Abstract

Background: There are multiple stakeholders involved in the introduction of augmentative and alternative communication (AAC) systems to children with complex communication needs. However, stakeholders such as speech-language pathologists (SLPs) and teachers who are external to the family unit play a key role in planning and implementing interventions. If this intervention is unsuccessful, it can result in parent rejection or abandonment of the AAC system. There are however no studies exploring the contribution of external stakeholders to AAC rejection and abandonment from the perspective of parents who have experienced such unsuccessful interventions.

Aim: The present study aimed to explore parents' perceptions of how external stakeholders may contribute to the rejection or abandonment of an AAC system.

Methods: Data was collected as a part of a larger study that explored parent experiences of AAC rejection and abandonment. Within this study, semi-structured interviews were completed with 12 parents who had rejected or abandoned an AAC system introduced to their child with complex communication needs. Data related to external stakeholder contributions was extracted from the interview transcripts, and thematic analysis was conducted.

Results: Analysis revealed four themes which captured the role of external stakeholders in the rejection and abandonment of AAC systems: (a) parents were influenced by the attitudes and experience of professionals; (b) parents did not feel supported by SLPs; (c) communication between stakeholders was not effective; and (d) parents had difficulties using AAC without a supportive community.

Conclusions & Implications: This study highlights the importance of family-centred service delivery when introducing an AAC system to the parent of a child with complex communication needs. SLPs may support parent acceptance of AAC systems by using

family-centred practices such as listening to parents, acknowledging their expertise, and

finding compromises.

What This Paper Adds

What is already known on the subject

Existing systematic reviews on the barriers and facilitators to the provision and use of augmentative and alternative communication (AAC) systems have identified influential factors related to the attitudes of and support provided by family members, the services provided by speech-language pathologists (SLPs), the support of other members of society, features of the AAC system, and the person with complex communication needs themselves. Studies included in these reviews, however, have presented data from the perspective of professionals and parents who have accepted AAC systems rather than parents who have rejected or abandoned a system.

What this paper adds to existing knowledge

This study is the first to explore AAC rejection and abandonment from the perspective of parents who have had this experience themselves. Parents described rejecting or abandoning AAC systems in response to a perceived lack of family-centred AAC service delivery. For example, systems were abandoned as a result of parents not feeling supported by SLPs, communication breakdowns between the SLP and parent, and SLPs who provided recommendations based on their own beliefs.

What are the potential or actual clinical implications of this work

Results from this study suggest that SLPs may support parent acceptance of AAC systems by using family-centred practices including listening to parents, acknowledging their expertise, and finding compromises. AAC acceptance may also be promoted when SLPs expand their skills and knowledge in principles of AAC intervention, connect parents to other parents of children with complex communication needs, and provide a level of support that is commensurate with the needs of the family.

"We were just kind of handed it and then it was smoke bombed by everyone": How do external stakeholders contribute to parent rejection and abandonment of AAC systems?

Augmentative and alternative communication (AAC) is a collection of tools and strategies centred on adding to or replacing the verbal communication of people with complex communication needs. The approach encompasses the use of both aided and/or unaided AAC systems (Beukelman and Mirenda, 2013). Unaided AAC systems consist of natural nonverbal communication as well as formalised manual signing systems. Conversely, aided AAC systems involve some form of external tool, which may be either high-tech (i.e., electronic aids) or low-tech (i.e., non-electronic or paper-based systems) (Speech Pathology Australia, 2012).

The Participation Model of AAC (Beukelman and Mirenda, 2013) provides a systematic process for conducting AAC assessment and intervention. The model highlights the need for clinicians to identify barriers to participation related to both opportunity (e.g., parent and teacher skills and attitudes) and access (e.g., potential for skill development, environmental adaptations, and utilising AAC systems). This information can then be used to plan and implement interventions that will enhance the participation of the person with complex communication needs.

One prominent opportunity barrier (Beukelman and Mirenda, 2013) to increased participation for young children with complex communication needs is parent rejection or abandonment of the AAC system that has been introduced (Johnson et al., 2006). AAC rejection occurs when parents dismiss the notion of AAC prior to any attempt with a system. Conversely, AAC systems are considered abandoned when parents obtain but discontinue use of a system, despite the continued need for the system as identified by the professionals involved (Johnson et al., 2006). Without access to an AAC system, children with complex

communication needs are likely to have limited opportunities for communication, language, literacy learning, and socialisation and fall progressively further behind their typically developing peers (Drager et al., 2010, Light, 1997). Therefore, it is vital that researchers and clinicians understand why AAC systems are rejected or abandoned so that they can use this information to promote the acceptance of these systems and thus enhance the participation of children with complex communication needs.

Existing literature has identified barriers to the provision and use of AAC systems (Baxter et al., 2012, Donato et al., 2018, Moorcroft et al., 2018) as well as factors that may contribute to AAC rejection and abandonment (Johnson et al., 2006, Moorcroft et al., 2019). Together, these studies have consistently identified five key factors that contribute to the acceptance versus rejection or abandonment of AAC systems: (1) the attitudes of and support provided by family members; (2) the services provided by speech-language pathologists (SLPs); (3) the support of other members of society; (4) features of the AAC system; and (5) the person with complex communication needs themselves. For example, Moorcroft et al. (2018; 2019) discussed the impact of parents who did not accept the need for an AAC system or who prioritised goals relating to their child's physical functioning over those related to communication. In addition, studies have noted barriers stemming from SLPs who lacked adequate training in AAC or did not provide adequate supports to the family (Baxter et al., 2012, Donato et al., 2018, Johnson et al., 2006, Moorcroft et al., 2018, Moorcroft et al., 2019). In terms of societal supports, both Johnson et al. (2006) and Moorcroft et al. (2019) discussed the importance of support from other families who use AAC. Furthermore, Moorcroft et al. (2018) noted barriers related to a lack of social awareness or acceptance of AAC. Studies also noted specific features of AAC systems as barriers, including the ease of use, reliability, and voice and language of high-tech devices (Baxter et al., 2012). Finally, factors related to the person with complex communication needs included their cognition,

movement abilities, attitude, socio-economic status, and culture (Moorcroft et al., 2018).

While this information is important, the existing literature on the rejection and abandonment of AAC systems comes from the perspectives of professionals and parents who have accepted AAC systems rather than parents who have rejected or abandoned a system (Baxter et al., 2012, Donato et al., 2018, Moorcroft et al., 2018, Moorcroft et al., 2019). It seems remiss to attempt to explain and prevent AAC rejection and abandonment without first considering the expertise of parents who have experienced this process and can provide valuable insight.

In addition, while the existing literature suggests that there are multiple stakeholders who may contribute to AAC rejection and abandonment, it is often stakeholders external to the family such as SLPs and teachers who are responsible for initiating and supporting parents through AAC intervention (Calculator and Black, 2009). Throughout this process, SLPs should adhere to the principles of family-centred care (Calculator and Black, 2009, Mandak et al., 2017). Family-centred clinicians consider the needs and concerns of the family as a whole, provide parents with choices in all aspects of intervention, and incorporate child and family strengths (Epley et al., 2010). In addition, the family-professional relationship should include mutual collaboration, respect, sensitivity, honesty, trust, listening, and understanding; and services must be individualised to meet the needs and resources of the family (Epley et al., 2010). SLPs have, however, reported that while they may intend to provide family-centred AAC services, barriers including inflexible forms of service delivery (Beatson, 2008; Lindsay, 2010; Watts-Pappas et al., 2008), resource limitations (Beatson, 2008), inadequate confidence (Watts-Pappas et al., 2008), parent expectations (Beatson, 2008; Watts-Pappas et al., 2008), and misaligned clinician and parent views (Beatson, 2008; Iacono & Cameron, 2009; Lindsay, 2010) have prevented this practice, thus warranting further investigation from the family perspective. Therefore, the current study aimed to explore parent perceptions on

the contribution of external stakeholders to the rejection or abandonment of an AAC system for their child with complex communication needs.

Methods

Research Design

This study utilised a qualitative descriptive approach, which is an effective means of exploring barriers and facilitators within healthcare (Pati et al., 2016). As is standard practice for qualitative descriptive research, purposeful sampling and individual semi-structured in-depth interviews were used to explore parent perceptions (Sandelowski, 2000). Individual interviews were selected over focus groups to ensure confidentiality for participants and their respective service providers.

This study received ethical approval from The University of Queensland Human Research Ethics Committee A (Approval number 2017000353).

Participants

Participants were parents of children with complex communication needs aged 0 to 16 years, who rejected or abandoned an AAC system for their child when he or she was between the ages of 0 and 6 years. Maximum variation purposive sampling (Patton, 2015) was used to recruit parents of children with a variety of diagnoses and who had been introduced to a range of AAC systems. No exclusion criteria were applied to this study, and parents remained eligible to participate if they had accepted other AAC systems that had been introduced to their child. A total of 12 parents were recruited via organic and paid Facebook advertising ($n = 7$), their private SLP ($n = 1$), their child's school ($n = 3$), and AGOSCI ($n = 1$), an Australian organisation that supports people with complex communication needs. An additional nine parents expressed interest in the study but did not meet the inclusion criteria or did not respond to attempts at further contact.

Participants were aged 28 to 55 years (M = 41 years) and were all biological mothers of a child with complex communication needs. All participants spoke English in the home environment and had completed some form of post-school education. They were located in Queensland, AUS (n = 9); New South Wales, AUS (n = 2); and Utah, USA (n = 1). While international participation was not anticipated, the research team deemed that the participant in the USA may offer valuable information that was not location specific. The participants' children (6 female, 6 male) were aged between 3 and 16 years (M = 8 years) at the time of the interview. The children's primary diagnoses included Autism Spectrum Disorder (n = 5), Intellectual Disability (n = 1), Cerebral Palsy (n = 1), Angelman Syndrome (n = 1), Mowat Wilson Syndrome (n = 1), and Rubinstein Taybi Syndrome (n = 1). Two children had undiagnosed neurological disorders. Given the retrospective nature of the study, the types of AAC systems that had been rejected or abandoned by the parents could not be verified and have therefore not been reported.

Data Collection

Data for this study was collected as part of a larger project which sought to explore parents' experiences with AAC rejection and abandonment. Consenting parents completed an individual semi-structured in-depth interview face-to-face (n = 8), via the phone (n = 2), or via video conferencing (n = 2) at a time convenient to them. Prior to commencement of the interview proper, parents of children over the age of 6 years (n = 5) were asked to reflect specifically upon their experiences when their child was 0 to 6 years old. A topic guide was used during the interviews which was developed based on an extensive review of the AAC literature and driven by the research questions. Key prompts were: (a) Tell me about your child and how he or she communicates, (b) What things have you tried to support his or her communication? (c) Tell me about your experience with AAC, starting from when you first heard about it, and (d) How do you think your speech pathologist impacted on what happened

when AAC was introduced? Adjustments were made to the topic guide following a pilot interview with the parent of a child aged 4 years who had abandoned her child's AAC system.

All interviews were conducted by the first author, who is a Certified Practicing Speech Pathologist and PhD candidate who had prior experience in the introduction of AAC systems to children with complex communication needs and their families. The first author had a prior therapeutic relationship with one participant; however, the abandoned system that the parent discussed had not been introduced by the author, so this relationship was not considered to have biased results. The other authors had no previous relationship with the participants. Mean length of the interviews was 40 mins (range: 26 - 59 min) and all interviews were audio recorded.

Following the interview, parents were asked to complete a questionnaire which collected their demographic information as well as information about their child and members of the household. The interviewer met frequently with the research team before and during the data collection phase to discuss any personal value systems that had the potential to reduce neutrality during interviews (Ahern, 1999).

Data Analysis

Data analysis was conducted using thematic analysis, an established method frequently used in qualitative descriptive and health science research (Braun and Clarke, 2006). The research team followed the steps outlined by Braun and Clarke (2006) to complete the analysis. Interview recordings were transcribed, checked for accuracy, and sent to the participants by the first author. Four participants responded that they did not require changes to their transcript, and one participant reported that while she wished to continue participation in the study, the transcript was too confronting for her to read. The remaining participants provided no response and therefore their data was included in analysis as

originally transcribed. In line with the aims of the study, the first author then extracted all data related to the contribution of external stakeholders to AAC rejection and abandonment. External stakeholders were defined as all people and organisations who were not family members of the child with complex communication needs. This data was then systematically coded and the data relevant to each code was collated. The coding was discussed and reviewed by the research team. The first author then sorted the codes into themes and subthemes which were later reviewed by the second and third authors who are speech pathology academics with extensive clinical and research experience in qualitative methods. Themes were refined until consensus was reached across all three authors. Analysis was completed by selecting compelling extracts from each transcript to support the themes (Ahern, 1999) and relating the findings to existing literature. Analyst triangulation (Patton, 2015) and regular research team meetings ensured dependability and avoided analytic blindness (Ahern, 1999) throughout this process. Participants were provided with a written summary of the study's findings and were given the opportunity to provide further comments. One participant responded and requested no changes; however, she commented that it was "interesting hearing what other people said. This is a lonely road to travel and you half feel crazy when you say no to AAC, so nice to hear I'm not the only one".

Results

Parents reported rejecting and abandoning a variety of unaided and aided (low-tech and high-tech) AAC systems. Many parents described a complex journey with AAC, wherein they worked with more than one SLP and attempted to use a variety of AAC systems. These systems were then abandoned after varying lengths of time, ranging from a couple of weeks to two years. While each parent's journey with AAC was unique, thematic analysis revealed four themes which captured the role of external stakeholders in the rejection and abandonment of these systems: (a) parents were influenced by the beliefs and experience of

professionals; (b) parents did not feel supported by SLPs; (c) communication between stakeholders was not effective; and (d) parents had difficulties using AAC without a supportive community. These themes are discussed in depth below and the themes, subthemes, and example participant quotes are presented in Table 1.

Theme 1: Parents were Influenced by the Beliefs and Experience of Professionals

Four parents reported that the beliefs and subsequent advice of the professionals supporting their child influenced their use of AAC systems. For example, Parent 4 abandoned AAC because her child "got it right at the cusp of changing [SLPs] and the new speechie just didn't feel like it was appropriate because it stifled free speech". Other parents described abandoning systems upon their children commencing at schools that strongly discouraged the use of their existing AAC systems. These parents reported the staff from these schools believed the system may confuse their children, prevent speech, or was only appropriate for academic tasks. Given the parents had invested emotionally and financially in the schools, they reported feeling as if they had no choice but to follow the advice of the new professionals: "We started there and of course we're paying an awful lot of money, we want to get the most out of it so we did exactly what they wanted us to do" (Parent 10). Although following the advice of professionals, these circumstances have been considered AAC abandonment for the current study as the parents involved reflected that they should have persisted with their use of the system despite the professionals' advice not to:

> We were doing what the professionals told us to do, even though the professionals
> knew nothing and we actually knew more than they did, but we took their word.
> (Parent 9)

Five parents faced barriers when they acknowledged their expertise in their child but were disregarded by professionals who considered themselves as the only expert:

I just felt like all the power was in their hands and I'm the stupid mum who doesn't

know anything about AAC you know. So, and so I just felt like they looked at me

like I just, I'm stupid and naïve, and I need to trust them. (Parent 5)

Six parents also reported that the SLPs' training and level of experience contributed to

AAC abandonment. Inexperienced SLPs were reportedly less familiar with different

diagnoses, could not see beyond the child's age or physical presentation, did not appropriately

arrange the environment, and were less able to work with families to set and achieve goals.

Conversely, experienced SLPs had "more tricks up their sleeve" (Parent 7) and were able to

"think outside the box" (Parent 11) but were not always available for frequent sessions.

Interestingly, parents discussed both experienced and less experienced SLPs who appeared to

introduce the AAC system they were most familiar with and believed in as opposed to

selecting the system that was the best fit for their child. In one instance, a parent commented

that her child's SLP continued to push her with the system used commonly within their

organisation despite admitting that it was not successful because "she felt pressure from her

boss" (Parent 13).

Theme 2: Parents did not Feel Supported by SLPs

Parents also reported abandoning AAC systems for their children when they felt that

they received inadequate support from their SLP. Two parents reported that they were not

provided with a clear plan and goals for intervention and wanted their SLP to "show a

treatment plan or a care plan rather than just winging it" (Parent 3). Five parents also noted

difficulties implementing AAC when their SLP did not provide them with a clear plan of

action for home tasks after each session.

Beyond planning, ten parents reported that they were unable to implement AAC

systems due to their limited training in how to use the system, a lack of SLP follow-up,

infrequent interactions with their SLP, or a complete absence of SLP support. Without

extensive training, parents were unable to introduce new vocabulary and expressed confusion

with how to implement the systems: "I felt like I didn't know what on earth I was doing"

(Parent 8). For some parents, AAC systems were reportedly introduced without any follow-

up or training at all: "I feel like we were just kind of handed it [AAC] and then it was smoke

bombed by everyone" (Parent 4). For those parents who did have some degree of SLP

support, many felt that the sessions were too short, infrequent, or disjointed for their needs.

Multiple parents also described their attempts to introduce AAC to their child with

little or no involvement from an SLP due to an inability to access services. Although

circumstances varied, this lack of support was reported to be the result of clinics closing,

SLPs refusing services if parents opted to use AAC, and the inability to find a service without

a full caseload. Some parents described "struggling through" (Parent 10) and using the

internet to search for whatever information they could; however, as Parent 9 reflected:

> We abandoned it [AAC] because like I mean, if your speech therapist is not gonna
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> help you with communication . . .and school's not gonna help you, and the doctors are
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> all sort of saying "not our department and we're not gonna help you" then, you know,
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> how do you problem solve? How do you get help?

Seven parents reported that, had they been provided with individualised support,

coaching, and encouragement they would have been more likely to accept and use their

child's AAC system. Parent 2 reported that she needed education, to "see the proof" that

AAC worked, and "to be coached to the point where… it is a habit, like you know like a

personal trainer but for [AAC]." Five parents also wanted resources to assist them in their

learning such as written instructions, instructional apps, a list of how to access different

vocabulary, supportive literature, cheat sheets, and summaries that can be passed on to

different members of the community. Parent 4 did, however, caution against SLPs relying on

resources for learning: "I mean we got a big, chunky manual and what have you and we had specialists that were saying go use this".

Theme 3: Communication Between Stakeholders Was Not Effective

Parents reported that ineffective communication between themselves, allied health professionals, and educational professionals also contributed to the rejection and abandonment of AAC systems. Three parents reported that they did not buy-in to AAC because their SLP did not provide them with adequate explanations as to why AAC was required or why a specific system had been selected. As Parent 2 reflected:

It's like a bombshell, like "you have to do this [use AAC]" and it's like "woah what is this?" you know, and not really going through the steps of explaining it and selling us the idea. (Parent 2)

Five parents felt that they were not given a choice about the use of AAC and that they were pressured, managed, or sold down a particular pathway based on the philosophies of the SLP or organisation their child was receiving services from. Parent 13 described having only recently received her child's diagnosis, but within two SLP sessions being "told that this [AAC] was really a non-negotiable and she [the SLP] was pushing it on us".

Furthermore, seven parents described their experience of a constant struggle and fight with professionals who did not listen to themselves or their child. For example, Parent 5 described abandoning AAC following an ongoing fight with her child's school:

So it was like all year fighting with them to add more vocabulary, I just wanted more. . . They did eventually by the end of the year … so then his board ended up with 70 words … but … now he's started another year at school with a new teacher, and they're still doing core words, and now he's back to 20 words instead. . . so for me I'm just like well whatever, you do what you're gonna do, I'll do what I'm gonna do at home, it's just not worth the fight.

As well as begging for additional or reduced vocabulary, parents reported arguing with professionals over which system should be used, and, as described in Theme 1, having their ideas shut down without acknowledgement or compromise. Some parents also shared their concerns regarding SLPs who did not listen to their children's communication attempts or treat them age-appropriately: "He [my child] abandoned AACs because of his sheer frustration that people weren't taking him seriously" (Parent 9).

Finally, five parents reported difficulties when professionals such as SLPs, occupational therapists, physiotherapists, carers, and teachers did not work together cohesively as an interdisciplinary team. For example, Parent 4 noted the need for additional collaboration and training between her child's SLP and day-care teachers.

Theme 4: Parents had Difficulties Using AAC Without a Supportive Community

Eight parents described the importance of a supportive community around themselves and their child when beginning to use an AAC system. Where AAC systems were not consistently used by all members of the community, including health professionals, teachers, church members, and carers, parents reported feeling like they were "doing it all alone" (Parent 11). Parent 11 said that she "gave up" on using AAC when it was not embraced by her child's early education setting. She was worried that, by being the only person "making her use [AAC]", it would impact on their relationship (Parent 11). Parent 7 had actively but unsuccessfully attempted to seek further community support in the form of a university student to assist in implementing her child's AAC system:

> We just need someone paid half the amount [of an SLP], a quarter of the amount, just doing it [modelling AAC]. Coming in for longer, doing it, doing it, doing it, doing it, and like so it's just repetition repetition, that the parents don't have time to give. (Parent 7)

Parent 10 discussed in depth her experiences with the education system and attributed her abandonment of her child's AAC system to an inability to find inclusive education for her child. In the absence of an appropriate school in their local community, the family "searched wildly for solutions" and had their "vulnerability exploited" when the child commenced at a private school that discouraged use of his existing AAC system (Parent 10).

Finally, Parent 2 reflected that having support from other parents of children with complex communication needs may have enabled her to continue using her child's AAC system. She described the need for "positive peer pressure" in the form of face-to-face support groups or virtual groups via social media that consist of parents who can encourage each other.

Discussion

This study aimed to explore parent perceptions on the contribution of external stakeholders to the rejection or abandonment of an AAC system for their child with complex communication needs. Thematic analysis revealed that parents were influenced by the beliefs and experience of professionals; parents did not feel supported by SLPs; communication between stakeholders was not effective; and parents had difficulties using AAC without a supportive community. Overarching these themes was a perceived lack of family-centred AAC service delivery. Family-centred care represents a partnership between parents and professionals, and SLPs must acknowledge the expertise of parents whilst remaining sensitive to their unique needs, priorities, and stressors (Mandak et al., 2017). While there is extensive literature advocating for family-centred AAC service delivery (Beatson, 2008, Brotherson, 2004, Calculator and Black, 2009), parents provided multiple descriptions of clinician behaviour that were contrary to the recommended family-centred practices. This finding is consistent with and elaborates on the existing AAC literature as discussed below.

Firstly, parents reported that the beliefs of the professionals supporting their child influenced their use of AAC systems. Parents discussed SLPs and teachers who reportedly believed that the use of AAC may confuse their children or prevent speech development, thus resulting in system abandonment. Despite the research evidence contrary to beliefs that AAC will prevent speech development (Millar et al., 2006, Romski and Sevcik, 2005), similar beliefs have also been noted in existing studies on the barriers to AAC use (Moorcroft et al., 2018). Furthermore, parents reported rejecting or abandoning AAC systems when the professionals involved appeared to believe they were the only experts in the child and AAC. While some parents did see their SLP as the expert and opted to follow their advice, others who wished to contribute their own expertise on their child often felt as though their input was disregarded. Similar variance was noted by Marshall and Goldbart (2008), wherein parents differed in their desire to be viewed as experts on their child or on AAC and described varying professional responses to their parental expertise. Newton (2000) describes this phenomenon as "power struggles", wherein providers who are not family-centred act as gatekeepers to services and may be unwilling to try strategies suggested by parents due to their own beliefs. Therefore, as advocated in The Participation Model of AAC (Beukelman and Mirenda, 2013), SLPs introducing AAC systems must consider the research evidence and identify and address barriers stemming from the attitudes and beliefs of themselves and other stakeholders.

Findings also showed that the SLPs' level of experience contributed to AAC rejection and abandonment. For example, some parents commented that inexperienced SLPs had limited knowledge and skills which prevented their acceptance of AAC. The impact of SLP experience is highlighted in The Participation Model of AAC (Beukelman and Mirenda, 2013) and has been discussed in multiple studies wherein SLPs have identified a lack of skills and experience as an obstacle to AAC intervention (Baxter et al., 2012, De Bortoli et al.,

2014, Moorcroft et al., 2018, Moorcroft et al., 2019). An SLP interviewed by Moorcroft et al.

(2019) also commented that, with experience, she was able to focus her attention on her

interactions with the family rather than the details of selecting a specific AAC system, thus

enhancing her ability to work as a family-centred clinician. Therefore, the successful

introduction of AAC systems may be supported by increased theoretical and practical

experience in AAC for SLP students as well as workplace supervision and mentoring for

practicing clinicians. This training may need to incorporate principles of family-centred

practice as well as the specifics of AAC assessment and intervention.

Parents also reported abandoning AAC systems for their children due to a lack of

support from their SLP. Many parents reported receiving little to no training in the use of

AAC systems and noted that, had they had been provided with individualised support,

coaching, and encouragement, they would have been more likely to use the system. Again,

individualised support is a critical element of family-centred practice (Epley et al., 2010) and

limitations in support and services have also been noted in the existing literature. For

example, Baxter et al. (2012) described family difficulties accessing AAC services and noted

that the amount of therapy provided was not always based on individual needs. Likewise,

Moorcroft et al. (2018) reported that some SLPs had inadequate time for the implementation

of AAC systems. Finally, SLPs interviewed by Moorcroft et al. (2019) commented that AAC

systems were abandoned when they were unable to provide adequate support to families due

to insufficient funding, the setting of their workplace, or their difficulties communicating

with parents. While SLPs working within larger organisations may have little capacity to

change their clinical practice based on these findings, policy makers and funding bodies may

need to reconsider the emphasis placed on parent support following the introduction of an

AAC system (Beukelman and Mirenda, 2013).

In addition, parents commented that ineffective communication between themselves, SLPs, and educational professionals contributed to the rejection and abandonment of AAC systems. Most prominently, they spoke about the lack of choice they were given with regards to AAC use and their fight with professionals who they felt did not listen to them. Interestingly, SLPs have self-reported such behaviours, noting that they would not introduce an AAC system if they felt a child could not use it effectively, despite a parents' wishes (Lindsay, 2010). Newton (2000) describes such breakdowns in communication, wherein providers and families are not able to find a common ground, as "negotiation failures". Within the existing AAC literature, conflicts between parents and professionals have been acknowledged, however predominantly reported from the perspective of the SLP. For example, both Beatson (2008) and Cress (2004) discussed difficult relationships with families and resulting clinician frustration when parents' perceptions or goals differed to that of their own. Therefore, results from the current study must be used to prompt clinicians to consider how ineffective communication with parents may be impacting the parents as well themselves and consequently aim to make family-centred decisions.

Finally, parents in the current study discussed the importance of having a supportive community around them when attempting to use AAC and one parent suggested that this support may come from other parents of children with complex communication needs. The benefits of parent to parent connections have been discussed by SLPs (Johnson et al., 2006, Moorcroft et al., 2019) and other parents (Donato et al., 2014, Marshall and Goldbart, 2008) in previous literature. For example, SLPs interviewed by Moorcroft et al. (2019) commented that connection with other parents provided reassurance, encouragement, and the inspiration to persist with AAC. Together, results from the existing literature and the current study suggest that there may be a role for SLPs to establish and potentially moderate both virtual

and face to face parent groups, and that parent participation in such groups may support their acceptance of AAC systems.

Clinical Implications

The prominent clinical implication of this study is the importance of family-centred practice when introducing AAC systems to children with complex communication needs. Most reported parent frustrations stemmed from SLPs who parents felt did not listen their ideas, opinions, and concerns, ultimately leading to the rejection and abandonment of AAC systems. In response to similar barriers reported in existing studies, Mandak et al. (2017) proposed a framework for family-centred AAC services that warrants in-depth consideration by professionals who support children with complex communication needs within the context of their family. As per the framework for family-centred AAC services (Mandak et al., 2017), SLPs must meet with and involve all relevant family members, demonstrate sensitivity towards family demands and stressors, identify unique family needs and priorities, and provide choices of intervention contexts and activities.

Clinicians may also engage families in the decision-making process by using decision aids; tools which provide evidence-based information to improve family knowledge of the available options and assist them to make decisions based on their personal preferences and values (Scalia et al., 2018). Where the SLP's clinical recommendations do not match with the family wants and needs, clinicians must work with the family to find a compromise that results in the acceptance of an AAC system. While this system may not be the most clinically appropriate choice for the child, it is reasonable to suggest that parent acceptance of any system is favourable to parent rejection and abandonment of AAC altogether. Once a system has been selected by the family, it is essential that SLPs then provide support and training to the family at a level that is conducive with their needs and priorities (Mandak et al., 2017).

Limitations and Future Directions

This study may have been limited by the representativeness of the sample. Parents who selected to participate in the study were all biological mothers, well-educated, spoke English as a first language, were knowledgeable about AAC, and were strong advocates for their children; however, the authors acknowledge that additional contributors to AAC rejection and abandonment may be present for other caregivers (e.g., fathers) or parents from different populations (e.g. low socioeconomic background, cultural differences). In addition, given participants were parents of children aged 0 to 16 years but were asked to focus specifically on when their child was aged 0 to 6 years, data collection was reliant on the accuracy of parents' past memory, and services may have changed since the time of their experiences.

Future research is required to further understand factors that contribute to the rejection and abandonment of AAC systems by parents of children with complex communication needs. Accordingly, a study has been commenced by the research team to determine what factors related to the family, external stakeholders, and AAC system most significantly contribute to this phenomenon. Research into the most effective methods for training of SLP students in AAC assessment and intervention and family-centred practice may also be warranted.

Conclusion

The current study is the first to purposefully explore the perspectives of parents who have rejected or abandoned an AAC system for their child with complex communication needs and highlights the contribution of inadequate family-centred AAC service delivery. Parents noted that when external stakeholders gave advice based on their beliefs, provided insufficient support, and used ineffective communication strategies, they were unable to commence or persist with AAC. SLPs may support parent acceptance of AAC systems by using family-centred practices including listening to parents, acknowledging their expertise, and finding

compromises. AAC acceptance may also be promoted when SLPs expand their skills in AAC intervention and provide the level and type of support that is commensurate with the needs of the family.

Disclosure Statement

No potential conflict of interest was reported by the authors.

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Table 1. Contributions of external stakeholders to parent rejection and abandonment of AAC systems

Theme	Subtheme	Example Participant Quote
Parents were influenced by the beliefs and experience of professionals	The perceived beliefs and subsequent advice of professionals influenced parent use of the system	"We were asked to stop [using the AAC system] because they felt it . . . would cause confusion and . . . it would stop him from learning to speak." (Parent 10)
	Parents felt devalued when professionals perceived themselves as the only "expert" in AAC intervention	"They [the education department] treat you all like idiots, instead of collaborating, instead of sharing expertise they are just toxic and they couldn't care less." (Parent 8)
	AAC use was impacted by the SLP's training and experience	"[Intervention is] just whatever they happen to know, but they're not really listening or tailoring it to kids with Mowat-Wilson syndrome perform better with this kind of approach. Um they just kind of use whatever speechie [SLP] approach they have been taught. That's what it feels like." (Parent 7)
Parents did not feel supported by SLPs	Parents were not provided with a clear plan for intervention	"I suppose it would have been good to have kind of a clear plan and kind of really push ahead with that rather than trying bits and pieces that never seemed to kind of consistently work for her." (Parent 6)
	Parents could not implement AAC without ongoing support from an SLP	"They gave it [the AAC system] to us, they showed us how to use it, and then they said 'Go!' and they didn't follow up. Oh, sometimes they'll ask in like at the other sessions, and sometimes like I'll complain and they'll give us some tips, sometimes. But you know, it's just all very much 'yeah see if you can use it.'" (Parent 2)
	Parents needed individualised support, coaching, resources, and encouragement to use their child's AAC system	"I think that if we were really shown the full capabilities of the system by the speechie [SLP] then it would just be ingrained in what we're doing every day." (Parent 4)
Communication between stakeholders	Parents felt SLPs did not provide adequate explanations	"Because we weren't given stories of other people using it [AAC] we were like 'What is this? Why? Why do I have to do this?' and 'It's such an effort to do it, I don't see the purpose' and yeah, other than she needs to communicate but we understand her fine." (Parent 2)

was not effective	Parents felt pressured to use the AAC system	"They [the SLPs] were very persistent on 'he needs a device.' Like within the first two sessions they like pushed it basically down our throats." (Parent 13)
	Parents struggled with professionals who did not listen to themselves or their child	"I think one of the problems I had was that I had um not very client-centred therapists. Um they didn't actually listen to what my needs were or my family's needs were and just steamed ahead regardless." (Parent 8)
	Interdisciplinary practice was limited	"[Service provider] was meant to be a transdisciplinary approach with the OT [occupational therapist] coming but she was meant to be liaising with the speech and the other physio or something in their centre but there was none of that." (Parent 3)
Parents had difficulties implementing AAC without a supportive community	The AAC system was not used consistently by members of the community	"At school they kept taking [the AAC system] off him. And so then he just started balking at it and would only use it for school work because that's the rules. And so even at home he would, he stopped using it so except for his homework." (Parent 9)
	Parents perceived the education system as not accessible or inclusive	"I really doubt in life whether it's just about the AAC. To us it was just, it's purely about … making schools wherever people are, making their local school accessible to each and every child. If that had been, if we had had a welcome in [town] at our local school, if they had said 'yes we are resourced to have your child here, we do this well, we do this confidently … we will take him and we will educate him', we would have gone, 'great, got what we need.' We wouldn't have been searching wildly for solutions." (Parent 10)
	Parent networks may support the use of AAC	"[Using AAC is] similar to you know trying to lose weight, you need a personal trainer to help, you know, tell you to keep on task, you need to keep using it, and pretty much checking in every day for at least the first thirty days. Um, and I know that's probably not feasible, but if you set up those like kind of um natural networks where you know it's the parents encouraging each other or posting stories about on Facebook, or on, you know about how little successes they've had, that might encourage other people to keep using it." (Parent 2)