Case Study

Possibilities of battery-free AACloth for augmentative and alternative communication: views of parents of children with cerebral palsy

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Received: 24 May 2023 / Accepted: 6 November 2023
Published online: 15 November 2023

Abstract

Cerebral palsy (CP) is a neurological disorder that primarily affects body movement, muscle coordination, and muscle tone. Non-progressive brain injury or abnormal brain development that occurs while the child's brain is under development causes CP. It is estimated that 40–85% of children with CP have communication difficulties. Children with communication difficulties can benefit from augmentative and alternative communication (AAC). However, studies have shown that several challenges in using AAC exist. Developing existing AAC methods and creating new AAC solutions are important to enable everyone to communicate and express themselves without barriers. This qualitative study aims to investigate how parents of children with CP would use a wireless and battery-free, passive radio-frequency identification (RFID)-based e-textile—AACloth—as an AAC solution. The research was conducted via an online survey. Parents with a child under 15 with CP and communication difficulties were included. Parents were recruited by distributing the survey invitation via the Finnish CP Association's monthly newsletter, Facebook page, and social media groups. Nine parents participated. Based on parents' views, the AACloth could solve some of the challenges associated with existing AAC methods. This research provides perspectives on what kinds of factors should be considered when developing existing and new AAC aids.

Article highlights

- The aim of augmentative and alternative communication (AAC) is to support the self-expression and communication of people with communication difficulties. However, there are several challenges in using AAC methods, making it important to develop the existing AAC tools and create new ones. For this reason, we asked parents of children with communication difficulties how they would use a wireless and battery-free, passive radio-frequency identification (RFID)-based e-textile—AACloth—as an AAC solution.
- All parents responding to the survey would attach the AACloth to their child's mobility aid or communication device; the child would control the AACloth with their hand.
- According to parents' views, the AACloth would be used in everyday communication situations in which the child could, e.g., express their will and ask for help.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s42452-023-05577-4.

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Keywords E-textile · AACloth · Assistive technology · Passive radio-frequency identification · Augmentative and alternative communication · Cerebral palsy

1 Introduction

Cerebral palsy (CP) is caused by damage during fetal life, birth or early infancy to the areas of the central nervous system that control movement, balance and posture [1]. CP causes many neurological disorders, such as permanent disorders in body movement, posture and coordination, negatively impacting one's motor skills and daily activities [2]. The overall prevalence of cerebral palsy is 2.11/1000 live births [3] and the most common cause of motor impairment in childhood [4]. The severity of motor disorders can range from mild motor abnormalities to severe disability. Moreover, people with CP may have associated disorders such as intellectual disabilities and communication difficulties [1]. According to the literature, the overall incidence of communication difficulties in children with CP varies from 40 to 85% [5–7]. Thus, CP can significantly limit a person's ability to function and participate [1, 8, 9]. A range of assistive devices can be used to support, promote, and maintain the functional capacity of someone with CP and their ability to participate, communicate, and interact [1, 10]. Children with CP can benefit from assistive aids such as mobility, sitting, and environmental management aids [10], as well as a range of augmentative and alternative communication (AAC) methods [11, 12]. However, using AAC often requires adequate motor and cognitive skills from the user, which can pose challenges for children with CP [1, 13, 14].

The purpose of augmentative and alternative communication is to ensure everyone has the opportunity for self-expression and communication [12, 15]. The National Joint Committee for the Communication Needs of Persons with Severe Disabilities has developed a Communication Bill of Rights highlighting that it is a basic human right to autonomy and communicate [16]. AAC methods are divided into assistive and non-assistive methods—often used in parallel [12, 17, 18]. Non-assisted AAC refers to non-verbal communication, such as gestures, facial expressions, or touch, which do not require the user or those around them to use separate devices. Assistive AAC refers to those methods requiring an external aid such as a communication folder or tablet [18]. Assistive AAC is further divided into technical and nontechnical [12]. Nontechnical AAC tools include communication boards and folders and alphabet boards, while technical AAC tools include electronic assistive devices such as speech-generating devices (e.g., Tobii Dynavox [19]) and computers, tablets, and phones with applications (e.g., Go Talk Now [20, 21]. Research suggests that around 97 million people worldwide could benefit from AAC [22] and that individuals with CP are one of the most typical user groups that could benefit from AAC [11, 12].

Although children with CP can benefit from technical and nontechnical AAC tools, various challenges exist [13]. Firstly, the motor disorders related to CP create several challenges. For example, fine motor skills may be insufficient for using sign language or signs as a communication method. Also, many technical and nontechnical AAC tools, such as pictures, communication folders, phone devices, or communication apps that can be downloaded to a tablet, rely on the user pointing, pressing, or swiping the correct picture or symbol to communicate [23, 24]. AACs can also be used by scanning [23], meaning items are sequentially displayed over time; user makes the selection by giving an appointed signal when the item of choice is presented. Thus, motor challenges can make using sign language and other AAC methods difficult, as when lacking sufficient motor accuracy, a person may accidentally press the wrong symbol or cannot press or swipe a symbol at all [24, 25]. Moreover, functional ability studies of children with CP suggest there may be a correlation between the severity of motor difficulties CP causes and the severity of communication difficulties [26]. Therefore, children whose speech is most affected by CP may have significant challenges using AAC.

Secondly, one's cognitive and linguistic skills affect what kind of AAC method one can use and the challenges one may face using it [14]. As approximately 50% of people with CP have varying degrees of developmental disabilities [1], it is possible that these disabilities will affect their ability to use different AAC methods.

Lastly, the challenges of using AAC may also relate to the environment, family members, and other communication partners. For example, not everyone understands sign language or gestures, so they cannot communicate using them [13, 18]. As well as this practical challenge, family members and others' attitudes and perceptions towards AAC usage can significantly impact how successfully the AAC system is implemented [27].

Challenges related to technical and nontechnical AAC systems also differ. Technical AAC tools are perceived as faster to use than nontechnical tools and more versatile and adaptable to different environments [28, 29]. Conversely, technical AAC tools are also perceived as challenging due to the maintenance the device requires and the need to recharge the battery [30]. Both, technical and

nontechnical AAC devices face the challenge of carrying them around, which can be cumbersome sometimes. For example, a communication folder can be large and heavy, and a communication tablet can easily be forgotten at home or otherwise unavailable [27, 31]. Despite the challenges associated with using technical AAC aids regarding the energy source and the user's motor and cognitive skill requirements [30], they reduce, e.g., the shame experienced by children while using the aid [32, 33]. Eye-tracking technology and brain–computer interfaces for AAC may solve, e.g., the challenges associated with difficulties in fine and gross motor skills. However, using of this kind of technology requires sufficient cognitive skills. This kind of technology is also expensive and tied to a specific location and is thus difficult for all potential users to reach. [23, 26, 34].

The potential of e-textiles and wearables as AAC solutions has only been explored recently [35, 36]. E-textiles and wearables could overcome challenges associated with using current AAC systems, such as carrying a device or folder and impaired fine motor skills. For example, new technologies can be used to detect body and limb movements, touches made on the surface of clothing, and to measure things such as heart rate or pressure [37–40]. Recent research and new developments have focused on gesture-sensing gloves [35, 36, 41], where the technologies used do not overcome previously presented challenges, such as the need for a separate energy source. Recently, research has started exploring using radio-frequency identification (RFID) technology without a separate energy source as a communication aid in e-textiles [42, 43]. Using RFID technology as an AAC tool has been investigated, e.g., in user interface gloves [42], as breath-based AAC system ExHIBit [44], and as wireless communication textile (WCT) patches attached to the table tray of a wheelchair [43]. In Vihriälä et al.'s [43] study, they investigated using patches fabricated with passive ultra-high frequency RFID technology in a user scenario where a child with CP sits in a wheelchair. As the child touches the tag, the touch interferes with the signal between the tag and RFID reader, causing the mobile application to read out the message programmed for this tag. Enabling the child to communicate with, e.g., the mother during eating, as in the user scenario of Vihriälä et al. [43]. These studies have made preliminary observations that RFID technology could be suitable as an AAC tool in e-textiles or fabrics, i.e., as the AACloth in this study.

This study aims to explore via an online survey how parents of children with CP and communication difficulties would use the AACloth for their child. Initially, the parents were asked to describe where and why they would place the AACloth. Secondly, they were asked to describe how the child would use/control the AACloth and what the child would communicate with the AACloth. In the next section, we consider the methods used in this study, which comprises participants, survey design, and data analysis. Section 3 presents the results of the online survey, and in Sect. 4 we analyze these results. Finally, Sects. 5 and 6 summarize the conducted study and its limitations.

2 Methods

2.1 Participants and survey design

Parents with a child under 15 with CP and communication difficulties were included in this online survey. In addition to these criteria, there were no other inclusion or exclusion criteria. Parents were unrequired to have any prior knowledge of the AACloth and RFID because the beginning of the survey gave all the necessary information. Parents were recruited by distributing the survey invitation via the Finnish CP Association's monthly newsletter and Facebook pages. The invitation was also shared via the following Facebook groups: Pirkanmaa CP Association, Parents and Friends of Special Children, Parents of CP Children, and Ideas for Speech Therapy. Permission to share the survey link was requested from the Finnish CP Association and Facebook group administrators. At the beginning of the survey, participants were told that participation in the study was voluntary and that an individual is unidentifiable from research results. The data protection notice was attached to the survey link.

Altogether, ten parents participated in the online survey. One parent answered only the survey's background questions; these answers were excluded from the analysis. The parents reported their children's ages, ranging from two to 12 years (median 6, mean 6.78, standard deviation 3.87). Based on the background information from the parents, seven of nine children used one or more AAC methods. The children used technical AAC, such as Go Talk Now, TobiiDynavox and eye-tracking technology and nontechnical AAC, such as pictures, communication folders signs, gestures, and facial expressions. Furthermore, all children also used one or more mobility aids, such as wheelchair, shower chair, panda chair, and mobility strollers.

The online survey was created using the O365 Microsoft Forms software. Before distributing the survey, an expert representative of the Finnish CP Association checked the survey and gave a few suggestions for corrections regarding its content to ensure the survey questions would be easy to understand for parents whose child has CP. No other pre-testing or validation of the survey was carried out. The survey was open for about 1.5 months during February-March 2022 consisting of five background questions and four open-ended questions related to the placement

Fig. 1 Screenshot from the video linked in the survey. The parents were told that AACloth could be designed to meet individual needs regarding appearance, size, and functionality

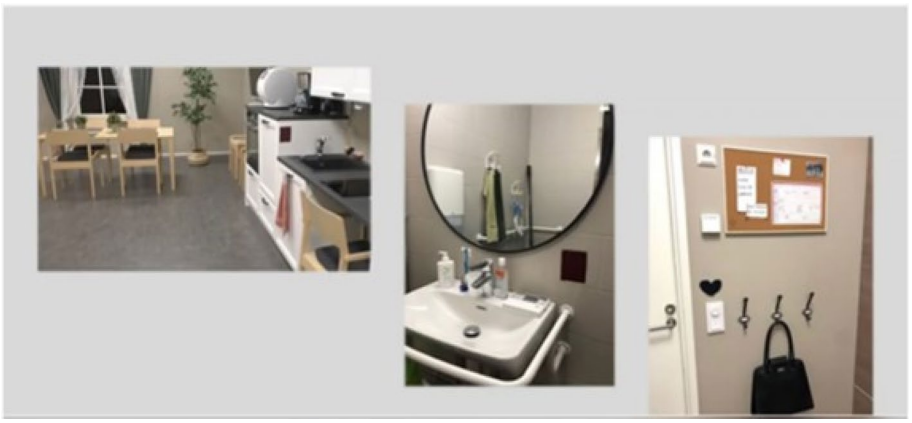

Fig. 2 Screenshot from the video linked in the survey. The parents were informed that AACloth is washable and requires no maintenance. Thus, it can be placed in any environment, such as the kitchen, bathroom, and hallway

and use of AACloth as an AAC solution (Online Multimedia Appendix 1). The survey also included a short description and video providing background information about AACloth and RFID (Online Resource 1, Figs. 1 and 2). The parents were told that AACloth is based on RFID technology, which utilizes passive RFID technology that can be integrated into a garment or fabric [45, 46]. The benefit of RFID technology is that it does not require a separate power source to operate because it gets energy from a smartphone or a separate reader. Moreover, this technology can be used as a user interface for a smartphone or computer. Furthermore, a few examples were also given on using AACloth. Parents were encouraged to freely share all their ideas without considering the feasibility of technical implementation. Parents were informed that completing the survey takes approximately 15–30 min. On average, parents spent 9 min and 59 s completing it. The fastest response time was 3 min and 5 s; the longest was 30 min and 43 s.

2.2 Data analysis

The data consisted of written answers to open-ended questions. The data were analyzed as follows. Firstly, the data was carefully familiarized by reading all answers to the survey several times. Secondly, the data was reviewed one respondent at a time to get as accurate a description as possible of each respondent's answers. Finally, the data was reviewed question by question to form a coherent picture of each answer. This study looked at the placement environments, ways of controlling, and communication situations mentioned in the responses in as much detail as possible; we also analyzed how often each topic was mentioned in the responses. Some quotes from the parents' responses illustrate the results section.

3 Results

3.1 Placement of the AACloth

Parents were asked to describe where and why they would place the AACloth. As seen in Table 1, the most popular place mentioned was for their child's assistive aid. Mobility aids were mentioned ten times. Five parents would place the AACloth in a child's wheelchair and three in a panda chair. One of these parents had answered the wheelchair and the panda chair as the places for the AACloth.

Table 1 Placement ideas mentioned by parents and the number of parents who mentioned the place

Where parents would place the AACloth	Number of parents who mentioned this place
Child's assistive aid	9
Mobility aid	8
Communication aid	1
Home environment	3
Child's clothes	2
Outside the home	1

A walking aid and special needs stroller were mentioned once in the parents' responses. A communication aid was mentioned only once. In this case, the parent would place the AACloth on a Tobii Dynavox device or its handle, and the Tobii Dynavox would be attached to a wheelchair.

The second most frequently mentioned placement was the home environment. Three parents mentioned four places at home: the dining table, bed rail, stairs, and edge of the bathtub. Additionally, two parents mentioned they would attach the AACloth to their child's clothes; one parent would also attach the AACloth to outdoor clothing. Only one said that they would place the AACloth outside the home, specifically, the car's dashboard.

Parents were also asked to justify their AACloth placement choice. Mostly, the parents explained their choices on a general level. For example, four parents hoped the chosen placement would help their child express their will, make choices, and ask for help. Similarly, one parent said, "the fabric would be useful there"; another said, "the child spends a lot of time in a wheelchair". Some parents gave more detailed explanations, such as "Because of the child's mobility disability, these places are the ones where he or she can touch himself or herself." Likewise, a parent who would place the AACloth on outdoor clothing said the communication buttons are seldom outdoors, which is why they would place the AACloth in outdoor clothing. Another parent said that interpreting is challenging outdoors, so they would place the AACloth on the wheelchair's table tray.

3.2 Operating the AACloth

Parents were asked to describe how their child would control the AACloth. In all answers, the AACloth was controlled by touching the fabric with a body part in some way. Six parents responded that their child would use one or both hands or one fist to control the AACloth. The most frequently mentioned way was pressing the fabric, answered by four parents. Other individually mentioned ways were swiping, tapping, slapping, crumpling, flicking, crinkling, making lines, and touching the fabric with the whole hand. As an illustration, one parent stated that their child would operate the AACloth "by making lines in different directions to show the options available"; the other said, "My child would slap the fabric. Hopefully, s/he would also learn to press it 'clearly,' and s/he could also learn to crumple the fabric." Although the word "hand" is not explicitly mentioned in the last two responses, it seems these children would use their hands to control the AACloth. One parent also hoped the AACloth would vibrate when touched so their child could receive tactile feedback when using it. One parent left this question un-answered.

3.3 Communication situations where the AACloth would be used as an AAC solution

In general, parents would use the AACloth in everyday communication. For example, one parent said they would use the AACloth as an AAC solution "in all possible situations to facilitate their child's communication"; the other would use it "for basic daily activities." One parent hoped by using the AACloth, their child could learn to answer yes/no and take the initiative to say, "I don't understand," in a discussion. One parent mentioned common everyday greetings, hoping their child could say "Hello" using the AACloth. Some parents described the communication situations in more detail. For instance, parents hoped the AACloth as an AAC solution would enable their child to express their needs and wishes in different environments: "What would my child like to do at school, in the bath, and on the car journey?" and "asking for things in different situations such as milk at mealtimes, warmer water in the shower, to say it feels cold outside, and to change positions when sleeping." Conversely, in four responses, parents mentioned expressing basic needs, such as asking for help or expressing pain. Two parents said the AACloth as an AAC solution could also help their child attract attention; these parents hoped the AACloth would allow their child to express the message, "I have something to say." One parent hoped that after this last-mentioned expression, their child would be asked follow-up questions to clarify the issue. In one case, the parent mentioned their

child's need to express themselves and help when they needed companionship.

4 Discussion

This study aimed to learn how parents think their children with CP would use RFID-based e-textile AACloth as a communication aid. Specifically, the aim was to discover parents' views about (1) where the AACloth should be placed and why, (2) how their child would control the AACloth, and (3) what their child would communicate with the AACloth. As far as we know, no research exists on the potential use of RFID-based e-textile as an AAC solution, as perceived by a critical stakeholder group: parents.

All parents responding to the survey said their child has a mobility aid; most parents would place the AACloth in their child's mobility aid. This decision seems practical since the child probably uses a mobility aid most of the day. In a study by Vihriälä et al. [47], also speech and language therapists identified attaching a textile-based AAC to a wheelchair as one possible user scenario when asked to elicit user scenarios for textile-based technology. In this user scenario, the speech and language therapists identified the user as a 5-year-old child with cerebral palsy. Previous studies have shown that one barrier to using an AAC aid is that carrying along a separate AAC device is difficult, and the device must be charged regularly [30]. A wireless and battery-free AACloth attached to a mobility aid could be one solution. The AACloth would always be available to the child when s/he uses the aid; a mobile phone-integrated RFID reader can power the technology attaching the power source to the mobility aid, as described in [43], is also possible. Somewhat surprising is that parents mentioned only a few placement ideas other than a child's mobility aid. The parents were told in an AACloth introduction text and video that the textile is water resistant and could be placed in different environments. The parents mentioned the following places: the bathtub's edge, the bed rail, their child's clothing, and the car's dashboard. These parents' wishes align with previous studies. For example, O'Neill and Wilkinson [25] interviewed nine parents with a child with CP and asked their views about using technical AAC tools in their daily lives. Parents specifically mentioned morning and evening care routines and outdoor activities such as swimming, cycling, walking, and horseback riding as a challenge to adapting AAC to daily life. Similarly, von Tetzchner et al. [48] pointed out that parents and professionals mentioned some everyday situations, such as swimming and transporting by bus or train, where children and young people using AAC did not participate, e.g., due to the aid's unavailability. O'Neill and Wilkinson's [25] and von Tetzchner et al.'s [48] studies reinforce the idea there are clear challenges in using current AAC methods, e.g., when bathing and going outdoors.

As mentioned, many AAC devices require adequate motor skills from the user. Therefore, one with CP may struggle using an AAC device due to impaired gross and fine motor skills [13, 24, 25]. In the AACloth introduction text and video, parents were made aware of the different ways to use the e-textile. In the video, e.g., the demonstrator pressed the smart fabric with their foot. Interestingly, all parents responded that their child would use the fabric with their hands or fist. Their child's motor skills may be even weaker in the legs than in the hands, so parents decided it would be best for their child to use the smart fabric with their hands. Conversely, the parents mentioned how the smart fabric would be used, such as by pressing, waving, and touching with the whole hand, which do not require such fine motor skills, unlike pressing a small picture on a screen or in a folder. Thus, their child may be able to press a smart fabric of a unique size in a unique place, even if the picture cannot be pressed from the tablet.

When asked about communication situations in which they would use the AACloth, parents' responses focused on everyday interactions, suggesting their children may have challenges communicating basic needs, such as asking for help, expressing pain, or needing to use the toilet. The results also show that parents would like more opportunities for their children to express themselves or influence things concerning them, such as the temperature of the shower or things they want to do on a car ride. Thus, for the AACloth to include vocabulary used in everyday communication would be important. Studies provide evidence to support this idea, as research by von Tetzchner et al. [48] states that daily situations, e.g., spending time with friends or during meals, and places, such as the kitchen and living room, are the occurrences and areas where communication aids are used most, according to parents whose children use aided communication. In Vihriälä et al.'s [49] study, also speech and language therapists mentioned ideas, e.g., to social interaction theme, when asked about purposes for usage of intelligent textiles. This theme included topics, such as, sharing information, refusing/accepting, social phrases, and the possibility to increase the amount of initiations, which are all close to topics that parents identified as important in this study.

5 Limitations

Our data consists of nine parents' responses to an online survey. Although the survey link was widely shared on various platforms, the sample size remained small. Thus, this study's results cannot be generalized to the views of all parents with children with CP and communication difficulties. Nevertheless, this study presents preliminary information about parents' views on using the AACloth as an AAC solution for their child. Interviewing the parents individually or organizing focus group discussions for parents to deepen their knowledge could allow the research to continue. Noticing that the selected group of parents, i.e., parents with children with CP, may have influenced the study's results is also crucial. Had the survey targeted another group of parents with children with complex communication needs, the results might have revealed different needs. However, people with CP are one of the most common groups who use AAC for communication [11, 12], which is why parents with children with CP were selected as this study's target group. Although the survey included information about RFID-based e-textile in text and video format, the parents may still have felt they needed more information to answer the questions more broadly, which could have also affected the study's results. Furthermore, being certain whether all parents responding to the survey read the text or watched the whole video or just partially is impossible, which may have influenced the survey's results.

6 Conclusions

Based on the parents participating in this study, their child with CP would benefit from an AAC aid that could be easily attached to different environments and does not require precise fine motor skills. Continued efforts are needed to make AAC more accessible to individuals with other types of motor and cognitive skills and communication needs. The AAC device should be easy to carry, and its control method and content should be designed individually, considering the individual's motor and cognitive skills and communication needs in different environments. Moreover, the development work should include users, their relatives, and other stakeholders, such as speech, physio, and occupational therapists.

Acknowledgements We thank Satakunta University of Applied Sciences SAMK for its cooperation in making the AACloth video.

Author contributions CE: Material preparation, data collection and analysis, writing original draft JV: Data collection and analysis, Review and editing, Supervision TV: Review and editing TI: Data collection and analysis, Review and editing, Supervision.

Funding Open access funding provided by Tampere University (including Tampere University Hospital). This work was supported by the Academy of Finland (decisions 332168 and 337861) and the Ministry of Education and Culture, Finland (TEKOS project).

Data availability The participants in this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research, no supporting data is available.

Declarations

Competing interests The authors declare no competing interests.

Ethical approval This study involved human participants who cannot be identified from the responses. A specific ethics approval was not required in accordance with Tampere University guidelines. This study followed the ethical guidelines of the Finnish National Board on Research Integrity TENK [50].

Consent to participate We obtained informed consent from all the participants. By responding to the online survey, participants agreed that they had read the privacy notice and that they consented to the use of the information they provided for research purposes.

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