Perspectives of Parents of Children with Cerebral Palsy on the Supports, Challenges, and Realities of Integrating AAC into Everyday Life

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Background

• AAC technologies should be designed to align with the unique needs and skills of children with complex communication needs (Blackstone, Bills, & Wilkins, 2007; O’Neill & Wilkinson, 2017)

• The design of AAC technologies can be modified to achieve a better fit between the technology and the needs and skills of the child (e.g., Drager et al., 2002; Fallon, Light & Asherbach, 2002; Light, Drager & Remsner, 2004; McCarthy et al., 2000; Wilkinson, O’Neill & McIlvaine, 2014; Worah, Light, McNaughton, & Benedek-Wood, 2015)

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  • Parents who participated

• Children who use AAC exist as part of a family system, whose strengths, needs, and skills cannot be fully understood outside of the family context (Mandak, O’Neill, Light & Fosco, 2017; Mnuchin, 1985)

• AAC technologies introduce additional demands on family members that may make them resistant to the integration of AAC technologies

• In order to ensure long-term adoption and use of AAC technologies:
  • Technologies must support children in working towards family-identified goals (Calculator, 2014)
  • Family members must be able to support their child in using AAC technologies (Anderson, Karida & Hourahine, 2014)
Previous research: Parent perspectives on AAC

**Priorities:**
Parents want to be involved in supporting their children’s use of AAC and they value AAC to enhance their children’s participation and communication.

**Challenges:**
Parents have experienced challenges in learning and programming technologies and working effectively with professionals.

Challenges:
Little is known about the specific AAC technology features that parents perceive to meet these priorities and address these challenges so that AAC technologies can be integrated into everyday life.

**Questions**
1. What are parents’ perceptions of how AAC technologies support their child’s participation in family goals and the functional contexts of everyday life?
2. What features of AAC technologies present challenges or supports to participation and integration of technologies into the functional contexts of everyday life?

**Method: Design**

**Qualitative research design using semi-structured interviews**

- **Why qualitative?**
  - Effective to describe and explain experiences from the perspective of participants (Bogdan & Biklen, 2007; Denzin & Lincoln, 2005)

- **Why semi-structured interviews?**
  - Ensures systematic data collection across participants
  - Additional questions can emerge from dialogue (Patton, 2015)
Method: Participants

9 parents (8 mothers, 1 father) of 8 children who:
- Had cerebral palsy
- Were between 6-14
- Used AAC technologies

<table>
<thead>
<tr>
<th>Parent(s)</th>
<th>Age</th>
<th>Degree or Program</th>
<th>Children at Home</th>
<th>Children</th>
<th>Age</th>
<th>School Setting</th>
<th>AAC Device</th>
<th>Time Using Device</th>
<th>Selection Technique</th>
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<tbody>
<tr>
<td>Allison &amp; Jacob</td>
<td>40 to 54</td>
<td>4-year degree</td>
<td>2</td>
<td>Zane</td>
<td>9</td>
<td>Inclusive</td>
<td>Proloquo2Go app on iPad</td>
<td>6 years</td>
<td>Direct selection- finger</td>
</tr>
<tr>
<td>Amelia</td>
<td>25 to 39</td>
<td>4-year degree</td>
<td>1</td>
<td>Julia</td>
<td>7</td>
<td>Inclusive</td>
<td>Proloquo2Go app on iPad</td>
<td>2+ years</td>
<td>Direct selection- finger</td>
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<tr>
<td>Lucy</td>
<td>25 to 39</td>
<td>4-year degree</td>
<td>1</td>
<td>Jackson</td>
<td>8</td>
<td>Inclusive</td>
<td>Proloquo2Go app on iPad</td>
<td>2 years</td>
<td>Direct selection- finger</td>
</tr>
<tr>
<td>Bailey</td>
<td>25 to 39</td>
<td>6-year degree</td>
<td>1</td>
<td>Felix</td>
<td>7</td>
<td>Segregated</td>
<td>NOVA Chat 12</td>
<td>2 years</td>
<td>Direct selection- eye gaze</td>
</tr>
<tr>
<td>Jackie</td>
<td>25 to 39</td>
<td>Professional degree</td>
<td>4</td>
<td>Hayden</td>
<td>13</td>
<td>Segregated</td>
<td>NOVA Chat 12</td>
<td>2 years</td>
<td>Direct selection- eye gaze</td>
</tr>
<tr>
<td>Kelli</td>
<td>40 to 54</td>
<td>Some college</td>
<td>3 (+2 step siblings)</td>
<td>Taylor</td>
<td>6</td>
<td>Segregated</td>
<td>NOVA Chat 12</td>
<td>2 years</td>
<td>Direct selection- eye gaze</td>
</tr>
<tr>
<td>Emily</td>
<td>40 to 54</td>
<td>Professional degree</td>
<td>1</td>
<td>Sadie</td>
<td>40 to 54</td>
<td>Inclusive</td>
<td>NOVA Chat 12</td>
<td>3 years</td>
<td>Direct selection- eye gaze</td>
</tr>
<tr>
<td>Shannon</td>
<td>40 to 54</td>
<td>Professional degree</td>
<td>3</td>
<td>Luke</td>
<td>40 to 54</td>
<td>Inclusive</td>
<td>NOVA Chat 12</td>
<td>5;6</td>
<td>Direct selection- eye gaze</td>
</tr>
</tbody>
</table>
Method: Procedures

- Parents completed a background questionnaire
- PI conducted the interviews via video conference (7 parents) or phone (2 parents)
- 45-80 minutes in length
- Recorded and transcribed verbatim

Data Analysis: Thematic Analysis

- Familiarize and identify big ideas
- Unitize and organize text
- Code data subset and develop initial codebook
- Identify and define themes
- Refine codebook and assess reliability
- Resolve discrepancies and sort data

Braun & Clarke, 2006; Campbell, Quincy, Osserman & Pedersen, 2013; Creswell, 2012; MacClaren, McLeod, Kay, & Milstein, 1998; Miles, Huberman & Saldana, 2014; Vaughn, Schumm, & Snagaj, 1996

Method: Research Quality Indicators

- Credibility (believability)
  - Triangulation of investigators
- Transferability
  - Thick description
- Reliability
  - Intercoder agreement
- Confirmability
  - Member check

Campbell, Quincy, Osserman & Pedersen, 2013; Creswell, 2012; Geertz, 1983; Given, 2008; Hays & Singh, 2014; Lincoln & Guba, 1985; Tracey, 2004

Results

- Integrating AAC into life
- AAC technologies
- Child needs and skills
- Parent responsibilities and priorities
- Process and decision-making

Themes

Integrating AAC into life
AAC technologies
Parent responsibilities and priorities
Child needs and skills
Process and decision-making
Integrating AAC Theme: Summary and Implications

SUMMARY
- Children used AAC technologies with various partners and in various everyday contexts

However, AAC technologies were not always available

IMPLICATIONS FOR PRACTICE AND THE DESIGN OF TECHNOLOGIES
- Professionals should ask families about contexts in which they value the use of AAC technologies, and brainstorm ways for families to integrate AAC into those contexts
- Manufacturers should continue to develop technologies that can be more easily integrated into life (e.g., durable, lightweight, greater accessibility in rain and sunlight, augmented reality features)
Results

AAC Technologies

Supports

Limitations

Ideal

Parent responsibilities

and priorities

Roles

Goals

Child needs and skills

Developmental

Communication

Psychosocial

Process and decision-making

Selection and customization

Learning technologies

Emotional responses

Integrating AAC into life

Family

School and community

Changes over time

Collaboration

• Programming challenges
• Cost of use and efficiency
• Poor physical design

It’s not intuitive. You definitely have to learn how to do it. And there are a lot of keys involved.

I think the time delay is really frustrating. So the time it takes him to type out even a short sentence, even though he’s got predictive text and he’s pretty fast at it, it still is a drag on the typical interaction people would have when they’re chatting.

If she wants to communicate with the device she’s basically forced to look on a screen all the time and it’s a bit cold. It’s not a good situation for someone who is as socially in tune as she is.

I would love a world where his thoughts could be vocalized...without the need to have all of this difficulty with muscle coordination going on.

There may be a word that she really wants, but there’s no way to give her that...I really can’t give her a slew of choices because of the motor...so I would say the device is limited because her mobility is limited.

AAC Technologies Theme: Summary and Implications

SUMMARY

• Current AAC technologies had features that supported participation and also features that presented barriers for participation

• Parents had unique ideas for improving the design of technologies

IMPLICATIONS FOR THE DESIGN OF TECHNOLOGIES

• AAC technology development must take a multi-disciplinary approach that includes children who use AAC and their families, clinicians, AAC researchers, rehabilitation engineers, and mainstream technology developers
Child Needs and Skills Theme: Summary and Implications

**SUMMARY**
- Children developed communicative competence using AAC technologies.
- Developmental needs and skills and psychosocial factors contributed (positively or negatively) to their ability to effectively use AAC.

**IMPLICATIONS FOR PRACTICE**
- Seek parents’ expert input on their child’s needs and skills.
- Use this expert knowledge to customize technologies.

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We aren’t going to rely on anybody else to do it. We’re doing it... He would not be at the place where he is if we hadn’t taken it on.
Parent Responsibilities and Priorities

Theme: Summary and Implications

SUMMARY
• Parents took a leadership role and managed multiple responsibilities

IMPLICATIONS FOR PRACTICE
• Demonstrate sensitivity to the competing demands of everyday family life

• Parents prioritized their children’s development of communicative competence and their independence and inclusion

• Engage in collaborative goal-setting with families to ensure that AAC technologies are responsive to family-identified priorities (King & Chiarello, 2014)

Results

AAC technologies
Supports
Limitations
Ideal

Parent responsibilities
and priorities
Roles
Goals

Child needs and skills
Developmental
Communication
Psychosocial

Integrating AAC into life
Family
School and community

We didn’t know what we were doing…so we were just figuring it out as a family.

Even if she can’t do long division and know osmosis, I don’t really care. Because it would get her farther in life to have those interpersonal communication skills.

We feel like her dietician and her nutritionist, I feel like her therapist, I feel like her teacher. And finally there comes a point where I also want to feel like Mom.
Results

We have managed to get really enthusiastic speech and language therapists who have been really up for this and have pioneered this in their department and have pushed themselves to learn new things and have really been very very supportive.

We’ve had a lot of push back from people across the board with implementing it at school.

Process and Decision-making Theme: Summary and Implications

SUMMARY

• Acquiring and learning to use AAC technologies was an ongoing process that required decision-making and collaboration with professionals

IMPLICATIONS FOR PRACTICE

• Form collaborative relationships with parents that are characterized by mutual trust and information sharing

• Improve training for professionals in the knowledge and skills needed for AAC assessment and intervention and working effectively with families

Limitations

• Results reflect the perspectives of a small group of well-educated, highly involved parents, with little diversity

• Data were collected at one point in time

• Results reflect only the experience of parents and not other important stakeholders (e.g., siblings, extended family, child using technology, care aids, school professionals, etc.)

Future Research

• Seek perspectives of a larger, more diverse group of individuals

• Various ages, diagnoses, and cultural and linguistic backgrounds

• Conduct longitudinal research to capture how experiences change over time

• Gain input from multiple stakeholders using an in-depth case-study approach

Key take-aways

• AAC technologies support children’s participation in family goals and everyday life!

  ◦ When family priorities, preferences, and routines are considered

  “We still have "work to do" to improve the technology design and collaboration with families.”

  “Hopefully in the future we [are] able to achieve much more”
References


