Opinions and perspectives of AAC users in a Victorian community setting: an inclusive qualitative study

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Short Abstract

Introduction: Alternative and augmentative communication (AAC) supports individuals with communication difficulties as a result of acquired brain injury (ABI), progressive neurological conditions, such as Alzhheimer's and Parkinson's disease, as well as developmental diagnoses, such as cerebral palsy, autism and intellectual disability. To date, research has been limited to specific diagnostic populations and focused heavily on the perspectives of family members, carers, medical professionals and speech pathologists regarding AAC implementation and uptake. Until now, there has been limited Australian research that captures and includes the opinions and perspectives of a diverse group of AAC users within the community.

Aims: 1) To explore the opinions and perspectives of AAC users across diagnostic populations. 2) To determine key themes regarding AAC usage including type, communication functions and overall satisfaction.

Methods: A qualitative research design with structured interviews was used with 10 AAC users from a Victorian community setting. A thematic analysis was conducted to ascertain themes from the survey.

Results: Preliminary research results outline key themes regarding the opinions and perspectives of AAC users. The results indicate varied AAC use in terms of AAC selection and social function.

Discussion: The perceptions of AAC users provides insight into how AAC is used and for what communication functions. This research highlights the importance of frequently supporting individuals with communication difficulties to share their opinions and perspectives on their AAC and use this feedback to review AAC implementation and use.

Long Abstract

Introduction: Alternative and augmentative communication (AAC) supports individuals with acquired or developmental communication difficulties (Light, 2009), resulting from acquired brain injury (ABI), progressive neurological conditions like Parkinson's disease and developmental disabilities, such as cerebral palsy, autism and/or intellectual disability.

To date, there has been ample research focusing on the perspectives of family members and health care professionals regarding AAC. Brock et al (2022) investigated the perspectives of carers regarding the use of different AAC interfaces with patients with aphasia. Berenguer et al (2022) and Laubscher et al (2023) explored parental perspectives on AAC. Moorecroft et al (2019), Pampoulou (2019) and Mackey et al (2022) researched the perspectives of speech pathologists regarding AAC. Research from a parental and speech pathology perspective highlights facilitators and barriers in AAC implementation, for example: time taken to learn AAC, opinions and perceptions regarding AAC, level of support required to implement AAC (parents, carers and/or speech therapists) as well as funding and costs associated.

Literature that focuses on the opinions and perspectives of AAC users is limited and often diagnosis specific. Research typically includes either individuals with developmental diagnoses (Cerebral Palsy or Autism) or individuals with an acquired diagnoses (acquired brain injury or progressive neurological conditions) respectively and tends to exclude those with severe language or cognitive communication difficulties. Research by McCall et al (1997), Martine et al (2008), Morris et al (2012), Smith and Connoly (2008) focuses on the opinions and perspectives of AAC users with Cerebral Palsy specifically. Johanson and colleagues (2012) researched the perspectives of people with aphasia who AAC. Donaldson and colleagues (2020) explored the perspectives of adults with autism who use AAC. At present, there has been limited studies that include individuals from a range of diagnoses.

Literature focusing on the opinions and perspectives of AAC users highlights recurring themes including, social identity associated with AAC, time taken to learn and use AAC, frustration relating to AAC as well as communication partners knowledge of AAC. Early research conducted by McCall and colleagues (1997) looked at the opinions and perspectives of AAC users with Cerebral Palsy. They used closed questions and semi-structured interviews to determine 1) whether AAC included adequate vocabulary and 2) the perceived advantages and disadvantages of AAC. Three key themes emerged from this research including AAC users' communication styles, features of various AAC systems and the impact that AAC had on the users' quality of life.

Huer and Lloyd (1990) reviewed 187 articles published between 1982 and 1987 to better understand the opinions and perspectives of AAC users. The following themes were identified in their research; importance of well skilled communication partners, communication strategies used in conjunction with AAC, AAC users' attitudes towards professionals as well as frustration with AAC. Morrison, Dudgeon and Yorkston (2012) explored the experiences of AAC users when communicating with medical professionals and they also found themes of frustration. This research outlined that often medical providers rushed responses, made inappropriate assumptions around cognition and initially communicated incorrectly before learning to use AAC effectively within conversation.

More recently, Donaldson, Corbin and McCoy (2021) explored the perspectives of speaking individuals with autism who began using AAC as adults. Their research found that AAC users with autism had experienced barriers in using AAC during childhood (forced to communicate with speech), only after becoming adults they had discovered AAC as another alternative form of communication. In this study, the emphasis for AAC users with autism was in respecting their choices in communication and normalising AAC use in everyday life. Broomfield and colleagues (2024) reviewed existing qualitative literature regarding people's experiences of using AAC. Their work incorporated feedback across diagnostic groups including AAC users with Cerebral Palsy, Traumatic Brain Injury, stroke and Amyotrophic Lateral Sclerosis. The review highlights key concepts that can be used to inform patient reported outcome measures across the following headings: values, communication outcomes and context. However, this research did not include those with severe cognitive communication difficulties. This research echoes that of Broomfield, Harrop and Judge (2019) who found no specific singular measure to capture the desired communicative outcomes for AAC users.

Throughout the literature, semi-structured interviews are typically used to support individuals with communication difficulties to share feedback regarding their AAC (Broomfield et al, 2024; Donaldson, Corbin and McCoy, 2021; Laubscher et al, 2023; Martine et al, 2008; McCall et al, 1997; & Murphy, 2004). These studies typically involve speaking individuals with higher-level language difficulties and/or mild cognitive communication difficulties. These studies include individuals who are able to answer questions in detail and initiate and/or generate spontaneous language. These studies, as well as others within the literature, do not include those with more complex communication needs who also use AAC.

Aims: Therefore, this research aims to: 1) explore and include the opinions and perspectives of a diverse group of AAC users with a range of diagnoses, language capacities or cognitive communication difficulties. 2) Explore opinions and perspectives of AAC users regarding AAC type, communication functions, communication partner related factors and overall satisfaction with AAC.

Methods: Purposive sampling was used to recruit 10 AAC users who live in Victoria. A qualitative research design with structured interviews was used. Structured interviews covered the following topics: demographic factors, primary AAC method, AAC communication functions and AAC usage. Likert rating scales were used to gather information relating to AAC reflections, ease of AAC use, whether AAC met their communication needs, satisfaction with their current AAC and factors that impact their AAC use. A thematic analysis was conducted to ascertain themes from the survey.

Results: Results from this preliminary research outline key themes pertaining to the opinions and perspectives of AAC users. The results indicate varied AAC use in terms of AAC type and communicative functions and highlights varied levels of satisfaction with their AAC.

Discussion/Conclusion: This research highlights the importance of frequently supporting individuals with communication difficulties to share their opinions and perspectives on their AAC systems and using this feedback to review AAC implementation and use. This gives individuals the opportunity to be included in the AAC process.

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