

ORIGINAL ARTICLE

Speech pathologists' perspectives on the use of augmentative and alternative communication devices with people with acquired brain injury and reflections from lived experience

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Abstract

Background: Communication changes following acquired brain injury (ABI) may necessitate use of augmentative and alternative communication (AAC). Speech pathologists regularly assist people with ABI and their families with AAC assessment and recommendations, as well as education and training on AAC use. To date, there has been no Australian research investigating the perspectives of speech pathologists working in the field of ABI and AAC. This research aimed to 1) Explore speech pathologists' insights regarding enablers and barriers to considerations and uptake, and ongoing use, of AAC by people with ABI and 2) Understand their perspectives on AAC acceptance, abandonment and rejection.

Method: A qualitative research design, with semi-structured interviews, was used with seven speech pathologists working across three Australian states. Interviews were transcribed verbatim, and thematically analysed. To triangulate results, the lived experience reflections of one co-author, who has an ABI and uses AAC, were drawn on.

Results: Seven themes were identified, relating to four of the five domains of the World Health Organization's assistive technology model. These included that AAC should be person-centred, with consideration of both products and personnel required, and with effective policy aiding AAC trial, uptake and use.

Conclusion: This research has highlighted considerations for AAC use by people with ABI, from the perspective of speech pathologists and aided by lived experience reflections. Speech pathologists need to understand the breadth of products, and good practice service steps, to ensure successful AAC use and skill development. Listening to the perspectives of people with ABI is central to that understanding.

Keywords: Assistive technology; brain injuries; acquired communication disorders; speech-language pathology

Introduction

Communication competence underpins participation in both daily tasks and – more broadly – meaningful life roles, and acquired brain injury (ABI) can lead to a range of life-changing and enduring communication impairments that affect this participation (Doyle & Fager, 2011; MacDonald, 2017; Sloan et al., 2012; Snow, 2013). Communication issues stemming from ABI may impact one or more aspects of the communication system, including motor speech, expressive and receptive language, using written language, cognitive communication and social interactions (Fager et al., 2006). Social use and integration of verbal and non-verbal communication

may also be impacted, resulting in difficulties in topic generation and maintenance, taking turns in conversation, knowing how much and what to say, reading facial expressions, and understanding the underlying intent of the communication (MacDonald, 2017).

The communication changes experienced after ABI require a range of interventions. A combination of restorative and compensatory communication strategies is recommended and, in some instances, interventions will include the development or application of augmentative and/or alternative communication systems (Fried-Oken, et al., 2012; Togher et al., 2023). The American Speech-Language-Hearing Association (ASHA) describes Augmentative and Alternative Communication (AAC) as any strategy or equipment that supplements or compensates for impairments a person experiences in order to understand or express a message (ASHA, n.d.). This includes unaided strategies such as facial expressions, gestures and signs, light technology or non-electronic options such as alphabet boards, choice cards or communication books, and high-tech / electronic specialised speech generating devices like a Lightwriter™ or Grid Pad™ (ASHA, n.d.; Fager et al., 2006; International Society for Augmentative and Alternative Communication (ISAAC), n.d.; Jamwal et al., 2017; Togher et al., 2023). Electronic AAC options can be accessed through direct touch, switching and scanning, or other alternate access options, including eye gaze, head stick or mouse control. In addition to specialised equipment designed specifically for this purpose, mainstream products – such as smartphones and tablets – can also run communication applications or link to alternate access options, such as a head-mounted laser pointer or mouse (Cook, et al., 2020). Following an ABI, a person may use a range of these strategies and equipment options to meet their needs in different situations. As such, it is important that person-centred assessment and interventions are considered (Cook, et al., 2020; Jamwal et al., 2017; World Health Organization, n.d.).

Speech pathologists are trained in speech-language production and comprehension, and can assess language and communication abilities, individual goals, and support needs (MacDonald, 2017; Togher et al., 2023). They are the main allied health professionals that undertake AAC assessment, trials, training and education, and make recommendations to individuals with ABI who may benefit from such communication aids (ASHA, n.d.). AAC interventions are however noted to require a collaborative team approach (NDIS Quality & Safeguards Commission, 2021). Multi-disciplinary AAC interventions need to include consideration of speech and language skills, as well as other factors that will impact AAC use. These include, for example, posture, seating and physical capacity, and new learning ability, behaviour and perceptual skills of the person with ABI. Physiotherapists, neuropsychologists and occupational therapists may therefore also assess and input across these areas of consideration (Togher et al., 2023). This multi-disciplinary approach then informs recommendations regarding AAC learning needs and direct or alternate access requirements; device mounting, reach and access; and positioning and postural support of the person with ABI (Cook, et al., 2020). AAC interventions may therefore include use of multiple or varied systems over the years post injury, within different environments, or depending upon the skills and familiarity of the communication partner (Fager et al., 2006).

It is useful to consider AAC within the World Health Organization (WHO) 5P people-centred assistive technology model, which looks beyond the assistive product alone (WHO, n.d.; WHO/UNICEF, 2022). The WHO proposes five components of assistive technology that intersect as part of an assistive technology (AT) ecosystem, and should be considered in relation to the UN Convention on the Rights of Persons with Disabilities and universal health coverage. These include consideration of the *person*, the AAC and other assistive *products* they may use, *provision* of these products, *personnel* required to learn and maintain their use over time, and the *policy* environment that enables (or may limit) access to, and funding of, AAC (WHO, n.d.). See Figure 1.

Specific to the person, it is well recognised that individual preferences must be closely considered in relation to the use of augmentative or alternative communication options (WHO/UNICEF, 2022; Togher et al., 2023). Research highlights the importance of matching an AAC system with the goals and preferences of the individual using the product, and including the person with an ABI throughout the entire assessment, recommendation and implementation phases



Figure 1. The World Health Organization (WHO) 5P people-centred assistive technology model (reproduced with permission of the WHO).

of AAC to reduce the risk of AAC abandonment and maximise acceptance (Blackstone *et al.*, 2002; Fager *et al.*, 2006).

Whilst used clinically for decades, very few studies have addressed AAC utilisation by individuals with brain injury (Togher *et al.*, 2023). The research that does exist is now somewhat dated, and exploration of AAC user perspectives is particularly limited (Blackstone *et al.*, 2002; Fager *et al.*, 2006). Past research has identified the importance of involving the AAC user wholistically in the design, research, assessment, selection, implementation and review of AAC (Blackstone *et al.*, 2002). It has also highlighted that people with ABI may accept both high- and low-tech AAC and use their AAC systems for extended periods of time, but may be more likely to abandon technology when loss of facilitator support is experienced, rather than rejection of the product itself (Fager *et al.*, 2006). A past literature review to describe AAC for adults with acquired neurological conditions identified various factors that can be either barriers or enablers to AAC implementation, including training for communication partners; amount of direct therapy for the individual with ABI; preferences towards or against AAC as opposed to use of verbal speech or gestures; and the authenticity of the AAC messages delivered in a social setting (Beukelman *et al.*, 2007). AAC technologies have advanced significantly in recent decades, however, and now include both mainstream and specialised AAC and go beyond just letter-by-letter message formulation strategies.

A past survey on factors that influence expectations and opinions regarding assistive technologies, including AAC, identified key considerations to include prior experience with technology; opinions and perspectives on technology; and funding and support to learn to use the device (de Joode *et al.*, 2012). More recently, Pampoulou (2019) conducted semi-structured interviews with six speech pathologists working with adults with acquired communication disorders to understand their views regarding AAC system acceptance. This qualitative research identified a range of factors that impact on AAC acceptance, rejection, and/or abandonment including: time since onset of ABI; acceptance of acquired communication disorder; depression and/or lack of motivation; the individual's and family's perceptions regarding AAC versus verbal communication; level of AAC support available (*i.e.*, via caregivers); and the time and cognitive demand required to learn to use AAC.

Considering the current evidence gap that exists – including that there are no publications in the Australian practice context regarding the use of AAC with people with ABI, or the role of the

speech pathologist in this process – this study had two key aims: 1) Explore speech pathologists' insights regarding enablers and barriers to considerations and uptake, and ongoing use, of AAC by people with ABI and 2) Understand their perspectives on AAC acceptance, abandonment and rejection. In addition, the study was designed to draw on the expertise of one of the co-authors of this article who has an ABI and uses AAC, to offer lived experience or 'insider' research expertise and investigator triangulation (Carter et al., 2014; Devotta et al., 2016).

Method

All procedures contributing to this study comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. This research received Human Research Ethics Approval from the Monash University Human Research Ethics Committee (Project ID: 31786) prior to the study commencing.

Design

Given the exploratory nature of this research, a qualitative design was used, guided by an experiential paradigm (Lincoln & Guba, 1985).

Participant recruitment

Purposive sampling was used to recruit qualified speech pathologists who were members of Speech Pathology Australia, currently working in community settings, and had a minimum of 2 years' experience working in the areas of both AAC and ABI. Information about the study was circulated via the national assistive technology peak body, the researchers' existing professional networks, and an ABI clinician email listserv. A total of eight speech pathologists contacted the research team from the study advertisement, of whom seven met the study inclusion criteria and provided consent to participate.

Data collection

Data were collected between February 2022 and May 2022, using a customised demographic survey and semi-structured interviews with each respondent. The survey was completed immediately before the interview, and – as well as collecting demographic data – each speech pathologist was also asked about their experience advising on AAC. A semi-structured interview schedule was developed to prompt discussion in the interview. It included an initial opening question asking for each respondent's definition of AAC, and then other open-ended questions guided by the research aims, and is available from the authors upon request. To aid reflection on AAC, in addition to semi-structured interview questions, the 12 items listed on the Quebec Evaluation of User Satisfaction with Assistive Technology (Demers et al., 2000) were utilised for discussion regarding each study participant's perceptions on the most important features or key considerations of AAC products and related services.

Each interview was conducted by the second author over the telephone or via video conferencing (depending on each respondent's preferred method). Interviews lasted between 45 and 60 min, were audio-recorded with participant consent, and transcribed verbatim using Otter.ai (Otter.ai, 2022). Transcripts were then reviewed for accuracy, and edited by the second author against the audio-recording. To ensure confidentiality, numerical codes were allocated for all study participants at the time of transcription.

To enhance the credibility and trustworthiness of data collection, several strategies were used (Krefting, 1991; Nowell, et al., 2017). Firstly, field notes were taken during each interview to

document initial themes and information emerging from that interview data (Liamputtong, 2020). After each interview, a written reflection was prepared by the researcher, to consider their subjectivity within the topic and thoughts that arose (Nowell *et al.*, 2017). Following, peer debriefing was undertaken on the conclusion of each interview by the second author with the whole authorship group (thus offering interdisciplinary debriefing across the three speech pathologists, an occupational therapist, and a person with lived experience of ABI and AAC use) (Roulston, 2010). Notes from this debriefing were added to the written reflection for each interview. Additionally, member checking was completed using a summary of participant interviews, which was then sent to each respondent for checking and feedback. This was guided by Carlson (2010), with quotes organised into categories to allow study participants to review and check if their responses were accurately summarised.

Analysis

Thematic analysis was used to interpret, describe and summarise the data (Braun & Clarke, 2013). Once each interview was transcribed, the data were independently analysed by two of the researchers (authors 1 and 2) in relation to the research aims, and in consideration of each of the domains within the WHO's 5P people-centred assistive technology model (WHO, *n.d.*; WHO/UNICEF, 2022). Initially data were coded inductively, with codes progressively collapsed into categories, and then themes. Once this had been undertaken independently, authors 1 and 2 then met for consensus work, with any discrepancies resolved via in-depth discussion to reach a negotiated consensus (Bradley *et al.*, 2007). The preliminary eight themes were then discussed via two separate meetings with all authors, as well as three individual meetings that undertook further indepth discussion between the first author and author number 4, who has lived experience of ABI and AAC use thus offering 'insider perspectives' and valuable investigator triangulation (Carter *et al.*, 2014; Hodkinson, 2005). Specifically, provisional theme maps and reflexivity data (field notes and reflective journaling) were discussed and it was apparent that two themes were overlapping and could be combined into one. This reflective process was used to confirm the results (Curtin & Fossey, 2007). Direct quotations and reflections, typed by Author 4 using their AAC device, were noted down in response to the final set of themes identified.

Results

The seven study participants were all female, ranged in age from 25 to 62 ($M = 42.1$) years of age, and had between 4 and 35 ($M = 19.3$) years of experience working as a speech pathologist, and at least two years in the ABI field. All respondents currently worked within community settings with people with ABI. Some had previous experience working in residential aged care, and one in an ABI rehabilitation hospital setting. All had experience working with a range of populations, in addition to people with ABI. Specific to AAC practice, all provided face-to-face speech pathology services and six of the seven also provided telehealth services. Five respondents were from Victoria, with one of these having previous experience working in South Australia and Western Australia, and one currently providing telehealth services into South Australia and the Northern Territory. One was from Queensland, and one from New South Wales, with previous experience working in Victoria.

Seven themes were confirmed from thematic analysis. In the context of the World Health Organization's 5P people-centred assistive technology model (WHO, *n.d.*; WHO/UNICEF, 2022), four of these themes related to the person; two related to products and personnel; and one related to policy. See Figure 2.

Each of these themes will now be discussed, with quotes provided from research participants and reflections made available through Author 4's 'insider' or lived experience perspective (Carter *et al.*, 2014; Devotta *et al.*, 2016).

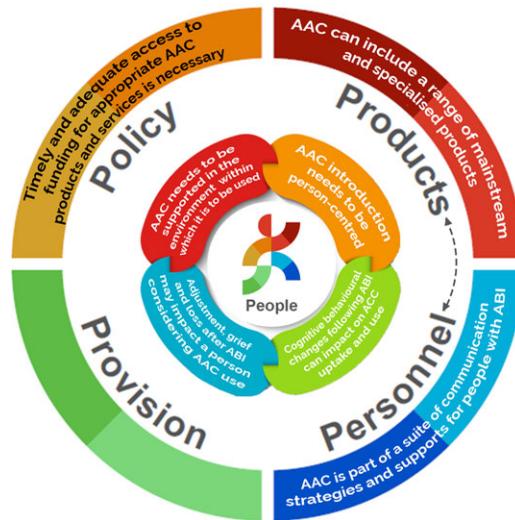


Figure 2. The seven identified, represented in the context of the World Health Organization’s 5P people-centred assistive technology model.

Theme 1: AAC introduction needs to be person-centred

Aligned with the WHO 5P Model domain of ‘People’, respondents described the need for AAC used by people with ABI to be person-centred across all components of the AT process, starting with how AAC was defined by the therapist. Information regarding AAC was customised in how it was “introduced to a client [for acceptance]” (P1) and also with consideration of “systems to support communication in the environments they [the person with ABI] move within” (P4). All respondents referenced the importance of linking AAC use to the person’s stated preferences and participation goals, including consideration of pre-injury activities: “The thing about ABI that I often ask [that’s different to working with people born with disability] is ‘what did this person enjoy pre-injury’? Because I am always looking for motivating reasons to communicate” (P4).

Specific to the issue of AAC preference, several respondents discussed culturally and linguistically diverse AAC users and how this cultural overlay may impact AAC acceptance and use. For example, P2 raised that acceptance of AAC may be impacted “. . . simply because of the cultural background”. P1 and P7 discussed issues with the availability of dialects on AAC: “The biggest barrier is . . . her first language is Arabic but it’s a certain dialect. So even the translations on a lot of the AAC stuff isn’t in the right dialect for her” (P1).

AAC introduction was also seen as dependent on readiness of the individual, as to the timing of the intervention. For example, P6 reflected that when one person they worked with, “. . . was in hospital, he was given a communication book but he just threw it away, hated it . . . initially [the person was] very self-conscious about using the technology but when it was gradually introduced they integrated it very naturally” (P6). The perception and preferences of the person with ABI and/or key supporters were also considered key to AAC introduction because “. . . If they don’t like it, they won’t use it . . . You can’t ignore what people prefer” (P5).

Reflecting on this, Author 4 said:

“I would never use any disability equipment for communication now because I feel that puts me in a box and paints me as disabled and that will hold back my progression and doesn’t represent how I want to be seen by other people”.

Theme 2: Cognitive-behavioural changes following ABI can impact on AAC uptake and use

Also focused on the WHO 5P Model domain of 'People', cognitive-behavioural changes experienced by people with ABI, and the impact of these changes on AAC uptake and use, was identified as a key theme across interviews. Reduced insight into the reasons AAC might be needed was reported to be a core issue. P4 said, "... some [people with ABI] don't have a lot of awareness of how they are communicating now and how difficult that is for other people". P6 described, "... they can speak, but it is really unclear, but in their mind it is still very clear so 'Why would I bother using a different system?'".

From her experience, Author 4 said:

"At the start after my traumatic brain injury, I couldn't express anything at all. I could hear people and it was so frustrating ... it was all this stuff coming at me and I had no way of responding and then they would do stuff with me and then they would roll me and I would feel like I was going to fall out of bed and I couldn't say 'stop, wait a minute, let me get my bearings' ... Things just happened like the nurses wanted it to. It led me to behave in ways I would never think I would. There was a stage where I would try to cry and try to scream but nothing came out so I'd just bite them. It was out of my control and I didn't like it because I'm a control freak. If I had not had the AAC along the way, I would be a very aggressive woman by now!"

Decreased initiation, and the need for others to support this cognitive function, was also raised. For example, one participant asked, "Can they use something to initiate a message?" (P7) and another said, "The main limitation for him is, he doesn't really initiate" (P2). Respondents discussed the need for highly motivating applications of the AAC to address this reduced initiation with references to motivation being linked to use of AAC. P4 reported "[I'm] always looking for motivating reasons [for a client] to communicate". The issue of slower rate of AAC output impacting on motivation was also raised: "I guess the main problem is it is not quick enough for his liking" (P2) and "That's fairly slow and difficult, you've got to be highly motivated to do it really" (P5).

Individual respondents referred to other aspects of cognitive functioning impacted by ABI and how these may be a barrier to AAC use, including memory and the need to consider integrating memory tools into the AAC system: "... individuals who have memory difficulties as part of the ABI" (P3); fatigue - "It is not that he rejects it, it just ... tires him" (P1) - and impacts on rigidity of thinking, "...[they may be] set in their ways in terms of what they're used to" (P6). The interplay between cognitive-behavioural factors was also noted as a potential barrier to AAC use for people with ABI. Following, study participants described how a mismatch between a person's skill with the AAC and their communication need resulted in frustration, and also how this combined with impulsivity: "... he can often throw the device if he gets frustrated ... It is not an abandonment, because he wants to use it but he throws it" (P1). They therefore considered it necessary to grade the introduction of AAC: "It's being mindful of that sort of graduated approach to learning and focus so that it's a successful experience for that communicator in terms of cognitive load, memory, learning" (P6).

Author 4 agreed that cognitive changes after ABI were a barrier to her learning, and also impacted fatigue further:

"My memory is the worse [since the brain injury]. You can deal with a wheelchair - annoying as it is - but it is hard to learn new things like AAC and it gets so tiring. It is all just a lot more work".

Theme 3: Adjustment, grief and loss after ABI may impact a person considering AAC use

Factors relating to grief, loss and adjustment to living with ABI were identified as another key theme in terms of acceptance AAC, linked to the WHO 5P Model domain of 'People'. P4 said, "There is that sense of loss that they have . . . there's obviously a lot of grief and social and emotional issues going on for those individuals and probably huge amounts of frustration to go with that" and P2 noted, "There is also the mental health factor coming into play like depression . . . [there are] periods when he is compliant and periods when he doesn't want to do anything [with AAC]".

The need to fit in and achieve social acceptance as part of adjusting to life post-ABI was also discussed in terms of how this impacted on acceptance of AAC: "Initially, [people may be] very self-conscious about . . . using the technology [for AAC]" (P6). In some instances, therapists report rejection of AAC because of "adjustment difficulty . . . coming to terms with what's happened [sustaining an ABI]" (P7). Therapists also described younger people with ABI who had abandoned AAC systems, ". . . because they felt like they didn't fit in because they have this system that no-one else has . . . that whole peer pressure thing happening" (P4). Family support was raised as key to the success of AAC implementation in the person with ABI's life, and all respondents mentioned the importance of family in the AAC trial and uptake process: "Family support really plays a role in acceptance of AAC" (P2). For some study participants, this combination of both the person with ABI's and the family's grief, loss and adjustment was identified as factors that influenced trying mainstream equipment, such as a smartphone or tablet, in contrast to a more specialised or bespoke AAC device.

Author 4 highlighted further the sense of loss of pre-injury communication skills and how this impacted on readiness to consider AAC: "If you just wake up and life had changed. You just want your voice back". She also agreed that uptake of AAC is impacted by social acceptance:

"You need to feel and look more a part of the [general] community".

Theme 4: AAC needs to be supported in the environment within which it is to be used

This fourth and last of the themes aligned with the WHO 5P Model domain of 'People' included all respondents talked about the importance of both the physical and the social communication environment to AAC use: "It's not just the family. It's you know, it's the carers that come in. It's their support network" (P7). The speech pathologists discussed the need for adequate and ongoing training - not just for the AAC user, but also for the support people around them - raising the need for learning opportunities so that people in the environment are ". . . able to support that process and . . . actually using and learning the system" (P6). They also identified the risk of abandonment of AAC when ". . . they [the person with ABI] haven't had someone to . . . properly teach how to use it [AAC]" (P2).

Although all respondents said that the services of speech pathologists were necessary for appropriate training on AAC, several also considered it important to identify a key family or paid supporter in the person with ABI's home and community environments. P3 discussed the value of "a few key staff members, or a support worker that can really help support the [AAC] process" and P6 described this as, "finding . . . an AAC champion in their [the person with ABI's] support team". Linked to the provision of information and training for both people with ABI and their family or paid supporters was the issue of managing expectations, with all respondents discussing that speech pathologists need to provide education around what AAC devices could support, including understanding the slower rate of communicating when using AAC. For example, P6 highlighted:

"when . . . expectations were graduated with how much use and when to use it . . . and supported with learning how to use it, the acceptance is high . . ." However, they have found the ". . . perceptions of family or even support coordinators that . . . [AAC] would just solve all their problems risks [AAC abandonment]".

Author 4 reflected:

“With the LightWriter™, naturally it was quite difficult to have to push every individual letter and have to think ‘is that even the correct way to spell it?’ because I’ve never been a good speller before or after [the injury]. Then I got really quick and people started reading my screen and I thought it was so rude. That was when I started to tape up the [LED] display. The LightWriter™ was so good at the start but then I then got to a point that it was so slow and sounded like a robot. Because I am often quite sarcastic, it really didn’t work so well. When I would get a point come to mind, I would look down to type and it looked like I stopped listening and I was being very rude”.

The importance of training was also highlighted by discussion about families or support workers who may inadvertently reduce the opportunity to use AAC because they know the person so well “... these brothers who are very in tune to his pointing and his attempts at speech that they talk for him a lot of the time anyway [rather than facilitating use of AAC]” (P1). Several respondents talked about the challenges of settings with high support staff turnover or “... support workers who come and go” (P4) and talked of the risk of abandonment of AAC when 1:1 supports were not engaged with the AAC use: “... the staff at the house didn’t have time to set it [the AAC] up because it’s quite cumbersome so it got shelved. He didn’t get any time to use it and practice” (P1).

The respondents discussed training for support people in their roles with AAC, which included ensuring equipment was charged and also to “... set up and to use devices” (P1). They also highlighted the need for modelling of effective AAC use in the particular environment to aid AAC uptake and use: “... definitely support as much modeling [of AAC use with the person] as possible” (P3). The combination of cognitive difficulties and support needs was also discussed, in terms of the need for support people to “... initiate a conversation..., give some scaffolding questions to get him to respond” (P3). Another aspect of the need for environment-specific training was that AAC strategies might need to vary depending on the environment in which they were to be used and therefore the training had to address these multiple needs: “What does this individual need in different environments?” (P4).

Author 4 also agreed that funding for training needed to be included, and she particularly highlighted the need for training for family on AAC integration:

“Family training is very important. If we are not encouraged by family, we just won’t use it because it’s such hard work. If family are not assisting, you are fighting a losing battle ... After the trauma of the ABI, you need the guidance of family about AAC because they are the people you trust”.

However, on managing expectations, Author 4 discussed:

“The slowness [of AAC] is very annoying because it holds up the conversation. More often the conversation has moved on before you can speak your mind. It is better than nothing, but it is not perfect and can also can definitely make you look and feel stupid”.

Theme 5: AAC in ABI is part of a suite of communication strategies and supports for people with ABI

Aligned with the WHO 5P Model domains of ‘Products’ and ‘Personnel’, study participants discussed AAC as being part of a suite of therapeutic interventions using “the strategies in combination with other forms of speech therapy” (P5). When defining what AAC was, they highlighted both high and light technology systems, as well as aided systems (e.g. communication dictionaries or

books, and unaided systems such as signing, gesture or body language). They also discussed the need to be sensitive and enable the person with ABI to feel they are also working on their speech production, not just alternatives to it: *“so you might work on . . . a lot of speech first, then . . . introduce AAC”* (P3). This combination of therapeutic approaches was also talked about in a return to work context, where a person may use *“. . . that system on their iPad as well as . . . supplement it with some speech and some low tech”* (P6). Participants described often using AAC as a backup to speech:

“I would say a lot of the clients that I work with do have a verbal capacity . . . So it’s [AAC is] more to support them when they can’t get their message across . . . the AAC is not always their primary mode of communication” (P3)

They also noted a need for AAC to be seen as an integral part of the suite of therapy, but that *“AAC is still not seen as a mainstream intervention”* and *“there’s still that ‘last resort’ feeling”* (P5). AAC was also described as being used as an element of therapy to help with recovery as well as compensation for lost skills: *“It’s not only to bridge communication but it is also therapeutic”* (P2).

Author 4 said:

“Reflecting on my AAC journey after by ABI, I had speech therapy all the way along and each step was such hard work. I used a thumbs up and thumbs down at the start [to indicate yes or no]. Then I had to learn to get more movement so I could point at pictures. The next step was to point at letters on my good ol’ trusty spell board. Then I got the LightWriter™. I typed letters and a mechanical sounding voice said the words”.

Theme 6: AAC can include a range of mainstream and specialised products

Specific to the WHO 5P Model domain of ‘Products’, respondents referred to AAC across the continuum of products from mainstream devices (e.g. smart phones or tablets) to specialised products (e.g. eye gaze text to speech technology), *“. . . looking more at a specialised systems for someone that needed access accommodations, if they’ve got sort of sensory or physical needs”* (P4). They also considered linguistic and cognitive access, *“most of the time, it probably does come down to (physical) access but then . . . language abilities [also need consideration]”* (P3). It was also noted that access to AAC equipment through mounting or positioning was crucial: *“[they need to] make sure it’s accessible . . . as much as possible, mounted to a wheelchair, so it’s easily accessible . . .”* (P3) and are *“. . . relying on it to be positioned correctly”* (P1). With both specialised and mainstream options, the need for an interdisciplinary approach was noted especially when considering access: *“Myself and the OT . . . we spend a lot of time talking through positioning [of the AAC] . . .”* (P4).

Author 4 added to the respondents’ observations, noting that the purpose and application of mainstream technologies might look different for people with disabilities:

“I might use mainstream AAC but I have to learn different ways of using it - so I might look like other people using their technology but it supports me more and in different ways. I need to learn how to use mainstream technology more so it doesn’t interfere with the social interaction . . . it can seem a bit rude to others if I am looking at my phone too much - I’ve got to learn to manage that situation”.

Other features of specialised equipment were also seen as an advantage when compared to mainstream devices. P6 described that there might be scope to *“. . . build more skills with one of those [specialised] devices versus just apps on the iPad . . . some of the environmental controls . . .”*

non-mainstream AAC that gives them options". P7 also talked of the value of AAC technology being used for more than just face-to-face communication:

"I also consider these devices as being an "... access point to other methods of technology ... so it's not just being a communication device but being able to get onto social media or your emails or your Google calendar or things like that".

Mainstream equipment, such as iPads running communication apps, was often considered because of the social acceptability of using what other people may use in everyday life: *"He would not entertain a standalone communication device ... he wouldn't use it, whereas he uses the iPad and he's happy to open up the other (AAC) apps when prompted"* (P1). It was also reported that it was sometimes an advantage if the AAC user had previous experience or knowledge of using mainstream technology: *"It was a great system for her because ... she already ... knew how to get in it, she ... knew how to send emails"* (P4).

Author 4 raised a point that had not been discussed by respondents regarding the timing of introducing AAC products:

"The [specialised] AAC might be seen as a means to an end while you work on yourself in therapy so you could not need it anymore. But some AAC like phone, computer, iPad, I would see as being used long term".

On the issue of mainstream versus dedicated devices, Author 4 also noted that often for people with ABI: *"Mainstream is more accessible and there is generally more knowledge around it"*.

Theme 7: Timely and adequate access to funding for appropriate AAC products and services is necessary

The final theme identified aligned with the WHO 5P Model domain of 'Policy', with respondents reflecting on inconsistencies in the funding of AAC systems in Australian assistive technology funding schemes. Some respondents had *"struggled to get funding for dedicated devices"* (P5). In contrast to this, P1 reported an *"unwillingness of funding bodies to fund mainstream devices"* even when the mainstream device can have AAC features. This was reportedly because the funder argued that mainstream devices were an everyday technology that most households would be expected to have. When AAC funding approvals were slow, the delays could result in loss of motivation by the person with ABI or in the prescribed equipment no longer being available:

"The delay with doing a trial and then actually getting the device ... sometimes does impact the client's engagement with receiving the AAC and ... there have been some occasions with technology just updating in that timeframe ... the technology has changed" (P6).

Therapists reported sometimes encountering a lack of understanding from funding bodies regarding the AAC needs of people with ABI: *"... some [government funding] planners would prefer to fund multiples of a cheaper option even when it is not recommended as the best option by the therapist"* (P5). The issue of funding for AAC equipment and therapy for people with ABI who have less visible cognitive communication disabilities was also identified: *"There's also people who may have hidden disabilities like it's not as visible as ... physical impairment or paralysis"* (P2). Respondents advised it was necessary for speech pathologists to *"... know how to actually word things [in funding applications]"* (P7) to ensure successful funding applications.

Author 4 reflected on this:

“My key goals are to increase my employment and public speaking roles and to keep building my social networks. I’d like to be able to do the educational talks at a full capacity - to have my own voice instead of the digitised voice which is precise and quicker. The digitised voice conveys my personality in the sense of the words I use but it doesn’t link in with facial expressions and humour like when I talk. But I will keep needing some AAC as well as getting my speech better.”

All respondents discussed the importance of having adequate funding of therapy hours for customisation, training and grading of AAC skill development for both the person with ABI and their key supporters. Study participants outlined the many stages; from assessment of goals and needs; multiple AAC trials of adequate length and duration; liaison with other professionals (particularly occupational therapists); submitting a detailed assessment and funding application; AAC set up, implementation and frequent reviews including training and creation of support resources; trouble-shooting and ensuring the AAC option continues to be relevant to the person over time: *“You need to have . . . a realistic understanding of how much time it actually takes”* (P7). In addition to adequate funding for therapists, respondents raised the need for support workers’ hours to integrate the AAC into the environment: *“. . . it is bigger than [just] speech pathology”* (P7). The need for speech pathology was clearly stated by all in the AAC supply and implementation process, but respondents also discussed the need to build up the skills of both the person with ABI and their paid or informal supporters to ensure use in the person’s chosen environments: *“I can’t be there every single day. This needs to be implemented every single day”* (P7).

Author 4 concurred that funding was a key issue: *“It’s been obviously good to have funding through the NDIS [Australia’s no-fault National Disability Insurance Scheme] because all disability equipment is so expensive and so often you can’t work if you are disabled”*. Author 4 also reflected that the therapists experience of AAC funding applications was also an issue: *“It is very important to have a very experienced speech pathologist to recommend AAC”*.

Discussion

This is the first Australian study to explore the perspectives of speech pathologists working in the field of AAC in the community with adults with ABI. In addition to the clinical perspective, this research offers a co-researcher view of lived experience of AAC use after ABI, considering speech pathologists’ responses. The World Health Organization’s 5P assistive technology model provided a useful framework to analyse study results, demonstrating the importance of person-centred practice in the field of AAC, whilst acknowledging the assistive technology ecosystem – including products, provision, personnel and policy – which must be well coordinated to achieve effective AAC outcomes (WHO, n.d.; WHO/UNICEF, 2022). Elicited through an initial enquiry to study participants about how they defined AAC, this research highlighted that definition includes a breadth and many types of AAC that may be used for communication after ABI. Broadly, the American Speech-Language-Hearing Association (ASHA, n.d.) defines AAC as all of the ways that someone communicates besides talking. Providing further detail, the international peak body for AAC - the International Society for Augmentative and Alternative Communication - details AAC to include *“speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices”* (ISAAC, n.d.). Participants in the current study added further detail to these definitions, identifying use of mobile phones, Notes apps or visual diaries as other methods that the person with ABI with may consider when building a suite of AAC supports, and also how these may vary in their use across the environments where the person completes daily activities.

The cognitive-behavioural and communication impairments that result from ABI are well documented (MacDonald, 2017); however, the current study describes how these impairments impact specifically on AAC use. As a result of cognitive impairments, a consistent environment is necessary for learning (Ponsford, et al., 2013). Evidence indicates that after ABI, people will transition across a range of housing and support options, leading to changes over time in the key support personnel in their lives (Sloan et al., 2012). As a person's skill and environments change, AAC methods are modified to accommodate and support these transitions, making these AAC interventions an ongoing and dynamic process (Doyle & Fager, 2011). For effective ABI rehabilitation, both people with ABI and their families, as well as clinical teams and funding bodies, need to be aware of the effects of cognitive-behavioural and communication changes and have realistic expectations regarding the amount of support and time required for learning and integrating successful AAC use.

Acquiring disability after birth leads to potential reflections on life before versus after the injury, which can impact grief and loss experience (Ponsford, et al., 2013). Participants in this study identified that pre-injury lived experience can be both a barrier and an enabler to AAC uptake and use. For example, the person may grieve for the loss of verbal communication which can lead them to be reluctant to attempt AAC, or in contrast have pre-injury technology experience and skills which can be a bridge to accepting AAC solutions. Aligned with the current study's finding about grief and loss impacts on AAC uptake and use, Pampoulou (2019) also identified that time since onset of disability and adjustment to loss contributed to the acceptance or abandonment of AAC systems. The current study further highlights the importance for both speech pathologists and other health professionals working with people with ABI and their families to consider the potential overlay of grief and loss, and how it may impact the initial uptake and ongoing use (or risk of abandonment) of AAC.

When working with people with ABI, AAC systems need to be tailored to the individual's goals, and the communication system must be shown to be highly functional from the outset (Pampoulou, 2019; Togher et al., 2023). The current study strongly endorsed and added to previous literature, particularly in highlighting the links between the person's self-perception of their communication and the type of AAC tool they believed would best represent them in community interactions. While speech pathologists need to ensure AAC options are suited to the language and access capacities of the individual, they also need to prioritise the views of the person with ABI and how they see themselves engaging in the community (particularly when deciding between specialised or mainstream AAC). Funding bodies need to be aware that the equipment requested for people with ABI will reflect not only the individual's skill level, but also their style of communication and how they want to be perceived by others.

Aligned with this consideration in clinical practice, the current study also highlighted that people from culturally and linguistically diverse backgrounds may experience additional barriers to AAC assessment, trials and implementation. People with ABI who were from non-English speaking backgrounds were often faced with high-tech AAC devices that were not equally accessible for them (because their first language was not available on the AAC equipment). Where family members were from non-English speaking backgrounds, this created a further barrier to their support of the AAC because their language was not represented. There is currently limited evidence to guide speech pathology input for people with ABI from these diverse backgrounds. Brain injury may cause people to rely more on their first language. This factor – when coupled with sociocultural considerations that may impact on AAC acceptance – is a new finding of this research that warrants further investigation of possible links between cultural diversity and AAC acceptance, rejection or abandonment.

Aligned with findings reported by Jamwal et al. (2017), the current study has indicated that some people with ABI may preference mainstream technologies over more specialised products. Both familiarity and social acceptance of mainstream products can be an enabler to AAC use (Fager et al., 2006). Pre-injury skills retained after the ABI can also further enable ongoing use

of mainstream products in new ways for AAC. However, there will often be a requirement for specialised or alternative access (e.g. head mouse or pointer; customised language interface or visual accessibility features) to use the device. For both current as well as future speech pathologists, understanding both the breadth of products, alternative access or customisation features, and range of strategies that may be used as AAC is important. The World Health Organization has recently documented the importance of such specialist skills (and funding for both specific assistive products like AAC and associated assistive services), in contrast for generalist skills that may be used to access low cost, low risk AT (WHO/UNICEF, 2022).

In addition to the need for adequate and appropriate funding for AAC products, the findings of this study emphasised the need for adequate funding for the people to support the implementation of AAC equipment successfully. Inadequate funding for the required multidisciplinary therapy input relating to AAC assessment, provision, set up and training is a barrier identified through the current study, which is consistent with Beukelman et al. (2007) and Fager et al. (2006). Both of these research groups highlighted that AAC assessment and intervention requires an ongoing, multidisciplinary approach that may include multiple AAC systems over the years. The current study findings highlighted particularly the AAC training that is required, given the importance of a consistent social and support environment for people living with ABI (Sloan et al., 2012). This importance of AAC assessment, provision, and training has been also been documented in Recommendation 6 of the INCOG guidelines on cognitive communication (Togher et al., 2023).

It has been almost two decades since Fager et al. (2006) highlighted the importance of identifying, training and monitoring support personnel as a critical component of AAC enablement. The current research reinforced that training is still a critical component in successful AAC use, highlighting the significant role informal and paid supporters hold in the lives of people with ABI who require AAC options. Capacity building is required not just for the person with ABI but also these key supporters. Recently in Australia the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission (2021) has made available a free online training module, focused on supporting effective communication from the perspective of people with disability. This training includes a focus on how such approaches can build choice and control, and communication rights. In addition to these general education resources and guiding principles, both funding for – and provision of – targeted training specific to ABI is required over the long term, not just early post injury. This training is required for both the person with brain injury, as well as support people, to value the investment of time and effort in the use of the AAC systems. This wider recognition of the value of the AAC by those in the environment is critical - not only during the delivery of supports, but also as part of enabling AAC skill development and use more broadly in everyday life. The current research indicates that therapy funding needs to be allocated for training and capacity building of both the person with ABI, as well as key supporters. Therefore, there is a need for speech pathologists to make clear AAC funding requests not only for the equipment, but also for the multidisciplinary therapy that will be required for the provision and successful integration of AAC over time (Togher et al., 2023).

It has previously been identified that due to other caregiving demands associated with acquired disability, supporters may deprioritise the important role they hold as communication facilitators (Pampoulou, 2019). For both family and paid supporters, this may be due to the perceived time associated with effectively implementing electronic AAC systems (e.g. setting up a technology-enabled AAC system for use; waiting for a typed response from the person with ABI). Thus, there may be a preference of the supporter to use fast gestures or yes/no questions, rather than taking the time to implement AAC devices to support the individual with ABI to respond. Given this, there is a need for speech pathologists to reinforce the longer term benefits of time and effort inputted to AAC use and skill building. This also points to a need for adequate family or paid supports to enable time to integrate AAC use. It may be difficult for funding bodies to understand the extent of supports required for people with cognitive-communication impairments – this in

turn places onus on speech pathologists or other team members to advocate with, or at times on behalf of, people with ABI and their families for such support.

Limitations of study

There are limitations of the current study that require consideration. Firstly, due to convenience samples, speech pathologists were only recruited from three states of Australia (whilst noting they continued work across four states). Considering the current work was limited to the Australian context – and that international perspectives may differ given variations in assistive technology access, funding and service delivery (WHO/UNICEF, 2022) – future research would benefit from the inclusion of both national and international perspectives. It should also be noted that the participants in the current study all worked in community settings. Perspectives of additional speech pathologists, including inpatient clinicians, would be valuable and may consider the early post injury experience of ABI and AAC use. Finally, the research drew on lived experience expertise of one co-author who experiences ABI and uses AAC to offer an insider perspective (Carter *et al.*, 2014; Devotta *et al.*, 2016). Whilst this offered lived experience expertise for individual reflection on the study results, it is not seen as representative of views of the broader ABI population. Future research that includes exploration of lived experience of research participants with ABI and/or their families, rather than just via co-authorship, would be valuable. Such research would benefit from the use of mixed methods, including both published measures and in-depth interviews, to understand both user experience of AAC as well as outcomes achieved and any barriers to use.

Conclusion

ABI can impact both expressive and receptive communication skills and lead to the need of AAC. This research has highlighted the important considerations raised by speech pathologists regarding the use of AAC by people with acquired disability (as compared to the experience of disability from birth), and some of the impacting factors to uptake and use. These factors include comparisons of pre- versus post-injury life, experiences of grief and loss, as well as goal setting and enablement of meaningful participation via AAC. It is important for speech pathologists to understand both the breadth of AAC products that may be considered for use by a person with ABI and their family, as well as the necessary steps to ensure successful use and skill development over time. Listening to the perspectives of the person with ABI is central to that understanding.

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