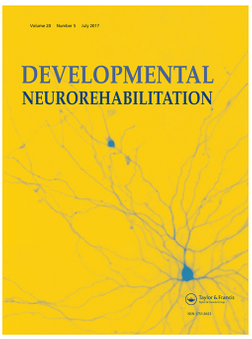

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ORIGINAL ARTICLE

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Gaze-based assistive technology used in daily life by children with severe physical impairments – parents' experiences

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ABSTRACT

Objective: To describe and explore parents' experiences when their children with severe physical impairments receive gaze-based assistive technology (gaze-based assistive technology (AT)) for use in daily life. *Methods*: Semi-structured interviews were conducted twice, with one year in between, with parents of eight children with cerebral palsy that used gaze-based AT in their daily activities. To understand the parents' experiences, hermeneutical interpretations were used during data analysis. *Results*: The findings demonstrate that for parents, children's gaze-based AT usage meant that children demonstrated agency, provided them with opportunities to show personality and competencies, and gave children possibilities to develop. Overall, children's gaze-based AT provides hope for a better future for their children with severe physical impairments; a future in which the children can develop and gain influence in life. *Conclusion*: Gaze-based AT provides children with new opportunities to perform activities and take initiatives to communicate, giving parents hope about the children's future.

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Activities in daily life; cerebral palsy; eye tracking controlled system; self-help devices; parental hope; qualitative

Introduction

All children, regardless of disability, have the right to grow to their full potential and participate in society.[1,2] In Sweden, as in many other countries, children with physical impairments live with their parents, and to promote the children's participation, health, and well-being in daily life, parents take on several roles. Parents often act as interpreters for their child, they advocate for their child in different situations,[3] and educate others in how to best support their child.[4]

The most common cause of physical impairments in early childhood is cerebral palsy with a rate of about 2 out of 1000 live births.[5] Cerebral palsy is defined as a group of permanent disorders that involve motor impairment, often accompanied by other developmental disorders like disturbances in cognition and communication.[6] Children with cerebral palsy with severe motor impairments and without speech are a small group for whom it is especially challenging to be a parent. These children are dependent on the assistance in all activities[5,7] due to profound motor and communication impairments, and concomitant difficulties such as cognitive impairments.[6,8] They require a personal assistant or a parent to be with them at all times,[9] for example in play, communication and in feeding.[5,7,9] Research indicates that children with severe physical impairments and without speech have limited opportunities for social interaction[10] and are involved in few activities, with little diversity.[11,12] The children's participation in activities is especially compromised for those that are not able to control any body parts voluntarily other than their eye movements. Such restricted participation may have a negative impact on their learning and development.

Assistive technology (AT) refers to a multiple of devices that are used to enhance performance and reduce the negative impact of conditions on daily functioning for persons with impairments.[13] The use of computers as AT can promote independence and learning of children with severe physical impairments such as cerebral palsy by gaining access to a variety of activities within play, education and communication.[14] Gaze-based AT is a computer controlled by eye gaze, and may be one way to provide children with severe physical impairments and communication impairments with opportunities for self-determination and activities.[15,16] A few case studies propose that gaze-based AT shows promising results for children with severe physical impairments to enable them to perform activities.[17–21] If so, a gaze-based AT can be used by children to explore and participate in activities, leading to new opportunities for learning and development.

Non-verbal children with the most severe motor impairments need to rely on their facial expressions and their eye gaze in interactions with other people.[22] Communication difficulties occur with unfamiliar partners but sometimes even with those that are familiar to the child.[23] Some children have low-tech communication boards or books with pictures for eye gaze pointing to facilitate communication. Nevertheless, it can be difficult for others to interpret what picture the child is looking at. Instead, parents often communicate with these children by asking yes and no questions, and children respond to these by indicating yes or no by, for example, showing different facial expressions or looking up or down. Hewitt-Taylor[9] found that parents experienced that their children need to rely on others making the effort to initiate interaction with them as they not could initiate interaction by themselves. Another finding was that parents experienced their children

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to be underestimated, or misunderstood as not wanting to interact, or misunderstood as not understanding, due to their difficulties interacting and communicating with other people.[9] Hence, parents worry about how the future will be for their child with profound impairments, such as whether they will be able to live on their own or whether they will achieve a sense of purpose in life or have a productive future.[24]

Focusing on parents' experiences of gaze-based AT in daily life may give valuable knowledge about how gaze-based AT can be used in everyday life by children with profound impairments. Earlier studies have shown that children can learn over time to control a gaze-based AT with their eye gaze, and that it can be usable for activities in daily life.[25,26] These studies have provided evidence for increased eye gaze performance over time, and found that using gaze-based AT provided children with an activity repertoire. Nevertheless, parents' experiences are needed to more fully understand what happens in day to day life with a gaze-based AT and what children's use of gaze-based AT means to parents. Qualitative research using interviews to explore parents' experiences of gaze-based AT is lacking and is therefore urgently needed. Parents are the main people who support the child in using any intervention in the family context,[27] such as in the use of gaze-based AT. Professionals therefore need to understand how parents experience and view children's use of gaze-based AT so they can be better prepared to support parents and children in their everyday life. The aim of this study was therefore to describe and explore what it means to parents when their non-verbal children with severe physical impairments receive a gaze-based AT to use in daily life.

Methods

A hermeneutical approach informed by the Gadamerian perspective[28] was chosen in this study to provide the opportunity to go beyond what is immediately given in the parents' stories, and to gain a deeper understanding of what it means to parents when their children use gaze-based AT in everyday life. According to Gadamer,[28] all understandings are situated within traditions. An historical awareness and reflexivity are therefore necessary for researchers so they can be aware of pre-understandings and fore-meanings grounded in their own expectations and in traditions instead of in the parents' experiences. Hermeneutical interpretations always take place within perspectives. The first author was experienced in gaze-based AT and in working in a pediatric rehabilitation center. This study was conducted from the stand point of Occupational Therapy, which concerns human doing and how doing activities can contribute to different dimensions of meaning in people´s lives.[29] With this perspective, this study focuses on parents' experiences of how their children with severe impairment might go from a position of not being able to do, to situations of doing activities when using their eye gaze to control a gaze-based AT.

Study context

A gaze-based AT is a computer that is controlled with eye gaze. The software in the gaze-based AT was individually adapted, by a multi-professional communication team, with pages with pictures and speech output relevant to each child's specific needs for activities and communication. Selections on the computer were made by children by pointing to a certain picture with eye gaze, and gazing on it for longer than the pre-specified dwell-time, usually about one second. When a picture was selected, the speech output spoke out the pre-specified message, for example 'I want to go out'. During the present study all children used the gaze-based AT at home and in school. They were supported by a multi-professional communication team over a period of nine to ten months. The present study is part of a longitudinal project in which children with their parents and teachers participated in a gaze-based AT intervention program over 9–10 months to implement the gaze-based AT at home and at school. The longitudinal project investigates gaze-based AT for children with severe physical impairments. The current study focuses on parents' experiences.

Participants

Eleven parents (six mothers and five fathers) to eight children that used a gaze-based AT, participated in the present study. In the case of three children, both parents participated, whereas either a mother or father participated for five children. The parents were recruited from the longitudinal project.[26] The inclusion criteria for this study were parents who had a child (1) that started the gaze-based AT intervention at one pediatric rehabilitation center in Sweden during August 2010 to April 2013 with planned usage at home, (2) aged 5–15, and (3) with severe physical impairments, without speech. An exclusion criterion was children with planned gaze-based AT usage only at school. This criterion was set up to ensure that all included parents gained experiences in children's use of the AT. The included parents had a mean age of 42.2 (SD 3.2) and there were between one and four siblings to the child that used the gaze-based AT. These eight children were between five and fifteen years old at the start of this study. All children had cerebral palsy with severe impairments in both manual ability and in gross motor function, and with a profound need of assistance in all everyday activities. All children had tried other computer input devices before the gaze-based AT but only two of them had the ability to control another device, such as a switch. Due to the severe motor impairments all eight children were assessed to have best developmental opportunities with a gaze-controlled device. In Table 1, children's characteristics are summarized. No child had speech and they used facial expressions and eye gaze as their primary communication methods. All children had a low-tech communication board or single pictures for eye pointing, but parents reported that these were seldom used for communication at home. Two children were assessed to have normal cognition, four children had unspecified cognitive impairments, whereas for two children it had not been possible to assess cognitive level due to their profound impairments. The children attended a special school, a special preschool, or a mainstream school.

Interviews

The interviews were performed during August 2010 to February 2014, and the parents of each child were interviewed twice, resulting in 16 interviews. The parents were interviewed at the beginning

Table 1. Children´s characteristics.

Characteristics	Children (n = 8)
Boys	8
Age m (sd)	9.5 (4.2)
Use of other computer devices (before gaze-based AT)	
A single switch	1
Head-controlled mouse	1
No device	6
Diagnosis	
CP dyskinetic	4
CP spastic diplegia	2
CP spastic tetraplegia	2
Gross motor function (GMFCS)*	
Level IV	4
Level V	4
Manual ability (MACS)*	
Level IV	5
Level V	3
Communication function (CFCS)*	
Level IV	7
Level V	1
Cognition	
No impairment	2
Unspecified cognitive impairment	4
Unknown (not been possible to assess)	2
Vision	
Refractive error	3
Alternating strabismus	2
Hearing	
Hearing impairment (no need for hearing aid)	2
Epilepsy	3

* GMFCS: Gross Motor Function Classification System,[30] MACS: Manual Ability Classification System,[31] CFCS: Communication Function Classification System,[32] scales I–V, with V representing the most restricted ability.

of the child's gaze-based AT usage and about one year later. This was done to get a better understanding of how parents' experiences unfold over time in their lives as their children receive and use a gaze-based AT in daily life. Having data from the first interview also made it possible to relate to this interview during the second one, for both interviewee and interviewer. Joint interviews (with both parents, in the case of three children) or individual interviews (three mothers and two fathers) were conducted, depending on what parents preferred.[33] The first interview consisted of two open-ended questions covering; (a) how the child had been using computer devices up to that point, (b) thoughts about the child starting to use the gaze-based AT. The second interview had four open-ended questions as follows; (1) how the child had been using his/her gaze-based AT, (2) what parents thought it meant to the child to use the gaze-based AT, (3) what it meant to the parents that the child used the gaze-based AT, (4) thoughts about the child's use of gaze-based AT in the future. Probes were used, such as: Would you explain that? Tell me more about it? Could you give me an example? The purpose of these probes was to clarify and increase the depth of responses.[34] For example, when parents said that, by using the gaze-based AT, their children could do things they could not do before, they were encouraged to give examples of and describe such occasions, and tell more about their experiences of their children's doing before the gaze-based AT. The interviews were held in the participants' home or in a separate room at a paediatric centre, depending on what the parents preferred. The total interview time for all interviews was 11 hours.

Data analysis

The interviews were recorded on a digital recorder and then transcribed verbatim. The hermeneutical analysis was consistent with Gadamer's philosophical hermeneutics.[28] Initially, all transcripts were read through several times to try to understand what the texts were about. This was done to get a sense of the whole.[28] Sentences and parts of the text were brought out that described something about the participants' experiences in relation to children's gaze-based AT usage. With the intention of remaining open-minded toward the text there was a search for things that had not been thought of before or that were surprising in some way during this process. The hermeneutical task is to enter into dialogue with the text by asking questions and trying to find the answers.[28] The analysis was guided by questions such as: What events are described in relation to gaze-based AT and which of these seem to be important for parents? Experiences with a similar interpretation were brought together in six sub-clusters. The sub-clusters were then further explored and compared with each other by moving back and forth between participants' descriptions and sub-clusters to search for similarities and differences between the sub-clusters. Sub-clusters representing similar meanings of experiences were brought together, which resulted in three clusters. There was a move back and forth between the 'steps' described above in finding sub-clusters and clusters. During the whole process all the authors discussed and reflected upon variations and nuances in the participants' descriptions of their experiences, and then carefully discussed rival interpretations of the participants' experiences. A striking finding during the analysis was that expectations and hopes for the children's future were present in the participants' descriptions of the children's gaze-based AT usage. To deepen the understanding of the clusters and sub-clusters, Mattingly's work[35] considering the creation of hope in everyday life among parents of children with serious impairments or conditions was used. To do this, clusters and sub-clusters were compared with each other and further explored by moving between them and the research of hope.[35] During this process, new overall upcoming pre-understandings were validated against the participants' experiences, sub-clusters, clusters and the research of hope[35] in a back and forth process, and revised until the overall understanding integrated both sub-clusters and clusters in the interpretation. The overall understanding that emerged was that children's gaze-based AT usage shapes a hope for parents of a better future for the children. They hoped for a future in which their children could use their inherent potential to develop and to gain influence in life.

Valid interpretation

To establish valid interpretations,[28] namely finding the most plausible interpretation given the context of the present study, all three authors participated in the reading of interview transcripts and in the analysis and questioning of interpretations. The phrases and texts were brought out from transcripts by the first author and then discussed with the co-authors who were experienced in qualitative research. This was done to verify that phrases were related to the phenomenon and that no sentences or parts of texts that could be related to the meaning were ignored. Peer-examination between the co-authors was also used during the research process. For example, potential meanings that were raised by each author during analysis were critically examined by the other authors during discussions. A reflexive diary was used by the first author throughout the whole process with the intention to

make her aware of her own bias through pre-understandings of the phenomenon. These were raised with the other authors during peer-examination and constantly revised in the diary during the whole process by the first author. To allow readers to judge the transferability of the findings to other contexts[34] the criteria for selection of participants, the children's impairments, the research process including the procedure of the interviews and the analysis, were carefully described. In addition, colleagues were also used for peer-examination at seminars during the research process.

Ethical considerations

The study was approved by a regional ethical review board in Uppsala, Sweden (2010/316). All parents were informed that they could withdraw from the interviews at any time without giving any explanation.

Results

The findings comprise the following three clusters: (1) demonstrating agency, (2) opportunities to show personality and competencies, and (3) infinite possibilities (see Table 2). These clusters led to an overall understanding concerning parents' hope for the children's future and this is presented last in the findings.

Demonstrating agency

The gaze-based AT made a huge difference for parents, as it provided the children with opportunities to demonstrate agency in the situation by using the gaze-based AT to express basic needs and show choices and self-determination.

Expressing basic needs

Parents described that children had tried several devices over the years without being able to control any of them. For the parents, the gaze-based AT was a tool that finally had provided their child with a language which gave the child opportunities to take his or her own initiatives to express basic needs, which had not been possible before. The parents described how the speech synthesizer in the gaze-based AT spoke out for them what the children had chosen to communicate. Children for example took the initiative to express basic needs such as being thirsty, that they had an itch, or were in pain. One parent reflected on the new situation where the child by himself took the initiative to express being thirsty: '*…so many times he's been thirsty, but no one even thought about asking him. It's just a small piece of evidence of what a huge impact it has.' (Parent 3)* Children initiating to express their needs meant that parents could give a timely response to these needs. Before the use of gaze-based AT, parents' needed to find out what the right question would be to ask the child in each situation during the day. However, as the children became able to express their needs this gave parents insight about earlier potential missing opportunities for them to meet their children's needs.

The children taking their own initiatives also meant for the parents that children sometimes expressed needs the parents did not know they had, for example the need for help with pain. These unknown needs were surprising for the parents and indicate that the children´s self-perceived needs became more obvious for the parents. One parent explained how the gaze-based AT made them understand more about the child's pain: '*Without this computer, he would have cried and cried from his pain without us knowing where it hurt. Now we know.' (Parent 4)* This quote illustrate the relief parents expressed when they understood where in the body the child had pain, and thus could help the child, for example by giving a pain killer or doing stretching exercises. The gaze-based AT was seen as an opportunity for all people involved with the child to better understand what needs the child perceived. This was a relief as parents did not need to worry so much that others not would be able to understand the child's needs.

Table 2. Sub-clusters and clusters.

Clusters	Sub-clusters
Demonstrating agency	Expressing basic needs
	Choice and self-determination
Opportunities to show personality and competencies	Personality becomes visible
	Competencies become visible
Infinite possibilities	Always more steps to take
	Handling the gap

Choice and self-determination

For the parents, the gaze-based AT gave the children the opportunity to do activities on their own which had not been possible before. Children took advantage by using the gaze-based AT to show their own will through what they chose to do. That children were doing something on their own, regardless of activity, was important in itself for the parents as the children had become independent in a situation. This was emphasized by parents to be a new development. Through the gaze-based AT, children showed what they were interested in doing, for example, they chose on their own to play games, listen to music or look at photos. According to the parents, doing things independently made the children grow in self-worth as they discovered what they were capable of doing. From this, children used the gaze-based AT to demonstrate agency in the situation by showing their will.

The analysis revealed that parents put a high value on the fact that their children could show what they wanted to do, as this had been difficult before. At the same time, being able to independently do things meant for the parents that activities the child chose to do were not always in accord with the parents' preferences. For example, if the parents asked the child to tell them something, the child could shut down the communication pages and instead use the gaze-based AT to play a game, or watch a video. One parent reflected on her child's action in this way: '*I don't want to do this as you want, sort of… (chuckles). It's so great. It's on his conditions, it truly is. It's been so good.' (Parent 1)* This quote highlights that even if there were disagreements between children and parents, the most important thing for parents was that their children could now show their will and also had gained power over what to do.

Seeing that children could show and express their will, the gaze-based AT was imagined to help the children to 'speak up' for themselves when moving away from the parents to live in other residences. If the children used the gaze-based AT with the speech synthesizer to tell things to others, this would be

easier for other people to understand, than interpreting the child's facial expressions. One parent reflected on what this meant to her: '*Yes, it also feels a bit better as when he moves [away from home] he will actually be able to communicate. Now, whether they'll listen or not remains unknown, but at least he will be able to express his thoughts and viewpoints. And he can actually tell us stuff in confidence, as well.' (Parent 2)* This illustrates that parents were concerned about the children's vulnerable future situation, and how the gaze-based AT relieved them somewhat by giving them hope that it could give the children opportunities to demonstrate agency even later in life.

Opportunities to show personality and competencies

For the parents, the children's use of gaze-based AT uncovered the child's inside as the inherent personality and inherent competencies became more visible for them and for other people.

Personality becomes visible

This sub-cluster was related to occasions when the children's personality became more visible during gaze-based AT usage. The parents described how the children took opportunities to express their sense of humor and feelings to other people in situations at home and in school when using the gaze-based AT. Parents knew their child's personality well but a child would reveal personality to a greater extent during gaze-based AT usage than without, which gave new insights into the child's personality, such as 'being as much a teaser as the father'. Parents described how children used the gaze-based AT to tease and play jokes on different people at home and at school.

Personality becoming visible was also characterized by occasions when children used the gaze-based AT to express feelings and to become personal with others. Parents emphasized that children took the opportunity to use the gaze-based AT to express their feelings directly to a relative or a classmate. One parent for example, described when her child met his aunt and they were sitting at the gaze-based AT and how the child suddenly went into the communication pages in the gaze-based AT to express his feelings to the aunt. This quote shows how the child's feelings became visible to the aunt: '*So, he simply activated it [the gaze-based AT] and said. "I just want to tell you one thing; I love you"…That was just ground-breaking. It goes to show that he has a lot inside that he couldn't express before.' (Parent 2)* As this quote shows, it was a big event for the parent that the child could express his feelings. These occasions, when children expressed their feelings or sense of humor, was a sign for the parents that their children had finally been given a language as they, with the speech synthesizer in the gaze-based AT, were able to tell things to others on their own initiative, which was not possible before.

Competencies become visible

The analysis revealed that when children used the gaze-based AT the children's inherent competencies became more visible to the parents. Their competencies became visible as children showed that they knew how to perform different activities on the gaze-based AT. This confirmed competencies parents already sensed their children had, although they had not been sure. It was also important for parents that other people would be able to see their children's competencies during gaze-based AT usage, and would thereby better understand their child. For example, it would make it easier for a teacher to understand what the child needed to learn. Being able to see children's competencies also highlighted the child as a 'learner', as it became visible to parents that children learned new things when using gaze-based AT. The following quote shows how a parent experienced that the child gained competencies by using the gaze-based AT: *'He loves his computer, big time. He has mastered it. I dare say he's the best user in our family (chuckles). When we use it, he knows exactly how it works.' (Parent 5)* The above examples show how parents noticed that children learned new things by using the gaze-based AT. For parents, the revelation of these competencies highlighted the child as a 'learner', who could gain new own experiences and learn new things through the gaze-based AT usage.

Infinite possibilities

For the parents, the gaze-based AT opened up infinite possibilities for the child to do and learn new things. Infinite possibilities meant that there would always be more steps to take for the child to develop by using the gaze-based AT, but also created a gap between what the children were doing and might be doing in the future. This gap needed to be handled by parents.

Always more steps to take

Taking further steps was related to having finally found a tool that the child could control on its own. Parents described that their children currently used the gaze-based AT for short periods during the day and that gaze-based AT usage could be tiresome for the child. Nevertheless, they imagined a future when the gaze-based AT was used more regularly by their child. For the parents, the gaze-based AT had a wide area of use, with few limitations for their child. Therefore, overcoming the children's profound limitations with the gaze-based AT opened up infinite possibilities to take further steps in providing the child with challenging activities to encourage further development. Learning new abilities such as to write, read, count, and to go surfing on the internet and perform tests in school were mentioned by parents and can be seen as challenging steps. For the parents, being able to perform activities with the gaze-based AT also offered an opportunity for children to find something meaningful to do in life, such as a hobby. In the infinite possibilities there was hope for what the future could hold for the children. This is illustrated in the following quote, in which the parent of a five-year-old child with normal cognition, expressed her feeling about overcoming child´s profound limitations with the gaze-based AT. *'All of a sudden something is offered that opens up possibilities. I guess it is because our child has so few abilities of his own. Unexpectedly, there are no boundaries, barriers are all gone or could disappear.' (Parent 5)* This example shows how the parents thought the gaze-based AT gave children many opportunities to develop. Such opportunities had previously been limited.

Handling the gap

For the parents, there was a gap between what the children were doing and what they might be able to do in the future with the gaze-based AT. For the parents, the infinite possibilities meant that they felt a great responsibility to invest more in the gaze-based AT usage. The responsibility created feelings of insufficiency of not doing enough to provide the child with the right level of challenging activities and opportunities in gaze-based AT usage in daily life. The huge area of potential usage also created uncertainty about what the next step to take should be. At the same time, parents needed to cope with the children's slow progress.

The analysis revealed that parents used two different strategies to manage the dilemma between children's abilities and all the possibilities they saw with the gaze-based AT. In both, parents emphasized the need of holding back their own expectations of the children's gaze-based AT usage. Those who felt uncertain about their child's mental capacity underscored the need to take one day at a time, not worrying about the children's capacity and looking at the gaze-based AT as a fun tool for the child. Parents who felt their child had the capacity to take all possible development steps by using the gaze-based AT emphasized that the children themselves needed to discover the benefits, as the following quote highlights; '*He will grow, he will not stay at the age of six. Then it is important that he develops when it comes to computers, and discovers what he can do with the gaze-based AT.' (Parent 7)* Parents felt that they had to be patient and wait for the child to decide if they would use the gaze-based AT to benefit from all its possible advantages.

Hope for a better future

The overall understanding of what it means to parents when their children use gaze-based AT in daily life is that it shapes a hope of a better future for children, where they can use their inherent potential to develop in their own direction and gain influence in their future life. The clusters show both the children's actions when using the gaze-based AT, and how these actions created a hope among parents about the child's future. The hope that was shaped, seemed to be closely connected to the different occasions that parents spoke about when children used the gaze-based AT. Parents often came back to the same occasions during the interviews, which Mattingly[35] highlights as common for significant experiences. The occasions parents spoke about were significant experiences that nourished the hope of child development and caused a partial shift in parents' views on their child's future - a shift from seeing the child as being in totally need of assistance, dependent on others, and out of own control in future, to seeing the child having possibilities to develop and gaining some control over their own life in future.

The gaze-based AT uncovered the inherent potential in the child as both the child's personality and competencies became visible and that the child was revealed as capable of using their potential to demonstrate agency in the situation through what they did and expressed when using the gaze-based AT. Parents hoped that other people would be able to embrace their own view of the child, and see what they already sensed. This generated a hope that significant others would be able to better understand the child, and thereby provide the child with the right level of challenging activities to support the child to develop. The hope of a better future was also related to parents' views on children's use of gaze-based AT as a language, and this view opened up possibilities to gain influence later in life. '*So hopefully in the future, he has it [the gaze-based AT] as his speech as well. Being able to tell; hey how are you? What's your name? What's up? Yes, like carry on a conversation with somebody*'. *(Parent 6)* Parents hoped that children would initiate conversations and by that gain more influence on life with gaze-based AT as a language. This gave parents some relief from their worst fear of a future vulnerable situation.

A tension was found between the infinite possibilities that parents hoped for, and what children actually did in the present situation. The analysis revealed a consciousness among parents about this gap and the uncertainty about whether their hopes would be fulfilled in the future. Hope is the future of 'what if' and opens up a world of possibilities, but hope gives no promises or guarantees, and therefore are parents prepared for disappointment.[35] Handling the gap between the children's abilities and all possibilities seemed to include 'what if not'. Nevertheless, the gaze-based AT usage in daily activities was important for parents in the present situation as children could do and express things that had been impossible before. In the present situation of children's gaze-based AT usage, together with the hope about their children's future, parents found reasons why the gaze-based AT was worth supporting in daily life.

Discussion

This study contributes to the understanding of what it can mean for parents living with a non-verbal child with severe physical impairments who receives and uses a computer controlled by their eye gaze in daily life, and who has no other options for independent action. The findings show that children's use of gaze-based AT can make a huge difference for parents, by providing the children with new opportunities to express things that matter to them and by providing them with opportunities to initiate and perform activities independently, opportunities they did not have before. These are important findings as it is known that these children are dependent on assistance in all activities,[5,7] have limited opportunities for social interaction[10] and usually need to wait for others to initiate interaction with them.[9] According to Kielhofner,[29] a change in the environment (e.g. receiving an assistive technology and guidance in its use), may initiate a change in the individual's actions and doing due to a better fit between the individual and the environment. Discovering new ways of doing and expressing abilities leads to opportunities to learn and develop.[29] Hence, children's opportunities to actively participate in activities and in interacting with others seemed to increase with the gaze-based AT usage, which may give opportunities for development and learning. Therefore, gaze-based AT may be an important intervention that can give opportunities for non-verbal children with severe physical impairments to grow and participate in society, rights which are articulated for all children by the United Nations.[1,2]

An important clinical implication of this study is the hope that was formed among parents, a hope that professionals need to be aware of. The creation of hope among parents is confirmed by other research on AT for children with severe impairments.[36,37]

This finding in the present study is important as hoping for a possible good future creates meaning in people's lives,[38] and helps families manage the child's impairments day by day.[35] Professionals must therefore respect hope and dare to ask parents about their feelings, thoughts and hopes related to children's gaze-based AT use, and not avoid discussing certain issues due to the professionals' own fear of not being able to provide what parents hope for. Becoming aware of the future-orientation[38] among parents is to understand the direction in which parents are looking. This is important to be able to make a common ground between parents and professionals, making a joint effort and working in the same direction when supporting children's gaze-based AT usage. Moreover, professionals must be aware of their own expectations[38] of gaze-based AT as these may be the same or interfere with the parents' view. For example, professionals may focus on gaze-based AT as an AT for communication. Parents on the other hand may consider children's opportunities for play and accessing entertainment as likewise important.

Another important finding was that seeing all the possibilities of the gaze-based AT made parents feel a great responsibility to provide children with challenging activities in the gaze-based AT to support learning and further child development over time. However, they also felt an uncertainty about what type of activities and content in the gaze-based AT would best support their child's development in the near future. Other research confirms parents' feelings of responsibility for child development[36] and their significant role in implementing an AT at home.[7,27] The findings of the present study indicate that professionals need to collaborate and give advice to parents concerning the long-term use of gaze-based AT. Case studies show that parents need guidance over time on how to expand the activity repertoire of a gaze-based AT,[21] and support on how to individually tailor the content of the software to the child's changing needs over time.[18] Donegan[18] proposes a 'can-do attitude' by adults when adapting the software, to provide the child with challenging activities to support development of competencies over time. According to Karpov,[39] Vygotsky's approach was that children need support and instruction to develop, and this may be especially important in gaze-based AT usage, since adults need to adapt the content so it provides the right challenge to support their child's development over time. Professionals need to collaborate with parents in finding what skills the child is ready to develop next as children grow older to allow continued opportunities to develop their social interaction and independence in performing preferred activities.

Gaze-based AT is becoming more accessible as AT. Therefore, based on the findings in this study, other children with similar impairments should have the opportunity to be investigated for gaze-based AT to determine any benefits from its use. For instance, professionals should highlight the use of gaze-based AT to express basic needs, feelings and to allow self-determination for children with such profound impairments. Another clinical implication is that children's gaze-based AT usage may create hope among parents that give them reason to support the child with the gaze-based AT in the present situation.

Future research studying hope from the teacher's perspective regarding pupils' use of gaze-based AT in the school setting would add valuable knowledge for service providers. Further studies should also include the children's perspective on gaze-based AT.

Limitations

The parents who were invited to take part in this study all participated with their children in the same gaze-based AT intervention at one specific pediatric rehabilitation center. It could have strengthened the study if parents from several centers had participated. Intervention programs may differ between centers, which is why including parents from several centers may give more variation of experience. In addition, this study informs about parents to children with successful use of gaze-based AT, as all included children had continued use over time. However, this may not be the case for all children and therefore parents' experiences may differ for children with discontinued use of gaze-based AT over time. Another consideration is that children's own perspective of gaze-based AT usage is equally as important as parents', and would be valuable as a complement to parents' experiences. Due to these children's profound impairments and difficulties in communicating, it was not possible in this study to interview the children. Nevertheless, since the findings of this study show these new opportunities to interact and communicate by using gaze-based AT, it may be possible to give children opportunities to share their experiences in future research. In addition, children with milder physical impairments may also use gaze-based AT in daily life. The findings in this study are probably not transferable to other children apart from those with severe physical impairments that are without speech.

Conclusion

In conclusion, this study shows how gaze-based AT can provide non-verbal children who have severe physical impairments with new opportunities to participate in activities and to take initiatives to interact with others. In relation to not having such opportunities in the past, children's new doing and communication opportunities shapes a hope among parents for a better future for their children, where they can use their inherent potential to develop in their own direction and gain influence over their future life. Future research in a larger sample of children with comparisons between ages, between children's conditions, as well as evaluating changes in self-determination and communication abilities over time would be beneficial.

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Declaration of interest

The authors report no conflicts of interest.

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