

A Pediatric BCI Program for Children With Severe Neurological Disabilities: Thematic Analysis of Family Perspectives

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Research

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Abstract

Background: Children with severe physical disabilities and no expressive communication have few options for interaction and engagement with the world around them. There is a need for new technologies and programs dedicated to this population and brain computer interface (BCI) can provide new opportunities for independence. We established a novel, family-centered, clinical BCI program for cognitively capable children with severe disability. Here, we aimed to understand the potential impact on participants from the perspective of families to help guide program development and future modifications.

Methods: Children in the program were aged 6-16 years with severe physical (non-ambulatory, minimal hand use) and communication disabilities and estimated grade 1 cognitive capacity. Parents and caregivers of participants were invited to complete semi-structured interviews to discuss their impressions and opinions of the program. Children were invited to complete a simpler “yes”/ “no” questionnaire about their experience and interests. Thematic analysis was performed according to established methods.

Results: Seven parents/caregivers and 4 children from 6 families with nearly 300 hours of experience with the BCI program participated. Thematic analysis revealed that despite limited initial BCI knowledge, the program elicited positive emotional responses including feelings of enhanced independence, inclusion, and recognition for parents and children. Families were interested in contributing to BCI development to enhance their child’s future.

Conclusions: Clinical BCI programs may have positive impacts on children with disabilities and their families. Continuous engagement of parents and children is imperative to create programs and technologies that will meet the needs of this population.

Trial registration: The current study was approved by the University of Calgary Research Ethics Board, study ID:REB15-2567.

Background

Children with severe neurological disabilities and preserved cognitive function are deprived of many fundamental human rights as outlined by the UN’s Convention on the Rights of Persons with Disabilities¹. Quadriplegic cerebral palsy (QCP) is a common example where many have no ability to walk, use their hands, or communicate. Despite such severe physical dysfunction, many are highly capable intellectually but have little ability to interact with others or their environment. This situation is analogous to the locked in syndrome (LIS) well described in adults with brainstem strokes, amyotrophic lateral sclerosis, and related conditions^{2,3}. Augmentative and Alternative Communication (AAC) devices and other assistive technologies (AT) may help but are often limited in their effectiveness⁴. New solutions for such children deprived of many fundamental parts of life such as social interaction, inclusion, self-expression, and independence are urgently needed.

Brain computer interface (BCI) technology may provide new opportunities for such children to explore and engage with the world. BCI converts the user’s voluntary brain activity into computer commands that can then be used to control effector devices in their environment^{5,6}. Implantable BCIs have allowed paralyzed adults to produce functional upper extremity movements or to control robotic devices^{7,8}. Non-invasive options are rapidly emerging, many using electroencephalography (EEG) to record brain signals from the scalp⁹. Such systems are increasingly able to bypass neurological deficits to realize clinical utility in rehabilitation populations^{5,10,11}. To date, most BCI studies have been in adults, with children relatively neglected. However, we have demonstrated that typically developing children and those with perinatal stroke are able to use a simple EEG-based BCI system^{12,13}. Clinical experts in neurological disability have confirmed the high potential utility of BCI including for severely disabled children¹⁴.

While BCI technological progress is advancing exponentially, clinical programs are only just emerging. Preliminary, unpublished data from our clinical BCI program in children demonstrates early evidence supporting feasibility of such programs. Direct engagement of the children and families participating in such programs brings the potential to understand the needs and goals of end users. Such knowledge has the power to directly inform and optimize future directions of BCI technology and program

development. We therefore interviewed children with severe neurological disability and their parents participating in a clinical BCI program and performed a qualitative analysis to better understand the most pressing issues from the family’s perspective.

Methods

RECRUITMENT

All parents and care givers involved in the BCI program were approached to be interviewed. Children were invited to complete a brief questionnaire if they had been enrolled in the program for more than 3 months. Exclusion criteria for the child questionnaire were the inability to communicate “yes” “no” responses or if their BCI sessions had only been temporary as hospital inpatients.

Participants in the BCI program were children aged 6-16 years with severe neurological disability (nonambulatory, no functional hand use, severe communication impairment) and evidence of at least grade 1 cognitive capacity identified and referred by clinicians with relevant expertise. Each underwent initial screening to assess their ability to use simple BCI systems. Families then entered a custom designed, patient-driven program consisting of weekly visits to try different systems and tasks as outlined below.

The current study was approved by the University of Calgary Research Ethics Board.

BCI APPLICATIONS

A variety of BCI systems, paradigms and tasks were employed. Three commercially available, EEG based systems used were: 1) EMOTIV EPOC+ (EMOTIV, San Francisco USA), 2) g.tec intendiX (g.tec, Schiedleberg, Austria), 3) g.tec mindBEAGLE (g.tec, Schiedleberg, Austria). A description of each system is included in Table 1.

Table 1
BCI Systems. Description of BCI systems used in this program along with associated paradigms.

BCI System	Conductive Solution	International EEG System	Recording Electrode Configuration	Sampling Rate	Filtering	Associated Paradigms
EMOTIV EPOC+	Saline	10-20	14 channel AF3, AF4, F3, F4, F7, F8, FC5, FC6, P7, P8, T7, T8, O1, O2	128Hz	Bandpass filter: 0.16-45Hz	MI*
g.tec intendiX	Gel	10-10	8 channel Fz, Cz, P3, Pz, P4, P07, Oz,P08	256Hz	Notch filter: 60 Hz	Visual P300
g.tec mindBEAGLE	Gel	10-10	16 channel FC3,FCz,FC4,C5,C3, C1,Cz,C2,C4,C6,CP3, CP1,CPz,CP2,CP4 and Pz	256Hz	Notch filter: 60 Hz	MI* AEP** VTP***

BCI paradigms were based on EEG event related desynchronizations (ERD) and event related potentials (ERP). ERDs produced by motor imagery (MI) were primarily used during game activities such as driving a toy car, guiding a Sphero SPRK+ robot through a maze, painting with the Sphero SPRK+, or playing single command computer games (Figure 1). Changes in the user’s brain activity during MI generated the ERD that were recognized by the computer and converted into commands for device control¹⁵.

ERP based paradigms included, visual evoked potentials (VEP), auditory evoked potentials (AEP) and vibro-tactile evoked potential (VTP). For VEP, children were asked to focus on flashing target letters on a communication board (Figure 2). Attending to these targets creates a positive inflection in the EEG at 300ms (P300) that is time-locked with the stimulus that the computer uses to infer the desired selection¹⁶. For AEP and VTP paradigms, participants counted the number of times a target sound or vibration occurred among frequent non-target distractors during AEP and VTP, respectively¹⁷.

PARENT INTERVIEWS

We conducted in person, semi-structured interviews with the parents and caregivers involved in the program. Program enrollment occurred gradually over 3 years therefore families were included regardless of total time involved in the program. As the first study

of its kind and given limited information on BCI use in children with severe disabilities, we emphasized open-ended questions to allow parents freedom to elaborate on any topics they found important and that we may not have considered. We offered parents of the same child the opportunity to complete interviews together, though their strenuous child care needs resulted in all interviews being completed by the one parent who was most engaged in the BCI program. It was important that interviewees felt as comfortable as possible, especially while sharing sensitive details about their child's abilities, hopes, and fears. For this reason, all interviews were conducted by a single experimenter who led the majority of BCI sessions for each participant and had built strong rapport with the families. Interviews were audio recorded.

CHILD QUESTIONNAIRES

Children with verbal communication or who could otherwise express "yes" and "no" were invited to complete their own questionnaire. Questions were designed with yes/no responses. Additional space was provided for children to elaborate if they had the ability to do so, either on their own or with parental assistance. The aim was to understand participants' preferences for BCI tasks, aspects of BCI training that they enjoy and dislike, as well as their interest in future BCI activities.

ANALYSIS

Thematic analysis was performed as outlined by Braun and Clarke¹⁸. Analysis was performed by the experimenter who conducted all interviews (ZJ). Audio recordings of interviews were transcribed verbatim with personal identifiers removed. First, each transcript was read for the researcher to gain familiarity with the content and the main analysis was performed using NVivo 12 software (QRS International, Burlington, USA). In a second reading, codes were identified and then codes were refined and gathered into initial themes and sub themes. Further refinement took place and overlapping items were combined to provide a rich set of diverse themes for each question. Finally, themes were named and interview excerpts were selected in support of each main idea.

Results

At the time of this analysis eight eligible children were engaged in the program. They had collectively completed nearly 300 hours of BCI training. Seven parents/caregivers were interviewed. All individuals accepted the invitation to be interviewed however, two sets of parents were unable to participate due scheduling difficulties. Four out of five children completed a brief questionnaire. A summary of the participant families is found in Table 2.

Table 2
Descriptive information for each respondent and corresponding child enrolled in the BCI program

Respondent	Relation to child	Occupation	# of Children	Marital Status	Child Age (years)	Child's Pathology	Child's Motor syndrome	Child Verbal Comm	BCI Use Time (hrs)
R1	Mother	Teacher	2	Married	8	Bilateral Schizencephaly	QCP*	N	18
R2	Mother	Previous: Teacher Current: Stay home Parent	3	Married	11	Extreme Prematurity	Dyskinetic QCP	Y	122
R3	Cousin/ caregiver	University Student	0	Single	14	Bi-lateral stroke	Mixed QCP	N	73
R4	Mother	Paramedic	1	Married					
R5	Father	Architect	1	Married	11	Kernicterus	Dyskinetic QCP	N	55
R6	Mother		2	Married	16	Brainstem stroke	LIS	N	7
R7	Father	Construction	8	Married	6	ANEC	Acute Brainstem Dysfunction	N	5

Thematic analysis resulted in 7 themes that are presented here in no particular order. Each theme is accompanied by several anonymized experts from our participant's interviews.

Theme 1: Limited BCI knowledge among families

The idea of limited or absent BCI knowledge was commonly referenced by most parents. At the time that families were invited to join the program, the majority of what they initially knew was provided to them by the referring physician: "...we didn't have any idea of what it would be or how it would be...it was this general idea of capturing the brain signal and putting it into some sort of motion..." (R5); "I had no idea about it, nothing" (R2); "I had no idea what so ever and was thinking about the study with adults where they were thinking something and moving an arm..."(R4); "In the beginning we had no idea this was real, it was just some fake idea that we had joked about..." (R3); "Familiarity with BCI at the beginning was minimal"(R6). After this initial introduction, families understood the general concept of the technology: "It's not that I fully get it...but I understood that it was using EEG technology to read his brain signals" (R1). All four children also identified that they did not know what a BCI was when they were first invited to the program.

Limited initial knowledge was not a deterrent to participation as all invited parents and children chose to attend a preliminary BCI screening session. Additionally, all families had autonomy over deciding the frequency and duration of their involvement in the program and all families who experienced initial BCI success continued with regular training.

Not only did families express limited technical understanding many were unaware that such a program or technology existed: "This is real? This is happening right now in the world, in our little hospital that we come to twice a week? It was super exciting and we were still in disbelief until we saw her do it by herself." (R3). As per this expert from R3, the sustained interest in participation may have been attributed to observing initial BCI success. Interest in participation may have also been related to a general lack of opportunities for their children as well as a candid explanation of the limitations of BCI. As part of the initial discussion around BCI, the referring physician explained that there are many people who may not be able to use the technology and that there were no guarantees of its efficacy.

As they have progressed through the program, some parents identified an interest in understanding more about the technology and how it works. While the level of information each family is interested in receiving has differed, there is a general consensus among parents that they themselves would like to know more about the BCI technology. This greater interest in understanding seemed tied to observing their child's success in using a BCI and also wanting to be able to share this knowledge with others. *"...if you guys have some kind of specific pamphlet or something that would be really nice. It's nice for us to explain it to other people so we are not giving the wrong information or so people don't feel like it doesn't make sense". (R1); "I would really like that background. I don't know if that's because I am medical and I always have that thought process in my brain. I think that answer would be really different for my husband. It depends on the person you're dealing with." (R4).* With regards to their children some parents feel that the basic understanding of BCI is appropriate for their child: *"(She) absolutely understands that she is controlling the BCI...I don't know that you need to explain more than you already have" (R4); "Just the general understanding is good, he is pretty young right now..." (R2).* Of our four child respondents, none indicated that they knew what a BCI was at the time of enrollment but only one child indicated that they still do not know what it is. Three participants expressed that they wished to know more about the technology.

Widespread lack of initial BCI knowledge amongst our respondents did not prevent their interest and participation in this program, suggesting that parents and children were open to new ideas and technologies. This theme suggests that there are likely other factors that contributed to interest in the BCI program such as, its novelty and observing initial success of their child using the technology.

Theme 2: Emotional response to program

Interviewees often reported positive emotional responses to the program on behalf of themselves and their child. Families responded positively to the prospect of being included in something novel when there are so few options available. While they may have had limited technical knowledge on how the BCI worked, for many the notion that their child could affect their environment with their minds was very exciting.

When we first heard about it I was like, "Oh my gosh this is so great", because we have been looking for something for (our child) that was something he could do. You know, kids are in extracurricular activities and he didn't have anything like that and we were just wanting him to have something outside of home or school that he was able to participate in (Respondent 1)

I was blown away at how amazing it was. The technology to me was super cool and that we had access to this technology. That is just showed up and we didn't have to search this out. (Respondent 7)

After witnessing their child's initial BCI success and progress throughout the program, these feelings of excitement seemed to continue for parents and children. Parents often identified that their children were not only excited and enjoying the program but were feeling a sense of pride in their BCI performance: *"...we framed it and went to see our friends and we took this painting, wrapped it up so that he could present it to his mom in front of all of our friends and he was so proud." (R5); "...I think it's given her, I don't want to say a sense of purpose, but I really do feel this accomplishment that "Hey look what I can do" and the fact that she did these things with her dad and cousin and she can beat both of them. She deserves to feel proud, she deserves to feel like wow I am better at this than somebody else. It's awesome" (R4).*

Responses suggested that enrolment in the BCI program is not simply an enjoyable and meaningful experience for the child but for the parents and family members as well: *"That first day was amazing, we had to show everyone that this was happening and look at what she can do" (R3).* A subset of parents did express feeling worried or vulnerable in the initial phases of the program, prior to their child's first BCI session. For some parents these worries were associated with previous disappointments when trying other programs or technologies.

"That fear of he might not be able to do it and activate the things was kind of hard to put ourselves out there because we tried so many different activities for him that he wasn't able to do." (Respondent 1)

"Everything that we try there's only the worry of disappointment. You get your hopes up about something, about where something is going and then you're just disappointed that it goes nowhere." (Respondent 4).

Respondent 7 was initially worried about whether his son still had cognitive capacity after his diagnosis and was relieved after the initial session saying: *"Most importantly for me it was in that interaction I knew that (he) was still there. At that point I was really worried about him."* (R7). Another parent expressed worry about the appearance of the device and if it would cause discomfort: *"I wanted something discreet in appearance. Along with the appearance and drawing more attention to our daughter, the only worry I had was it going to cause her any physical or mental pain."* (R6).

These emotional responses are closely tied to the idea that an unmet need was potentially being filled by this program. For some it is the excitement of finally finding a program that caters to their child's abilities and allows children to express themselves in a new way. For others this program has answered some important questions about whether their child is still aware of the world around them. Even the initial fears expressed by parents were closely related to not having had success in previously explored opportunities. It is evident that these families have been actively searching for a space that is designed for their child's unique needs and that this is the first time for most if not all, that they have found that.

Theme 3: Independence

The most commonly occurring idea throughout our interviews was the concept of independence. Many parents felt that this program was their child's first opportunity to experience true independence: *"...prior to this he wasn't able to do something on his own"* (R5); *"...my son was having independence and loved it, that was just what made the difference"* (R2). This program was also an opportunity for children to feel a sense of ownership over their actions when much of their experiences to date have been very passive.

"...so much stuff will come home from school and it's like, you can tell (he) did not do that. I know my son's capabilities. It's just so nice and for him too. I'm speaking for him but it's just really nice for him to create something and know that he did it." (Respondent 1)

"...he was able to relate to it as his own product. I think it's the biggest impact on him because he was able to, through BCI, translate his effort into something physical for the first time in his life". (Respondent 5)

"(Her) activities involve going to the mall or watching a movie. There's not really any active or many active things that she can do. So having an activity that she can do physically and look forward to has really impacted us." (Respondent 4)

Experiencing this newfound independence played an important part in maintaining the child's interest in the program: *"I think that it's a motivator and it keep him engaged...he doesn't have a lot of those, "I did this all by myself", moments."* (R1). When asked what they enjoyed about the program, all children indicated that they liked being able to control things on their own. It is important to consider that for these children, participation in the BCI program is heavily dependent on those around them. Parents and caregivers must bring the child to each session, children often require assistance to maintain appropriate seating position, the headset placement and technology are controlled by the researcher. Although the majority of these sessions require assistance, the moments where the child is able to create something of their own volition is impactful enough to provide a feeling of enhanced independence. This highlights the idea that even seemingly small gains in function are significant for children and families in these situations.

Theme 4: Inclusion

The idea of inclusion appeared throughout many interviews. Respondents discussed inclusion both within and outside of the BCI program. Parents who had been searching for an activity that their child could take an active part in felt that the program had provided a sense of belonging. Being included as a member of a team was an important consideration for families and children: *"I feel like I'm a broken record but it just is really nice for us to belong to something. Something else because we didn't have that before."* (R1); *"This was not just like okay there's another doctor that will be looking at you but he will be a researcher and he gets to take part in this research. He's all of a sudden smiling and trying to tell everybody that he's a researcher."* (R5).

Parents made frequent reference to their child being included in conversations: *"You are communicating with her as opposed to communicating to her through someone else"* (R4); *"From day one you have been willing to understand him..."* (R5). Some also shared that they enjoyed the inclusion and interaction outside of BCI training. This idea was supported by responses from children

as all participants expressed that they felt their communications were understood by the BCI team. These responses have highlighted

"Sometimes we start with the BCI and we end up staying for hours just to catch up and talk to you. It's about the human connection for (her)." (Respondent 3)

"This is so nice for her. She gets forgotten in everything that happens. At school people talk at her so I think anything that she does where people are talking with her and asking her for her involvement is amazing...it's that personal connection" (Respondent 4).

Inclusion has extended past the program into the home setting, where parents described changes in family dynamics.

"When they come here and they see that it's [their brother] doing it independently they are like, "What?!". They get competitive with him. Especially with the trucks, his brothers are like, "Oh I'm going to beat you". They get competitive and see him as an equal not as their disabled brother that they always have to help or assist or accommodate". (Respondent 2)

All children referred to some form of inclusion or interaction as something they liked about the program, this was either playing games with their families, meeting other kids that use the BCI or spending time with the BCI team. In addition, all children agreed that more participants should be invited to join the program and that we should organize camps for them to meet other children and practice BCI together. These responses highlight the domino effect that was seen by many families through their involvement in the program. Giving a child the opportunity to participate and contribute allows others to learn new ways to interact and relate to them. Integrating children in discussions and taking time to understand their communication styles and their BCI ability provides a foundation for inclusion and a catalyst point for change in their interactions outside of the program.

Theme 5: Recognition

Families often referred to feeling that their input and contribution to the program was valued and recognized. Parents consistently described the importance of feeling that their thoughts and feelings were truly being sought and implemented: *"They wanted all of our ideas so they could make build something different and better" (R1); "I feel like we do influence the program, our feedback is heard and listened to" (R5).* This idea is closely related to the idea of inclusion but differs in that it incorporates the families effect on the program. There is significant emphasis placed on recognizing the lived experiences of the children and their families and using these experiences to shape the program. Seeing the effect of their suggestions and influence on the program is likely motivation to continue involvement as many families have not had the opportunity to share their needs and see them come to fruition: *"It's a unique thing to work with a team that is really actually interested in what you want out of it or is interested in what you have to say and actually listens to you" (Respondent 4).* There are suggestions that may not be ready for implementation such as those including a need for more advanced technologies however this should not negate discussions around what families would like to see in the future.

Theme 6: Personalization of sessions

Respondents often referenced the various ways that BCI sessions were tailored specifically to them or their child. Personalizing activities for each child played a key role in maintaining their involvement in the program.

"They asked him what else he wanted or what he liked and he said video games and immediately, I think the next week you guys changed it from trucks to video games. That was because of (him)." (Respondent 2)

"It was obviously very helpful that we found painting and that she loves it so much but if we only had the car and every week that was all we could do we would be done; we wouldn't be coming here every week." (Respondent 3)

Families referenced the importance of having flexibility during BCI sessions and catering to the child's mood and interests; *"You honour what she wants to do" (R4); "...he wasn't loving the spelling as much as video games so you would split it half-half" (R2).* Personalization was identified as any act made to tailor a given BCI session to accommodate the child or the family. This included adjustments to scheduling, length of session, and types of activities introduced. Many of our participants have complex needs and schedules therefore flexibility was imperative to promote participant engagement. For almost all participants, this was the first

program that allowed for active participation. The option to personalize sessions and choose between activities may have been even more valuable for our participants who have previously been extremely limited in play and communication.

Theme 7: Thinking about the future of BCI

Involvement in the program has helped parents envision new opportunities for their child's future and ways that BCI technology can progress to meet their unique needs.

"To be honest it's so crazy you saying career because I have never considered that for him... I haven't really looked that far into it because I've never thought he would have the capabilities. That's what's really nice about this program, it just gives you a lot of hope. It makes you think there's a lot of possibilities for (him) in the future doing some kind of work." (Respondent 1).

Some families were interested in the advancement of specific BCI applications while others were interested in the improvement of technical components such as signal quality: *"That's where it can improve. The clarity of the signal...maybe the filtering of the signal. Improve the consistency and reliability so there is no unnecessary frustration on the kid's side" (R5).* Communication was most commonly referenced as an area that could impact their child's future: *"I do care if she can drive her wheelchair with her brain but I don't care about that as much as I just want to talk to my daughter" (R4).* Enhanced environmental and wheelchair control were referenced frequently along with BCI for support in school activities; *"If she could send signals with the BCI to control her wheelchair that would be amazing" (R3); "...be able to turn lights on or off or open and close a door or turn a microwave" (R7); "Educational things, writing or even reading. If the book was online and he could flip through the pages" (R2).* When asked to identify their top two choices for activities they would like us to develop further only one child indicated an interest in BCI for environmental control. Three participants chose gaming as one of their top two choices for further development. BCI for art, music, surfing the internet and using social media were also selected.

Discussion

Our successful long term engagement of families and their continued interest in exploring BCI technology has warranted a close look at the impact of such clinical programs for children with severe neurological disability. The idea that BCI can provide new avenues for independence is evident by the responses from our families, and is not entirely surprising. New found independence is certainly a driving component highlighting the impact and success of this program but is likely not the sole factor. The overarching idea of purposeful versus passive involvement is a key link across many of the identified themes. This idea is best described as a feeling of active and intentional contribution; and positively affects patient engagement and program development.

Social engagement for children is closely impacted by how accessible their environments are and the degree to which their interactions are positive¹⁹. For children with severe disabilities these opportunities for participation can be quite limited. Our respondents referenced little to no options for their child for engagement in activities outside of the home and some even experienced difficulties with participation in family activities. This lack of opportunity is a concern that continues through development as adults with CP and communication deficits may experience difficulties being accepted and participating in their communities²⁰. Although children with physical disabilities want to expand their social interactions beyond the family unit they often participate less frequently and are not as skilled as their peers^{21,22}. These difficulties are amplified for children with no movement or communication. This program has given participants the opportunity to play and interact in new ways by "leveling the playing field". Where once they were simply observers, our participants can now demonstrate competence or even superiority in tasks to others. Parents feel that they and their child are included as part of the BCI team which has also helped expand their child's social interaction outside of the family. Meaningful and inclusive interactions between the BCI team and families have certainly facilitated a continued interest in the program. Our findings also echo the considerations made in patient centered care including the importance of collaboration, communication and inclusion^{23,24}. Parents and children feel that their opinions are sought out and implemented which helps to personalize BCI training for each child and inherently promotes further success in the program and continued engagement.

Families have progressed from being largely unfamiliar with BCI initially to now considering new potentials for this technology in their child's future. Similar to patient and family engagement in health care, it is important to support active participation of our program members on multiple levels to optimize success^{25,26}. Including parent and child perspectives will address the disconnect

between user needs and types of BCI systems available, an incongruence that is commonly related to abandonment of AT²⁷. Functional independence is closely linked to quality of life (QOL)²⁸, and parents and children alike have expressed interest in BCI applications for wheelchair control. Parents and participants both expressed interest in advancing communication tools. This need is in line adult literature, where individuals with cerebral palsy have identified that their ability to participate in life is closely related to communication²⁹. Children were also keen to identify expansion of gaming and art activities as priorities for BCI development. The field of BCI gaming is growing exponentially but there appears to be a trade-off between developing games that can be controlled well with the BCI and developing games that are engaging¹¹. By pairing with developers and sharing user perspectives, we can expand the number of games available and the social network of these children through online gaming platforms.

Conclusions

Although AT have been shown to help improve the QOL for individuals with physical impairments their use may be limited by the severity of the participant's disability^{30,31}. Our BCI program addressed an evident need for new access methods for children with severe disability. Feedback from parents and children support the continuation of this program and have provided critical insights into the needs of this unique population.

Abbreviations

AAC: Augmentative and alternative communication

AEP: Auditory evoked potentials

AT: Assistive technology

BCI: Brain computer interface

EEG: Electroencephalography

ERD: Event related desynchronizations

ERP: Event related potentials

LIS: Locked in syndrome

MI: Motor imagery

QCP: Quadriplegic cerebral palsy

QOL: Quality of life

VEP: Visual evoked potentials

VTP: Vibro-tactile evoked potentials

Declarations

Ethics approval and consent to participate

Informed consent was obtained for all participants. The current study was approved by the University of Calgary Research Ethics Board, study ID:REB15-2567.

Consent for publications

Consent was obtained to share all participant images included in this manuscript.

Availability of data and materials

Datasets generated and/or analyzed during the current study are not publically available due to the private nature and length of full interviews but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author's contributions

ZJ was the lead researcher responsible for BCI session planning, participant training, family engagement, parent interviewing, data collection, analysis and manuscript generation. EZ was the lead researcher responsible for BCI program technology development, project inception, assisting in participant sessions and manuscript editing. DK assisted in participant sessions and manuscript editing, EKL assisted in BCI technology development, participant sessions and manuscript editing. AK was the principal investigator of this study responsible for project inception, participant recruitment and providing clinical expertise.

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Figures



Figure 1

BCI Activities and Clinical Applications. Sphero painting activity (2 left frames). Participants uses the EPOC+ headset to drive a sphero SPRK+ robot over a canvas covered in paint. Children chose their own colors and create unique artwork. A young participant uses the EPOC+ to drive a toy car while recovering from a severe neurological illness (top middle). Participants attempting to use the g.tec intendiX spelling system for communication after debilitating stroke (2 right frames). A young man proficient in BCI gaming tries a new popular commercial game modified for EMOTIV control (bottom middle).