescents with CP often experience activity limitations

and restrictions in participation [3]. Additionally, brain injuries in CP may affect other areas, leading to associated conditions such as intellectual disabilities, seizures, and sensory impairments. However, generalizing these issues to all children with CP may lead to misconceptions and overlook individual needs [4]. According to Adamson and Romski (1997), typically developing children produce their first words around 15 months while also following simple commands and identifying objects [5]. Research has primarily focused on language production rather than comprehension in young children. Smith and Hustad (2015) emphasize that parents provide valuable insights into their children's communication abilities, contributing to more precise intervention planning [6]. Augmentative and Alternative Communication (AAC) refers to various communication methods, including visual symbols, signs, and advanced technology, designed to enhance speech when traditional communication is difficult [7].

It includes both unaided modes like gestures and aided techniques such as communication boards and electronic devices [8]. Individuals with severe communication impairments rely on AAC to express themselves effectively. Some use AAC in specific contexts, while others depend on it extensively. Familiar communication partners can often understand spoken messages, but AAC is particularly beneficial when clarity is essential. Expressing needs and wants is a fundamental function of communication, particularly for individuals with severe impairments, as it involves a limited set of messages that are crucial for caregivers [9]. Parette (1997) describes AAC as a form of assistive technology commonly used by young children with disabilities, including communication boards and charts for message transmission [10]. Communication breakdowns in society can have negative consequences for individuals with severe communication disorders, emphasizing the importance of AAC interventions [11]. The 1990s saw the development of dynamic screen speech-generating devices, replacing earlier methods like eye-pointing, scanning, and sign language used in different cultures [12]. Text messaging has also become a widely accepted method of social interaction, with AAC users leveraging it for asynchronous communication. A study highlights the importance of assessing speech characteristics and underlying factors to understand the impact of AAC on communication outcomes. Speech subsystems such as respiration, phonation, resonance, and articulation can be affected in individuals with CP, influencing their ability to communicate effectively [13]. AAC intervention specialists are trained professionals who provide assessment, recommendations, instruction, and ongoing support for AAC users [14]. Speech and language therapy plays a crucial role in assisting individuals with communication, feeding, and swallowing difficulties. SLTs collaborate with caregivers, educators, medical professionals, and therapists to ensure comprehensive intervention [15]. This research emphasizes that SLTs also support adults with acquired neurological communication disorders, enhancing their ability to engage in meaningful interactions.

OBJECTIVE OF THE STUDY

To explore and analyze parents' perceptions of the necessity and effectiveness of Augmentative and Alternative Communication (AAC) systems for children with Cerebral Palsy (CP).

METHODOLOGY

This qualitative phenomenological study explored parents' perceptions of AAC system needs for children with CP. It provided insights into their views, beliefs, and experiences, following Hick's (2000) framework on qualitative research as an investigative tool to understand human perspectives. The study was conducted in the Speech & Language Therapy department at Centre for the Rehabilitation of the Paralysed (CRP), Savar, Dhaka. Parents of children with Cerebral Palsy (CP) at the age of 3-10 years from the SLT department at CRP, Savar, Dhaka. The study was conducted within 9 months from April 2019 to December 2019. The study included 7 participants.

Sampling procedure

Purposive sampling was utilized as it is an efficient, cost-effective, and quick method for selecting participants. The sample of seven was chosen based on specific inclusion and exclusion criteria. The researcher selected participants based on their relevance to the study, ensuring accessibility and suitability

Inclusion criteria

Parents of children with CP individuals who have speech

and language difficulties.
Parents of children with CP in the age range between 3-10 years.
Parents of children with CP who received therapy from SLT department at CRP.

Exclusion criteria
Parents of children with CP who can communicate speak.
Parents of children with CP age are less than 3 years old and more than 10 years old.
Parents of children with CP who had not received therapy from SLT department at CRP.

Data Collection & Analysis
Data Collection Tools
Data was gathered from parents of children with CP using a standardized self-inventory questionnaire containing 10 questions. Various tools such as an MP3 recorder, pen, paper, information sheet, and consent form were utilized during interviews for data collection.

Data Collection Procedure
Initially, the investigator explained the study's purpose to the clinical speech and language therapist and then to the participants. A self-designed questionnaire was used, and face-to-face interviews were conducted with parents of children with CP. Appointments were scheduled based on participant availability, and a consent form was signed before the interview to ensure understanding of the study's aim. The interview was conducted in a private setting to maintain confidentiality, and establishing trust was prioritized to obtain accurate responses.

Data Analysis
Content analysis was applied to interpret the data collected from interviews. The first step involved transcribing the entire interview in Bengali from the MP3 recordings, followed by verification through comparison with the English transcription to ensure accuracy. The transcripts were then reviewed multiple times to thoroughly understand the participants' perspectives. Additionally, the audio recordings were re-examined to validate the consistency of responses. Subsequently, data from each participant was organized systematically according to interview questions. Categories were assigned based on the responses, and recurring themes were identified through coding. The investigator analyzed these codes under each category, ensuring that they accurately reflected participants' views. Finally, the categorized data and coded themes were synthesized to derive conclusions regarding parents' perceptions of AAC system needs for children with CP.

Ethical consideration
The researcher obtained authorization from the BHPI resident ethics committee, as well as from the head of the SLT department and the research supervisor, to carry out the study. The head of CRP's speech and language therapy department then approved the data collection. Before data collection, the researcher explained the purpose of the study to each participant. Using a consent form, the researcher obtained the participants' consent. Because the investigator would keep the client's identity, address, and other information private, privacy would be maintained. The supervisor was informed of everything.

RESULT

The study aimed to explore parents' perceptions regarding the communication needs of their children with Cerebral Palsy (CP) and the role of Augmentative and Alternative Communication (AAC) systems. Through comprehensive analysis of parent interviews, four primary themes emerged:

Theme 1: Present Condition of the Child's Communication
Theme 2: Parent's Knowledge about AAC Systems
Theme 3: Parent's Opinion Regarding AAC Systems
Theme 4: Environmental Influence on Using AAC Systems

These themes collectively highlight the multifaceted experiences of parents in managing their children's communication needs and underscore the critical importance of providing comprehensive support systems, education, and resources to optimize AAC utilization for children with CP.

In qualitative research, organizing participant perceptions into distinct codes is essential for systematic analysis. The researcher has structured these codes into tables, each corresponding to a specific category derived

from the interview data. In these tables, 'P' denotes participants, with numbers 1 through 7 representing individual participants. This tabular presentation not only elucidates the findings but also enhances the transparency and trustworthiness of the analysis. Such an approach aligns with best practices in qualitative research, where tables are utilized to effectively organize and communicate data, thereby reinforcing the credibility of the study's conclusions.

Theme-1: Present the condition of the child's communication.

Category-1: Child's way to express his/her needs.

Children with Cerebral Palsy communication difficulty in severe level can't communicate verbally and most of the time they try to communicate non-verbally. On the above result we can see the P1, P2, P3, and P6 similarly mentioned that, their child use natural gesture for communication. P1 stated that, "*My child can't express his/ her needs verbally and can't communicate verbally with known and unknown person and expresses his/her needs by natural gesture and communicate with known and unknown person*". P2, P3, and P7 also included that, "*Their children communicate by physical manipulation"*. Two other P4 and P5 similarly stated that, the child can't rapid his/her needs. P5 indicated that, "*My child can't express his/her needs, I understand his/her needs by seeing his/her face"*. (Table 1)

Table 1: Child's way to express his/her needs

Code	P1	P2	P3	P4	P5	P6	P7
Expresses through natural gesture	✓	✓	✓			✓	
Expresses through physical manipulation.		✓	✓				✓
Cannot express verbally but use facial expressions to express the feelings & needs to parents.				✓	✓		

Category-2: Feelings of the child if he/she is not able to communicate.

When a child is incapable to rapid his/her moods to others, then he/she expresses feeling in different ways. On the above result we can see the P2, P3, P4, P5, P6, and P7 similarly mentioned that, the child becomes angrier when he/she unable to express the feelings for communication. P1, P5, P6, and P7 also included that, the child cries when he/she unable to express the feelings for communicating. P6 stated that, *"When my child wants to express his/her feelings to others but if the other person doesn't understand it, then the child becomes very angry and cries*". P1 and P2 similarly stated that, *"When the child wants to express his/her feelings to others but other person does not understand then the child tries to explain it again and again"*. (Table 2)

Table 2: Feelings of the child if he/she is not able to communicate

Code	P1	P2	P3	P4	P5	P6	P7
Cries	✓				✓	✓	✓
Becomes angry		✓	✓	✓	✓	✓	✓
Tries to explain again and again	✓	✓					

Theme-2: Parent's Knowledge about AAC system.

Category-3: Parent's knowledge about the AAC system.

Parent's knowledge about the AAC system helps to increase child's communication. On the above result we can see the P1, P3, and P5 similarly mentioned that, "*AAC system refers to communicating by sign language and showing pictures*". P6 and P7 also included that, AAC system refers to communicate through sign language.

Two other P2 and P4 similarly mentioned that, they don't understand about AAC system. Participant 2 specified that, *"I have no idea about Augmentative and Alternative Communication (AAC) system"*. (Table 3)

Table 3: Parent's knowledge about the AAC system

Code	P1	P2	P3	P4	P5	P6	P7
AAC system means using sign language.	✓		✓		✓	✓	✓
Use pictures to express the feelings and needs.	✓		✓		✓		
Don't understand about AAC system.		✓		✓			

Category-4: Any prior experience of AAC system use by child.

By using Augmentative and Alternative Communication (AAC) system many children express his/her feelings. On the above result we can see the P2, P4, P5, and P7 similarly mentioned that, *"The child never expresses his/her thought and needs by using Augmentative and Alternative Communication (AAC) system"*. Three Other P1, P3, and P6 similarly mentioned that, *"Their child has communicated using Augmentative and Alternative Communication (AAC) system"*. P6 indicated that, *"my child communicates at school using Augmentative and Alternative Communication (AAC) system"*. (Table 4)

Table 4: Any prior experience of AAC system use by child

Code	P1	P2	P3	P4	P5	P6	P7
Expressed his/her needs by using AAC system.	✓		✓			✓	
Didn't express his/her needs by using AAC system.		✓		✓	✓		✓

Theme-3: Parent's opinion regarding AAC system.

Category-5: Parent's satisfaction about the present communication status of the child.

Parents have many types of opinion about the child present communication. On the above result we can see the P1, P3, P5, and P6 similarly mentioned that, they are not satisfied with the child's current communication. P5 stated that, *"My child can't communicate at all. I am not satisfied with the child's current communication. I would be very happy if the child use at least natural gesture to communicate"*. Two other P4 and P7 similarly mentioned that, *"We are satisfied with the child's current communication"*. One other P2 specified that, *"I am satisfied with the child's current way of communication than before"*. (Table 5)

Table 5: Parent's satisfaction about the present communication status of the child

Code	P1	P2	P3	P4	P5	P6	P7
Not satisfied with the present communication skill of the child.	✓		✓		✓	✓	
Parents are happy with current level of communication of the child.				✓			✓
Parents are happier than previous communication ability of the child.		✓					

Category-6: Parents' opinion about Applying the AAC system.

Parents express different opinions about applying the AAC system. On the above result, we can see the P1, P2, P4, and P5 Similarly mentioned, providing an AAC system will be beneficial for the child. P5 stated that, *"Providing Augmentative and Alternative Communication (AAC)* system *will be benefited for the child because if he is unable to speak, he/she will be able to communicate by Augmentative and Alternative Communication (AAC) system"*. Two other P3 and P7 similarly mentioned that, *"We will try so that my child can talk if the child is unable to speak, then we will think about using Augmentative and Alternative Communication (AAC) system"*. P6 indicated that, *"If the child will use the Augmentative and Alternative Communication (AAC)* system *then he/she will be fully dependent on it and won't show the interest to talk verbally and I think it's a problem"*. (Table 6)

Table 6: Parents' opinion about Applying the AAC system

Code	P1	P2	P3	P4	P5	P6	P7
It would be helpful if the child used AAC system.	✓	✓		✓	✓		
Child will not eager to speak if dependent on AAC system.						✓	
First we will try to enable him/her to speak, if unable then think of AAC system.			✓				✓
It will be difficult to care materials of AAC system.	✓						

Theme-4: Environmental influence for using AAC system.

Category-7: Suitable communication environment for AAC system use.

In some places where children can't communicate so that everyone faces difficulties, in this environment children need AAC system. On the above result we can see the P3, P4, P5, and P7 similarly mentioned that, "*The Augmentative and Alternative Communication (AAC) system will be better to use in the own home environment*". P3 and P7 also included that, The AAC system will be better to use in the school environment. P1, P2, and P4 also included that, "*The Augmentative and Alternative Communication (AAC) system will be better to use in the social environment*". P1 and P2 similarly stated that, *"The Augmentative and Alternative Communication (AAC) system will be better to use in the home, school, and social environment for my child"*. P4 specified that, "*The Augmentative and Alternative Communication (AAC) system will be helpful for my child in social environment because my child wants to play with other children, but other children can't understand my child feelings"*. One other P6 specified that, *"Augmentative and Alternative Communication (AAC) system will be helpful for my child in the unfamiliar environment. My child will be able to communicate by Augmentative and Alternative Communication (AAC)* system *with people who don't understand my child"*. (Table 7)

Table 7: Suitable communication environment for AAC system use

Code	P1	P2	P3	P4	P5	P6	P7
Home environment will be helpful to communicate by AAC system.	✓	✓	✓	✓	✓		✓
School environment will be helpful to communicate by AAC system.	✓	✓	✓				✓
Unfamiliar environment will be helpful to communicate by AAC system.						✓	
Social environment will be helpful to communicate by AAC system.	✓	✓		✓			

DISCUSSION

The study's findings underscore the critical role of Augmentative and Alternative Communication (AAC) systems in enhancing the communication abilities of children with Cerebral Palsy (CP). Parents recognize the necessity of AAC to facilitate their children's expressive and receptive language skills. This recognition aligns with Smith and Hustad's (2015) research, which emphasizes the importance of early AAC intervention in supporting communication development for children with CP [6]. Children with CP often experience challenges in attention, communication, and participation, leading to developmental delays compared to their peers [16]. CP, the third most common disorder among children with disabilities, results from issues in the developing central nervous system, affecting normal developmental progress and limiting functional activity [17]. Diminished language abilities, often influenced by motor speech disorders, frequently lead to communication difficulties in children with CP [18]. Parents and family members play a pivotal role in understanding and interpreting the communication needs of children with CP. They can discern their children's requirements through expressed signs, tone, head movements, and gaze [19].

Both familiar and unfamiliar partners can readily interpret the interests and desires of children with severe complex communication needs through their behaviour. Families can assist in determining the content a child wishes to communicate, to whom, and how the message will be conveyed. Given that many children with CP face communication challenges, they often cannot express their needs verbally and may encounter mild to severe difficulties in verbal interactions. They frequently rely on natural gestures and physical manipulation to communicate. Implementing AAC systems is essential to enhance these children's functional communication skills. AAC encompasses methods and technologies that aid individuals in communicating when they cannot do so effectively, either temporarily or permanently [20]. Children with CP must contend with various physical and socio-emotional challenges, including weakness, stiffness, clumsiness, peer rejection, despair, frustration, anxiety, and irritation [21]. Frustration and anger can result from CP's negative impact on the emotional well-being of youths. Communication is fundamental for expressing emotions and building relationships; without it, individuals may feel isolated and incomplete [22]. When children with CP are unable to express their feelings, they may exhibit behaviors such as anger, crying, or repeated attempts to communicate. To comprehend these emotions, it is crucial to enhance their communication abilities. AAC practices involve supplementing or replacing spoken communication with other techniques. Effective processes are required to influence the perspectives of researchers and knowledge users in producing new knowledge in AAC. AAC technologies offer children with complex communication needs access to the power of communication [23]. Parents of children with CP must be informed about AAC systems, as these tools can significantly improve their children's communication. According to Cockerill et al. (2013), AAC can support children with CP in comprehending spoken language and serve as a means for expressive communication. For individuals who have lost speech ability, AAC is essential for communication [24]. Families and schools should be equipped to utilize AAC technology for children who may benefit from these devices [10]. Parental knowledge of AAC systems is instrumental in enhancing their children's communication. Parents often have high expectations for their children, and physical impairments occurring at or after birth are unexpected. A comprehensive understanding of CP can help families accept the disabled child as part of the family, providing support to parents by allowing them to discuss their feelings of fear and shame [25]. Families and professionals can develop intervention programs tailored to each child by understanding that various communication skills may be comparable. Parents can describe their children's current communication status, aiding in this process. Children with CP who have severe communication difficulties may be unable to communicate verbally or non-verbally, leading to parental dissatisfaction with their child's communication challenges. Implementing AAC systems can improve their communication. AAC methods and technologies assist individuals in communicating when they cannot do so effectively, either temporarily or permanently [20]. Unaided communication involves using one's body or sign language to support speech [26]. AAC systems encompass various forms of communication, including speech, signs, facial expressions, and other non-verbal methods, serving as

integral components of an individual's communication toolkit. Currently, existing AAC systems aid individuals with disabilities [22]. AAC offers children with significant communication disabilities the potential to enhance their communication, language, and learning. For AAC interventions to be effective, children must have access to appropriate AAC systems and receive adequate training to develop the linguistic, functional, social, and strategic skills necessary for efficient communication. Additionally, children should have suitable opportunities and support from their communication partners. Speech-language pathologists (SLPs) and AAC users often face challenges such as device abandonment and social acceptability issues [27]. Implementing AAC systems can enable children to express their feelings more easily, facilitating understanding from others. Parental involvement is crucial in providing AAC systems. Both school and home environments are suitable for children with disabilities to use AAC systems.

CONCLUSION

The lives of children with cerebral palsy were directly linked to communication issues. They were unable to lead fulfilling lives due to communication issues. They had various issues at home, at school, and in society. Since they are unable to communicate their requirements to others, the AAC system is crucial in assisting the youngster in expressing their everyday demands. Children with cerebral palsy would be able to express their needs, emotions, and expectations to others more quickly and perform better at home, at school, and in society if they could communicate with others either verbally or nonverbally. Perception by parents aids in gathering data regarding their children's communication. The primary focus of this study was how parents see the necessity for an AAC system for children with cerebral palsy who struggle with expressive language. According to the study's findings, parents of children with cerebral palsy believe that the AAC system will help their kids communicate more. Additionally, it was discovered that parents of children with cerebral palsy find this AAC system to be very acceptable because it enhances the child's statement. However, participants confirmed that the AAC technique had certain material restrictions. This study also aids SLTs in their job, and a speech-language pathologist can help a kid with cerebral palsy improve their verbal or nonverbal expressive abilities.

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