Understanding Communication About Sexuality for Adolescent AAC Users with Cerebral Palsy

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Short Abstract

Plain Language Abstract

Title: Understanding Communication About Sexuality for Adolescent AAC Users with Cerebral Palsy

Background: Sexual and gender identity development is an important part of adolescence (ages 10-24). Communication is important in developing sexual and gender identity because adolescents talk to peers, family, and romantic or sexual partners about these topics. There is some research about sexuality and adults who use augmentative and alternative communication (AAC), but very little about adolescent AAC users. In our study, we wanted to find out how adolescents with cerebral palsy who use AAC talk about sexuality and what they want to be able to talk about.

Method: We interviewed five adolescents with cerebral palsy. After the interviews, we worked with four of them to create materials to share our findings. Our advisory group, including AAC users with cerebral palsy, helped guide the research.

Results: The adolescents wanted more discussions about sexuality. Their AAC systems did not always have the words they needed to talk about sexuality. Privacy and the ability to make their own decisions about sexuality were important to them. They need more information about sexuality. They have clear guidelines for support workers who support their conversations about sexuality.

Conclusion: Adolescent AAC users want to talk about sexuality more. They need support to discuss and develop their sexual and gender identities.

Long Abstract

Academic Language Abstract

Background: The development of sexual and gender identity is a crucial aspect of adolescence (10-24 years) and is heavily influenced by interactions with peers, parents, educators, and romantic or sexual partners. For individuals with complex communication needs, such as those using augmentative and alternative communication (AAC), social participation can be significantly limited. In research with adults with physical disabilities and complex communication needs, Sellwood, Raghavendra and Walker described reduced opportunities to socialise with romantic or sexual partners, support workers as a barrier or facilitator to these interactions, and the need to communicate to communicate creatively in a variety of modalities, including online (2022). However, there is a notable gap in research concerning adolescent AAC users and their experiences and needs related to communication about sexuality. Most existing research about adolescent AAC users focuses on functional or negative aspects of sexuality such as menstruation hygiene, inappropriate sexual behaviour, and abuse, and primarily involves parents, teachers, and support personnel rather than the adolescents themselves (Cummins et al., 2020; Power et al., 2023; Power et al., 2020; Qian, 2017).

Approximately 30% with cerebral palsy have complex communication needs, with an additional 20% having some form of communication difficulty (Himmelmann et al., 2013; Nordberg et al., 2013; Novak et al., 2012). Yet the majority of sexuality research about adolescents with cerebral palsy excludes those with complex communication needs (Walsh et al., 2024). The research with adolescents with cerebral palsy who speak indicates that they also experience reduced social participation, including reduced opportunities to meet romantic or sexual partners (Björquist et al., 2015; East & Orchard, 2014a). In addition, like the adult AAC users, they report a lack of but desire for disability-specific sexuality education (East & Orchard, 2014a; East & Orchard, 2014b; Power et al., 2023; Power et al., 2020; Wiegerink et al., 2010; Wiegerink et al., 2008).

We do not know how adolescent AAC users experience interactions about sexuality, nor what they want from those conversations. Without this information, we cannot provide them with the supports they need to develop and express their identities during this important developmental period. This study aimed to fill this gap by exploring how adolescent AAC users with cerebral palsy experience and wish to engage in conversations about sexuality.

Methods: Our participatory research involved five adolescent AAC users with cerebral palsy. Each adolescent participated in 3-6 interview sessions each. Four of the adolescents chose to continue engaging with the research through co-designing knowledge translation materials. The research was designed with an advisory group consisting of AAC users with cerebral palsy, parents of AAC users with cerebral palsy, and someone with cerebral palsy who speaks. Member checking was completed with each participant. The lead researcher and four advisors analysed the data using reflexive thematic analysis (Braun & Clarke, 2022).

Results: The adolescents expressed a strong desire for more discussions about sexuality. They emphasized the importance of comfort and trust with their communication partners and noted that their AAC systems lacked the necessary vocabulary for such conversations. Issues of privacy and bodily autonomy were also significant but not always guaranteed. Knowledge translation priorities identified

include improving access to sexuality-related vocabulary, information from health professionals, and establishing guidelines for paid support workers. We will present the co-designed knowledge translation materials developed during this research.

Conclusion: This exploratory research identified that communication about sexuality is important to adolescent AAC users, and that further research is needed in order to understand how to support these young people in the development of their identities as sexual and gendered beings. Despite being exploratory, we were able to identify knowledge translation priorities. Based on our research, the previous literature, and the lived and clinical experience of our research team, we will make recommendations for adolescent AAC users and the people who support them.

References- full reference list provided upon request, unable to include in this text box