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ORIGINAL RESEARCH



“I’ve had a love-hate, I mean mostly hate relationship with these PODD books”: parent perceptions of how they and their child contributed to AAC rejection and abandonment

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ABSTRACT

Purpose: The introduction of augmentative and alternative communication (AAC) systems can enhance the participation of young children with complex communication needs. However, existing literature suggests that the knowledge, skills, and attitudes of the child’s parent may prevent ongoing use of the AAC system. Therefore, this study aimed to explore parent perspectives on the contribution of factors associated with the family unit to the rejection or abandonment of an AAC system for their child with complex communication needs.

Methods: Parents of children with complex communication needs who had previously rejected or abandoned an AAC system ($N=12$) participated in a semi-structured interview. Thematic analysis of the interview data was completed.

Results and conclusion: Analysis revealed four themes which captured family factors contributing to the rejection and abandonment of AAC systems: (a) parents lacked the emotional readiness and resilience to implement AAC, (b) implementing AAC was extraneous work for parents, (c) the child did not use their AAC system for communication, and (d) parents were not satisfied with the AAC system itself. SLPs must be aware of and account for these factors to enable the successful introduction of AAC systems.

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KEYWORDS

Augmentative and alternative communication; complex communication needs; rejection and abandonment; parents

► IMPLICATIONS FOR REHABILITATION

- SLPs may increase the acceptance of AAC systems by working with a multidisciplinary team to support parents through their grief and implement strategies to build their resilience in the face of adversity.
- SLPs need to acknowledge the existing demands on parents when planning AAC intervention and support parents to integrate AAC systems into their daily routines.
- SLPs must carefully consider the child’s motivation, sensory profile, and physical abilities as well as parent preferences when prescribing an AAC system. These considerations will give the child and parent the best opportunity for success with the system and consequently reward parents for the effort they have invested.

Introduction

The introduction of augmentative and alternative communication (AAC) systems can enhance the participation of young children with complex communication needs [1]. However, as detailed in The Participation Model for AAC [2], the knowledge, skills, and attitudes of the person who facilitates the intervention are potential barriers to improved participation. While a speech-language pathologist (SLP) may initially recommend an AAC system, it is the child’s parents who are the key communication partners and are therefore largely responsible for facilitating the intervention [3]. Consequently, when AAC systems are introduced, SLPs must provide parents with extensive training in the use of linguistic and social strategies for enhancing the communicative participation of their child [4]. Without (or in some circumstances, despite) this training, many parents face barriers that result in their decision to reject or abandon the AAC system, thus impacting upon their child’s participation. Rejection and abandonment of AAC systems is highly prevalent within clinical practice, with Johnson

et al. [5] reporting that only 39% of AAC systems introduced by SLPs were used by clients for more than one year. The remaining AAC systems were dismissed prior to any attempt (i.e., rejected), or discontinued despite an ongoing need (i.e., abandoned). The frequent rejection and abandonment of AAC systems suggests that parent implementation of AAC intervention within real-world family contexts yields significant challenges [3].

To understand these challenges, Moorcroft et al. [6] interviewed 16 SLPs who had introduced an AAC system that had been rejected or abandoned by the family of a young child with complex communication needs. Although the study found that there were a range of contributing factors which influenced the rejection or abandonment of the systems, including the service provided by the SLP and the features of the AAC system itself, most reported barriers to AAC use were related to the family unit. The SLPs in the study noted the impact of the way parents view their child, parents’ views on AAC intervention, and the capacity of parents to both use AAC and support their child more broadly.

For example, participants reported that parents who are grieving the loss of the child they expected respond differently to the introduction of AAC systems than parents who have accepted their child's disability. Furthermore, parents of younger children or children with less visible disabilities were reported to deny the need for AAC systems and therefore reject or abandon these systems.

Additional studies that have explored barriers to the use of AAC systems have identified similar results. For example, Bailey et al. [7] interviewed parents of high-school-aged children who used AAC and identified barriers related to limitations of the AAC system, inadequate training, and the lack of parent involvement in the AAC decision-making process. Furthermore, the authors noted that where the children had effective non-symbolic communication (e.g., gestures, facial expression, and vocalization), the parents were less likely to use their child's AAC system [7]. Goldbart and Marshall [8] also interviewed parents of children who used AAC systems and reported that parents varied in the degree to which they were involved in AAC decision-making, and had difficulties accessing SLP services at the standard they expected. Parents also reported feeling guilt and frustration with regards to the time they could invest in their child's communication and described feeling overwhelmed by the demands and pressures placed upon them [8]. Furthermore, Lindsay [9] explored the challenges faced by SLPs and occupational therapists who prescribe AAC systems, and noted barriers related to the usability of the technology, the impact of the child's ethno-cultural and socio-economic background, disagreements amongst stakeholders, and the child's age and capability to use the system that was prescribed. Professionals also discussed social barriers stemming from family members who did not see the need for AAC or prioritized their child's health and physical functioning over developing communication skills [9].

Although SLPs and parents in the existing literature have reported multiple family-related barriers to the use of AAC systems, the views of parents who have actually rejected or abandoned a system are significantly underrepresented. This gap is evident in two systematic reviews that explored barriers and facilitators to the provision and use of AAC systems [10,11]. Baxter et al. [10] reviewed 27 papers that discussed the provision and use of high-tech AAC systems specifically. From these papers, the authors concluded that family perceptions and support influenced the provision and use of high-tech AAC systems. For example, parents were reported to have a crucial role in supporting the introduction of AAC systems and were required to develop a high level of technical skills. In addition, parent attitudes towards technology were raised as a potential barrier to AAC implementation. While 11 of the 27 papers reviewed included the perspectives of family members, only one study included participants who were family members of a person with complex communication needs who was not currently using an AAC system [12]. Therefore, the barriers and facilitators to the use of high-tech AAC systems were predominantly presented from the perspectives of families who persisted with AAC, not those who had rejected or abandoned a system.

In response to Baxter et al.'s [10] review on high-tech AAC systems, Moorcroft et al. [11] conducted a systematic review on the barriers and facilitators to the provision and use of low-tech and unaided AAC systems. Moorcroft et al. [11] analysed data from 42 papers with reference to the International Classification of Functioning, Disability and Health (ICF) [13] and identified factors across the domains of body function (physiological function of body systems), personal factors (internal factors that influence

how disability is experienced by the individual), and environmental factors (the physical, social, and attitudinal environment in which people live their lives) that were barriers to or facilitators of AAC provision and use. For example, barriers to AAC use were presented by the person with complex communication need's own cognitive and physical abilities, attitude and preferences, cultural and linguistic background, and socioeconomic status. Environmental factors included attitudinal barriers such as parents who felt AAC was confronting and stressful, held low expectations for their child, or denied the need for an AAC system. Family members also posed a barrier when they lacked the time or skills to support the use of AAC. Of the 42 papers reviewed, 19 included the perspectives of family members; however, only two of these papers included family members of people with complex communication needs who may benefit from but did not use a low tech or unaided AAC system [14,15]. These studies did not specifically seek to include family members who had rejected or abandoned AAC systems; rather, these participants were an incidental inclusion. Therefore, as in Baxter et al. [10], most barriers to AAC use reported by Moorcroft et al. [11] had not actually lead to the rejection or abandonment of the system.

Together, Baxter et al. [10] and Moorcroft et al. [11] demonstrate a paucity of research from the perspective of parents who have rejected or abandoned an AAC system. Existing literature does however suggest that there are barriers related to the parents of children with complex communication needs that may have contributed to the rejection and abandonment of AAC systems [6–9]. In light of these reports, it is inherent that parents are given an opportunity to reflect on their contributions to the rejection and abandonment of AAC before using this information to inform clinical practice. Therefore, the current study aimed to explore parent perspectives on the contribution of factors associated with the family unit to the rejection or abandonment of an AAC system for their child with complex communication needs.

Methods

Research design

This study was a qualitative interview study utilizing a qualitative descriptive approach, which is an effective means of exploring barriers and facilitators within healthcare [16]. 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 their child was between the ages of 0 and 6 years. The research team opted to explore AAC rejection and abandonment by parents of young children specifically, so that with this information clinicians may be better able to support successful early intervention using AAC. No exclusion criteria were applied to this study. Maximum variation purposive sampling [17] was used to recruit parents of children with a variety of diagnoses and who had used a range of unaided, low- and high-tech AAC systems. A total of 12 parents were recruited via organic and paid Facebook advertising ($n=7$), their private SLP ($n=1$), their government school ($n=3$) and an Australian AAC Listserv ($n=1$). An additional nine parents expressed interest in the study but did not respond to further contact or were not eligible to participate due to the age of their child.

Participants were all biological mothers of a child with complex communication needs and were aged 28 to 55 years ($M=41$ years). All participants had completed some degree of post-school education and spoke English in the home environment. Their children (6 female, 6 male) were aged 3 to 16 years ($M=8$ years) at the time of the interview and their 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.

Data collection

Consenting parents participated in a semi-structured in-depth interview at a time and place convenient to them. Participants were located in Queensland, Australia ($n=9$); New South Wales, Australia ($n=2$); and Utah, USA ($n=1$), with a combination of in-person ($n=8$), phone ($n=2$), and video conference ($n=2$) interviews being used. Mean length of the interviews was 40 min (range: 26 – 59 min) and all interviews were audio recorded. Data was collected as part of a larger project which sought to explore parents' experiences with AAC rejection and abandonment. A topic guide was developed based on an extensive review of the AAC literature and the first author's clinical experience. Key prompts relevant to the current study 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. Follow-up questions prompted participants to consider why AAC didn't work for their child or family, and what would have made it easier for them to use AAC.

Adjustments were made to the topic guide following a pilot interview. Parents of children over the age of 6 years ($n=5$) were asked to reflect specifically upon their experiences of AAC rejection and abandonment when their child was 0 to 6 years old. 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 and are both highly experienced in qualitative research methodologies.

Following the interview, parents were asked to complete a survey which collected basic demographic information about themselves, their child, and other members of the household.

Data analysis

Thematic analysis of the interview data was conducted by the research team following the steps outlined by Braun and Clarke [18]. The first author transcribed the interview recordings, checked for accuracy, and noted initial ideas before sending the transcripts to participants for review. Four participants responded that they did not require changes to their transcript, and one participant reported that the transcript was too confronting for her to read. This participant was offered free support services and reminded that she was able to withdraw from the study; however, she chose to continue her participation. The remaining participants did not respond to the provision of their transcripts. All transcripts

were then systematically coded by the first author, and codes were sorted into themes and subthemes which were reviewed and refined by the second and third authors. Analysis was completed by selecting compelling extracts of data to support each theme and relating the findings to existing literature. Participants were then provided with a written summary of the study's findings and were given the opportunity to provide further comments. No participants responded to member checking.

Results

Parents reported rejecting and abandoning a variety of unaided, low-tech, and high-tech AAC systems. The systems most frequently mentioned were manual signs (e.g., Key Word Sign,¹ Makaton,² Paget-Gorman Signed Speech,³ and Signed English⁴), AAC apps on iPads,⁵ PECS,⁶ and PODD;⁷ however, there was inconsistent use of terminology when referring to specific systems (e.g., PODD to refer to any AAC system in book form). Parents reported abandoning AAC systems after varying lengths of time, ranging from a couple of weeks to two years. Overwhelmingly, the parents wanted to do what was best for their child and some reported feeling guilty for not persisting with or pushing for AAC earlier. Some parents had later accepted alternative AAC systems despite the challenges they encountered, and others were open to the idea of using AAC with their child in the future.

Each parents' journey with AAC was unique and most parents reported a combination of factors that together contributed to the rejection or abandonment of the AAC system. One parent exemplified this cumulative effect when she reflected: "Hearing myself I sound like it's all excuses, but it's kind of that when you add it all together that's why it becomes, you abandon the system" (Parent 11). The varied family factors contributing to the rejection and abandonment of AAC systems were organized into four themes: (a) parents lacked the emotional readiness and resilience to implement AAC, (b) implementing AAC was extraneous work for parents, (c) the child did not use their AAC system for communication and (d) parents were not satisfied with the AAC system itself. These themes are discussed in depth below and the themes, subthemes, and example participant quotes are presented in Table 1. It should be noted that parents also described multiple contributors to their rejection and abandonment of AAC that were related to external stakeholders such as SLPs, teachers and members of the community. These findings were not related to the aim of the current study and have therefore been presented in a separate manuscript [19].

Theme 1: parents lacked the emotional readiness and resilience to implement AAC

Four parents reflected that they or their family members had rejected or abandoned AAC because it was introduced before they had emotionally dealt with their child's disability. These parents described feelings of grief and saw AAC as an additional point of difference for their child. As Parent 12 commented:

I was in a position of, you could probably call it grief of not having a normal child. So, when you're like that there's so much psychology that goes into the parents of coping and realising that they're going to have a child that's not going to have the future that the rest of their children is [sic] going to have.

However, this parent also acknowledged that she was not consciously aware of her grief at the time. In addition, parents reported that their spouses, parents, and siblings also felt shame

Table 1. Parent perspectives on the contribution of factors associated with the family unit to AAC rejection or abandonment.

Theme	Subtheme	Example participant quote
Parents lacked the emotional readiness and resilience to implement AAC	Family members hadn't emotionally dealt with the child's disability when AAC was introduced	"I think it was the stigma with the fact that they [the child's grandparents] are very secret squirrel in the fact that she does have this disability. Um, I think that there's a lot of shame for them to acknowledge that this is what she's going through, and it's a very visual way for people to make the connection that she does have this. Um, they want to stick their head in the sand and say that she's happy, healthy, normal ... I feel like they're fairly counterproductive with the work that we need to do." (Parent 4)
	Parents did not have the emotional resilience and support to continue with AAC	"I don't think I had the patience, I don't think I had the resilience, emotional resilience to you know, make that part of the family routine." (Parent 11)
Implementing AAC was extraneous work for parents	Remembering and using AAC is a conscious effort rather than natural habit	"I think we cognitively um understood the reason for it, I mean just from my husband's behaviour I could see that he was convinced, but at the same time again it's coming back to those habits. It's instilling those habits, it was just, it's just such a hard thing to establish any habit let alone such a big one like communicating." (Parent 2)
	It was challenging for parents to implement AAC within the demands of their everyday life	"PECS is ridiculous like, I understand how PECS works if you're in an [education] setting or something where they've got people to help with that it's fine, but when you're a working mum with three kids, like working nearly full time and stuff I just don't have time for PECS." (Parent 13)
	Parents did not have time to make or program systems	"It [AAC] was getting a bit tricky to sort of just handle and her words were getting wider, her vocab was getting wider and more pictures were needed, and all the cutting out and the laminating and all that type of thing, every week, or every day." (Parent 12)
	The parent did not need the AAC system to communicate with their child	"And physio you have to do otherwise you start breaking your back like so I had some sore necks and things so I have to lift him properly ... but ... nothing in your life changes absolutely dramatically if you don't pick this [PODD] up. Cause we know him enough to know what he wants, what he, you know he wants to go and play, we didn't need to pick this up to say 'do you want to go and play with the ball', you just go 'do you want to play with the ball?' and he goes 'yeah I want to go.'" (Parent 7)
	Other family members didn't share the workload	"It wasn't just me on this journey, it was my husband, ... my brother, my parents, they were all people that see her [the child] daily and they weren't really embracing the system either. So I felt like I was pretty much the only one trying to really facilitate it." (Parent 4)
The child did not use their AAC system for communication	Child did not show interest in their AAC system as a means of communication	"He just walked away [when the AAC system was used]. We literally had to hold him ... Sometimes he might tap it just to get a response from the sound, but he never made the connection 'if I hit that button, I'll get that chocolate' ... He never got it." (Parent 13)
	Child used the AAC system as a toy	"It's something that you know is more considered to be a toy by the kids rather than a learning aide so um I find those cards all around the house, I find the stickers more so around the house." (Parent 4)
	The child wasn't developmentally ready to use the system	"I don't know, maybe it was a developmental thing, maybe he was too young, but we pushed it and pushed it and pushed it and I think at the end he was just like 'stop it!'" (Parent 13)
	Child wasn't motivated to communicate beyond specific topics	"When she was about one and a half ... she kind of hit her regression and she stopped eating orally ... and I think that actually hurt the signing. Cause I do think you know I would, I would use the signs with her ... when I was feeding her, and I think it did help her to understand or at least she knew what the signs were even if she wasn't doing them herself. Um but yeah, kind of once we lost the food as the key conversation topic it was really hard." (Parent 6)

(continued)

Table 1. Continued.

Theme	Subtheme	Example participant quote
Parents were not satisfied with the AAC system itself	Child's sensory and motor skills and preferences hindered AAC use	"We tried to do it, but she ate them, [child] ate the pictures (laughs). So not only is she not focussed enough to look at the pictures, but with the sensory processing part of it too, she'd eat the pictures, so it kinda doesn't work when you've got a kid who chews the pictures up and then spits them out on the ground." (Parent 3)
	Parents weren't rewarded for their work when their child didn't use the system	"Cause she can't move her hands either, so it's not like we can show her and then she echoes back. So, because we didn't get that feedback I don't think we persisted with it." (Parent 2)
	Parents did not perceive AAC systems as good value for money	"iPads are good but again there's all that risk of the cost of them. So every time to fix a screen was \$150 and after three times we just gave up and went well this is only gonna be in the house." (Parent 7)
	Parents felt the language was too simple or complex for their child	"It [the AAC system] was just always, felt limiting to me, it was always just two or three choices and that's it, and I just felt it was kind of beneath him I guess. I just always felt like he could do more than that." (Parent 5)
	Parents experienced functional difficulties with the AAC system	"So we did get a trial book after that um and it was huge. It was like, I don't know, a kilo, it felt so heavy! And it was awkward because as you can see like I'm holding her on my one arm and I feed her on the other arm, what am I gonna use to hold a PODD book? It's just impractical." (Parent 2)

and denial related to their child's disability that prevented the use of AAC systems:

He [my husband] hadn't emotionally dealt with the whole thing. So again, a point of difference from his point of view and he you know, I think he just hopes like hell one day she'll open her mouth and words will come out (laughs). So yeah, he just wasn't emotionally ready to deal with it [AAC]. (Parent 11)

For those parents who had initially accepted AAC, five reported that they lacked the emotional resilience and support to continue using the systems. Parent 10 described abandoning AAC following a sequence of family trauma that was unrelated to her child's disability; however, other parents discussed feelings of burn out, limited patience, and worry regarding the use of AAC specifically: "Because we went so hard so fast and we burnt out, and I was like at the point where this is ridiculous" (Parent 13). Parent 11 noted that emotional support from her husband "or anyone who was willing to offer it" may have increased her resilience and enabled her to continue the use of AAC:

It's the emotional support to keep going even in the absence of any or slow progress from her ... It's that sort of reminding myself, or reminding all of us, that her development trajectory is not as steep as other kids and we've just gotta keep plodding away. So it's the emotional support and the resilience to just, "you're doing a good job". You know, I can say that to myself, but when you're tired and, you know. (Parent 11)

Theme 2: implementing AAC was extraneous work for parents

Six parents reported that they abandoned their child's AAC system because using the system was a conscious effort rather than a natural habit or something they could easily incorporate into their routines. Parent 2 likened her attempts to use AAC to a failed New Years resolution:

Like it's the same with like "oh I'm gonna lose you know fifty kilos next year". You know, it's the same thing, New Years resolutions you have to

make into a habit and that's the problem, is just that we've never made [using AAC] into a habit. (Parent 2)

These parents also spoke about the conscious effort required to remember and carry their child's AAC system with them. Parent 7 said that AAC "wasn't the kind of thing you put in the nappy bag that you take with you" and Parent 13 "found it extremely hard to always remember the iPad, it's like, it's hard enough remembering your purse." To overcome these difficulties, Parent 2 reflected that:

Ideally would like I don't know three or four copies [of the AAC system] so we have one stashed at school, one at Sunday School, one in the car, one at home, you know, and just have it stashed all over the house. (Parent 2)

For those parents who did remember to have their child's AAC system with them, five then reported that it was challenging to implement the system due to the demands of their everyday life. These demands included the paid employment of themselves and their spouse, university studies, household duties, holidays, raising other children, managing challenging behaviours, completing personal care tasks for their child, and physically managing their child during day to day activities:

So when you're trying to physically juggle a kid, and a second child, and thinking okay well this is a perfect time because I should be modelling and saying to her you know "time to put your seatbelt on" or something, you're just trying to get the two kids in the car. And where's the iPad go, does it get attached to me? No cause it's not my voice, it's [child's] voice, but she's only little. (Parent 11)

Given her existing parenting demands, Parent 4 reported feeling overwhelmed when she realized that AAC "wasn't a case of just going off to a specialist and them teaching her something and her skipping off." These demands also meant that many parents did not have the time required to program or make their child's AAC system:

I hated PECS cause I did not, I don't have the time to laminate everything in the house. And that's what they [professionals] were

saying to me ... Like people would give me a file, they're like "no no you can't do that, you have to take a photo of every single thing then you have to laminate it and put Velcro on it". So I bought all the stuff, I tried, but I'm like this is no. (Parent 13)

To alleviate these difficulties, some parents reported that they would have preferred to be given a set of symbols to use rather than making their own or use a high tech AAC system that already contained much of the required language.

Five parents also reported that the work of AAC felt extraneous when they could successfully communicate with their child without the system. When parents could anticipate their child's needs, or the children could express themselves using a different AAC system, speech approximations, natural gesture, or their behaviour, parents reported that using AAC seemed "like a round-about way" (Parent 7) to communicate:

Like by then we already knew her cues, so we knew if she had um you know if she smelt we'd check her nappy or if she'd make funny sounds and we'd go "oh yeah I think she's about to throw up", so we'd put the bucket around her. You know yeah, it just depended on her cues so we're, we knew all the basics um yeah, so I don't think you know it's not really been an issue that we don't need to discuss about you know different TV characters and stuff like that. (Parent 2)

Parents also spoke about their reluctance to use AAC when their child had functional receptive language:

It feels like he didn't need that [AAC], like he understood what, like if you just say "do the shuffle dance" he shuffles around. Like you don't need to go like this [signed dance] ... He's not deaf. So all that just felt like a waste of time. (Parent 7)

Given the work required to make and implement AAC, four parents also reported challenges when other family members did not share the workload. Some mothers reported that the use of the child's AAC system fell almost exclusively on them without the support of their spouses, parents, siblings, and other children. Parent 8 also noted that "it was difficult and exhausting too you know for me to be taught one thing and then it was my job to go and do the thing all over again and teach it to another family member."

Theme 3: the child did not use their AAC system for communication

Eight parents reported abandoning AAC systems because their child did not make the connection that it could be used as a communicative tool. While some children reportedly looked at the pictures, other parents reported that their children showed no interest in the system whatsoever, and Parent 13 described her son having a particularly negative reaction towards AAC: "he just hated it, he never liked it". This parent reported following their SLP's instructions and restricted access to her child's preferred items until he requested them with the device, leading to frustration for both parent and child:

It was heartbreaking ... I'm using these powerful tools as a weapon against him and he would be throwing himself on the ground crying and howling, cause all he wanted was a drink of bloody milk and I was like "no you can't have it" like I was restricting access, "you have to push this iPad" for like twenty minutes so he was crying going "I just want a bloody drink of milk". (Parent 13)

Seven parents reported that their child did not connect their system with communication because they saw it as a toy or game. iPads were reportedly used for auditory and visual stimulation within the communication app or taken out of the app to access games. Low-tech systems were also used as toys by flicking through PODD pages, crinkling individually laminated

symbols, or pulling symbols off a Velcro board: "He just loved the sound of the Velcro tearing off, so it wasn't a reliable choice" (Parent 7).

Four parents suspected that their children were not using their system expressively because they were not yet developmentally ready. Such readiness was discussed in terms of age, health, cognition (e.g., understanding of consequences), and regulation:

So I think [child], particularly when [SLP] first started with her, was a nightmare child (laughs). She kind of didn't, if we went into the [service provider] offices she just couldn't cope and she spent most of the time crying or um she'd fall asleep. (Parent 6)

Two parents also identified a lack of motivating communication opportunities as a barrier to AAC use with their children. These parents reported that given their children were tube fed, not toilet training, and had limited and predictable activity preferences, "that kind of regular conversation so to speak opportunity wasn't there" (Parent 11).

Eight parents also reported that their children's sensory and motor preferences limited their child's and subsequently their own use of AAC. Children with attentional deficits were reportedly unable to engage for the full duration of a speech pathology session or focus on their AAC system to communicate: "Her attention span is very short which I think hampers any communicative device usage or any type of communication unless it's very quick" (Parent 3). Other children sought frequent oral input and therefore chewed or sucked on and destroyed elements of their AAC systems, meaning they were no longer available for use. Parent 11 reflected that such chewing also prevented other people from wanting to use the system: "You'd end up in Winter or something with this wet, chewy, gooey thing, which also means that no one else other than her mother's gonna touch it cause it's got her spit all over it." Parent 8 discussed her son's tactile defensiveness, which meant that he did not tolerate wearing an AAC device on his wrist or being touched to shape his use of signs. In contrast, Parent 3 reported that her daughter was better suited to sign language than symbol-based systems because she received proprioceptive feedback when her hands were guided through the movements and did not have a physical resource that she could put in her mouth. Finally, some children were unable to use their AAC system due to their limited fine motor skills which prevented accurate pointing and signing. Parent 6 reflected on her child's difficulties using a communication app on an iPad:

There were a lot of times where she'd just kind of do this massive swing at the iPad. I know she wanted something, but you were never kind of a hundred percent confident that what she was touching was the one that she actually wanted. (Parent 6)

When parents were not rewarded for their hard work (as discussed in Theme 2) by seeing their child use the system, they reported abandoning the system:

It's not necessarily that we weren't willing to [use AAC] ... it's just that what we were putting into it and not seeing any reward basically. Which I guess looking back it's kinda hard to say, cause I don't know, kids just develop language so slowly I guess, you have to model it so much. (Parent 5)

Parent 13 reported abandoning her child's AAC system, however said she would have absolutely continued use of the system had he been able to use it to talk to her. Similarly, Parent 6 reflected that while she had abandoned other AAC systems that her child didn't use expressively, she was committed to using PODD after seeing results with this system:

She had that one session that was just amazing and she was really engaged and everything, and I think that was kind of a good, I don't know how to put it, but kind of like an inspiration, [to] suddenly realise she can do this because we've been doing lots of other stuff and it's like yeah maybe, you know, I was never quite sure ... if she even had a clue what we were trying to get her to do ... So to be able to kind of I suppose realisation [sic] that she could do it and that it would work for her. (Parent 6)

Theme 4: parents were not satisfied with the AAC system itself

Parents also reported concerns with the cost, language level, and functionality of specific AAC systems that meant they did not commence or continue use of these systems. Firstly, three parents reported that they did not purchase and use a recommended AAC system with their child because they did not perceive the system as good value for money. This was particularly the case where the child had not yet demonstrated their ability to use the system:

She [the SLP] brought it [AAC] to our attention, we tried it, but again it was a big outlay, it was gonna be like \$400 and I was like you know what, I've spent that much money on books and puzzles and games that people have told us to buy, to outlay \$400 on an iPad piece of software that she's not necessarily shown that she's using the software, she's using the iPad because she likes the noise. (Parent 3)

Parent 3 therefore noted that a loan system may be beneficial to support parents to commence using AAC with their child. In addition, Parent 7 reported that she stopped using her child's AAC system because of the cost of having the screen replaced when it was broken.

Six other parents who had begun to use AAC abandoned the system because they believed the language it contained was either too complex or simple for their child. While some parents reported that the system that had been introduced was "too complicated too early" (Parent 7), others reported that their child's system was too limited in terms of vocabulary size, specificity, and word classes and therefore "just didn't seem to fulfil our communication requirement" (Parent 12). Parent 12 attempted to expand her child's AAC system to meet her needs, however noted limitations in this process:

I think it was getting too hard for both of us, because ... she needed more vocab, she needed more nouns, and we just weren't producing the nouns in pictures that she was searching for, but she couldn't communicate that to us. So her vocab was really limited by the pictures that we had printed out and you know Velcroed ... So it was really determined by myself and the early intervention teacher and the speech therapist about what words she would be using in our environment and that may have been limiting for her. (Parent 12)

Ten parents also reported a variety of functional difficulties that limited their use of AAC systems. Many parents said that AAC systems were abandoned because they were slow, difficult, and impractical to use. Parent 2 discussed being unable to express her desired message using her daughter's PODD and surmised that: "I've had a love-hate, I mean mostly hate relationship with these PODD books. I really hate them. I really don't like the format, it's not usable, not user-friendly at all" (Parent 2). Parents also commented that the AAC systems were either physically too big or small for themselves or their child. Where small symbol cards were reportedly easy for children to chew or lose, larger systems like PODDs were heavy for parents to carry. In addition, Parent 11 noted the PODD was "physically not compatible" with her child as "she was a small, three-year-old with brittle bones, and [was given] this massive book." An additional functional difficulty was the frequency with which systems were lost or damaged by the

child or his or her siblings. Parent 7 spoke about limiting her son's access to his communication app on the iPad and low tech PODD because of such damage:

And this thing [the PODD] gets wrecked all the time, like now look at it. It was \$150, I don't even know how the pages have been tearing out. Cause ... he just loves this thing in terms of flicking, so it becomes a toy, then I put it away to keep it safe, and then we don't use it. (Parent 7)

Parents also raised other functional concerns with the AAC systems including the absence of high contrast symbols, inaccurate pronunciation of vocabulary, and the child being unable to locate vocabulary within the system. Finally, Parent 10 reported that the language system introduced to her son was not functional because it is not recognized beyond the school environment:

I don't understand how anyone can have a school that's a school where you put all these kids together, like when I really think about it, you make them all do a sign language where no one else in the entire country speaks that language, and they're only learning a little bit of it anyway. And then they leave that environment, and if they still need to be able to communicate, there's no one else who can communicate in that language. It would be like, you know, learning some unusual little dialect of some native tribe in another country and you know dropping them in Australia and saying now talk.

Discussion

This study aimed to explore parent perspectives on the contribution of factors associated with the family unit to the rejection or abandonment of an AAC system for their child with complex communication needs. Thematic analysis revealed that AAC systems were rejected or abandoned when parents lacked the emotional readiness and resilience to implement AAC; implementing AAC was extraneous work for parents; the child did not use their AAC system for communication; and/or parents were not satisfied with the AAC system itself. These findings add to the existing literature to provide evidence for family factors that contribute to AAC rejection and abandonment and can be used to inform clinical practice.

Firstly, parents in the current study reported rejecting and abandoning AAC systems when they lacked the emotional readiness and resilience required to commence or continue use of a system. Parents described feelings of grief, shame, and denial in themselves, their spouses, and extended family members; however, not all parents were consciously aware of these feelings at the time they were present. This finding is consistent with SLPs interviewed by Moorcroft et al. [6], who noted that parents who accepted their child's disability were more likely to accept AAC systems than those who were still grieving the loss of the child they expected. While no studies have explicitly explored the relationship between parent grief and the use of AAC systems, grief has been noted to impact on other areas of intervention for children with disabilities. For example, Piggot et al. [20] noted that parents of children with cerebral palsy were unable to fully participate in home-based physiotherapy and occupational therapy programs until they had come to grips with their child's diagnosis. Interestingly however, when parents who had accepted an AAC system discussed barriers to AAC use, they did not raise the concept of grief and loss [10,11]. Together, these studies suggest that parent and family grief may be a mediating factor for the rejection and abandonment of AAC systems.

For those parents who had initially accepted AAC, some then reported lacking the required emotional resilience and support to continue using the system, thus leading to AAC abandonment. Resilience is the ability "to respond positively to an adverse

situation and emerge from the situation feeling strengthened, more resourceful, and more confident" [21, p.427]. Like grief, the impact of resilience has not been explicitly investigated in prior literature on the use of AAC systems; however, resilience has been explored in parents of children with special health care needs more broadly. For example, Ferrand et al. [22] assessed the resilience of parents of children in a neonatal intensive care unit at high risk of developmental disability. The authors noted that, when adjusting for the risk of disability, parents with low resiliency scores were ten times more likely to predict that their child would remain chronically ill and projected a higher health-related burden from their child's illness. Furthermore, McConnell et al. [23] surveyed 538 families of children with developmental disabilities and reported that irrespective of the child's level of behavioural problems, families are typically more resilient when experiencing high amounts of social support and in the absence of financial hardship. The relationship between social supports and resilience was also raised by a participant in the current study, who commented that had she received emotional support from her husband or anyone else, she may have had the resilience to persist with AAC. Therefore, while again tenuous, there is preliminary evidence for a relationship between parent resilience and the acceptance of AAC systems.

The second theme of the current study discussed the challenges parents faced in implementing AAC due to the extraneous work it required. Parents reported abandoning AAC because using the system required conscious effort in the face of existing parenting demands, and such effort was not warranted when parents could successfully communicate with their child without AAC. The multiple demands on parents of children with disabilities were acknowledged by SLPs when discussing contributors to AAC rejection and abandonment [6] and have been described in depth in previous studies. For example, parents of children with cerebral palsy who participated in a focus group reported increased time pressure, stress, and daily parenting tasks that made it challenging for them to implement positive parenting strategies [24]. The reported time pressures on these parents included hospitalizations, the need to complete therapy exercises with their child, organizing equipment and appointments, assisting with mobility, advocating for their child, and explaining cerebral palsy to others. These demands are increased for parents of children with more severe physical disabilities [25]. Furthermore, Goldbart and Marshall [8] discussed specific demands on parents of children who use AAC including the need to find information, arrange funding, make or program AAC systems, learn to communicate with their child, teach their child to use the system, train other stakeholders, and be proactive and advocate for their child. Therefore, when introducing AAC systems, SLPs must teach parents not only how to use the specific system but also how to incorporate modelling of the system into the child's everyday routines in a manner that is minimally laborious. SLPs may also reduce the demands on parents by making or programming the AAC system for them and taking responsibility for providing AAC training to the multiple stakeholders involved in the child's life. SLPs should also work with parents to develop individualized strategies for making the use of AAC habitual and thus less of a conscious effort and demand.

Given the time pressures of parenting a child with a disability, it is not surprising that parents who felt they could communicate successfully with their child without AAC opted against adding an additional demand. Similar results were found by Bailey et al. [7] and Lindsay [9], who reported that parents were less likely to use AAC if they could understand their child's body gestures,

intonation of verbalizations, facial expressions, and changes in body posture and level of body excitation. Although parents are adept at interpreting their children's communication [26], communication partners unfamiliar to the child are less likely to interpret these subtle cues. As the child becomes older, the lack of a more widely understood communication system may limit their independence and ability to communicate with members of society [9]. Furthermore, even with familiar communication partners, children with complex communication needs are not able to express the full range of communication functions without using an AAC system. These children may successfully use early communication functions, such as expressing feelings, asserting independence and gaining attention; however, even with the most attuned parent, functions such as telling stories, discussing past and future events, telling jokes, reasoning, and expressing abstract ideas are not possible without a robust communication system [27]. At this stage it is unclear how to best approach balancing the demands on parents and their ability to interpret their child's communication without AAC with the future communication needs of that child.

When parents did initially model their child's AAC system, some reported then abandoning the system when they were not rewarded by seeing their child use it to communicate. Instead, many children were reported to show no interest in their system, use it as a toy, or have sensory preferences or motor limitations that hindered use. Other parents reported that their children were not developmentally ready to use AAC or were not motivated to communicate beyond specific topics. Ronski and Sevcik [28] and Cress and Marvin [29] report that there are no child prerequisites for the introduction of AAC systems in terms of age, cognition, language, or sensorimotor skills. The gold standard of AAC clinical practice is to introduce children with complex communication needs to AAC as early as possible in order to foster their receptive and expressive language development [30]. However, health professionals interviewed by Lindsay [9] reported that children needed to show a "readiness" [9, p.213] to use AAC before they would prescribe a system. Consistent with reports by Lindsay [9], the current study suggests that when AAC is introduced to a young child with cognitive or sensorimotor impairments, these factors may at least temporarily prohibit the child from using their system expressively, and consequently contribute to parent abandonment of the system. Therefore, when prescribing AAC systems, clinicians must consider and address the child's motivation, sensory, and physical issues in consultation with the parents and a multidisciplinary team to select a system with which the child and family are most likely to experience early success. Clinicians must also encourage and assist parents to persist in their use of AAC in the absence of the child using the system expressively [6].

Finally, parents reported rejecting or abandoning AAC systems when they were not satisfied with the system itself. Parents raised concerns with the cost of purchasing and maintaining systems as well as the level of language within and functionality of those systems. Similar functionality issues have been raised in the existing literature on both high and low tech AAC systems. For example, Baxter et al. [10] discussed barriers to the use of high-tech AAC systems including the battery life, ease of programming, quality of the voice, vocabulary, and speaker volume. Likewise, Moorcroft et al. [11] noted barriers to the use of low-tech AAC systems such as issues with portability and storage, the limited range of vocabulary and syntax available, and the system being slow to use. Given the consistent reports of the impact of functionality issues in AAC systems, it seems logical that system developers must develop systems that are increasingly portable, robust, user-

friendly, efficient, and affordable. Multiple authors have also highlighted the need to incorporate end users such as children with complex communication needs and their peers in system design [9,31,32]. In the interim however, it is critical that SLPs seek and respond to parent feedback about the features and functionality of each AAC system trialled before then selecting the system that is the best fit for the child and family.

Clinical implications

This research highlights the need for SLPs to be increasingly family-centred in their introduction of AAC systems to children with complex communication needs. As detailed by Epley et al. [33], family-centred clinicians must consider the family as the unit of attention, provide families with choices, consider family strengths, foster the family-professional relationship, and provide individualized family services. AAC intervention must therefore consider the concerns and needs of the entire family, and as such SLPs must acknowledge the existing demands on parents and coach them to incorporate AAC into their daily activities. SLPs must also collaborate with parents to carefully consider the child's motivation, sensory profile, and physical abilities when prescribing AAC systems. Ultimately, however, parents must be given the choice about what AAC system will best meet the needs of themselves and their child, thus increasing parent satisfaction and giving the child and family the best opportunity for success.

This study also highlighted clinical implications related to the impact of parent grief and loss and resilience on the acceptance versus rejection or abandonment of AAC systems. Although only preliminary research, when the current study is considered alongside the existing literature, it suggests that parent and family grief and low resilience may be mediating factors for the rejection and abandonment of AAC systems. Therefore, when introducing an AAC system to the parent of a child with complex communication needs, SLPs may need to use the family-professional relationship [33] to open a space for discussion about grief and implement strategies to enhance parent resilience. Where these supports fall beyond the scope of an SLP, clinicians may refer parents to or conduct joint sessions with other professionals including psychologists, social workers, and counsellors. Such collaborations can be effective, as previous studies show that with psychological rehabilitation, parents of children with chronic health conditions have become more resilient despite a lack of change in their child's condition [34,35]. It is critical however that all clinicians involved also consider the strengths of each family member and view parents not as barriers to AAC implementation, but as collaborative partners in intervention with their own positive attributes and resources [33,36].

Limitations and future directions

Participants of this study were all highly educated, spoke English as a first language, were knowledgeable about AAC, and were strong advocates for their children. Therefore, given additional contributors to AAC rejection and abandonment are likely to be present for parents from different populations (e.g., cultural differences, low socioeconomic status), this study is limited by the representativeness of the sample. Furthermore, as parents of children up to 16 years of age were asked to discuss events from when their child was aged 0 to 6 years, data collection was also subject to bias from limitations in parent memory. In addition, services and AAC systems discussed by the parents may have changed since the time of their experiences.

Future research is required to further explore the potential relationship between parent levels of grief and resilience and the acceptance versus rejection or abandonment of AAC systems. Studies are then required to collate factors related to the family, AAC system, and SLP that contribute to AAC rejection and abandonment and determine which of these factors most significantly contribute to this phenomenon. Together, this information may be used to develop clinical recommendations for the introduction of AAC systems that may increase the rates of AAC acceptance by parents of children with complex communication needs.

Conclusion

This study is the first to explore how factors associated with the family unit contribute to the rejection and abandonment of AAC systems for children with complex communication needs from the perspectives of parents who have been through this experience themselves. Parents reported abandoning AAC when their child did not use the system for communication, if they were unsatisfied with the system itself, and because they saw implementing AAC as extraneous work. Parents also reported that they were unable to commence or persist with AAC without emotional readiness and resilience. SLPs must be aware of these factors when introducing AAC systems and, as family-centred clinicians, work with each parent to build upon their strengths and develop strategies for overcoming challenges to AAC implementation.

Notes

1. Key Word Sign is the use of manual signs and natural gesture to support communication. <https://www.scopeaust.org.au/key-word-sign-australia/>
2. Makaton is a language programme using signs and symbols to help people to communicate. <https://www.makaton.org/>
3. Paget-Gorman Signed Speech is an unaided augmentative sign system that supports language and communication. <http://www.pagetgorman.org/>
4. Signed English is a sign language dialect which matches each spoken word of English. <http://sign.com.au/>
5. The iPad is a product of Apple Computers Inc., Cupertino, CA, www.apple.com
6. PECS is a product of Pyramid Educational Consultants, VIC, Australia, <https://pecsaustralia.com/>
7. PODD is a product of Gayle Porter and The Cerebral Palsy Education Centre, VIC, Australia, <https://cpec.org.au/store/podd/>

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