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Developing romantic and sexual relationships: Exploring the lived experiences of people with complex communication needs

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This research investigates the lived experiences of people with complex communication needs in developing romantic and sexual relationships. The United Nations Convention on the Rights of Persons With Disabilities (2013) asserts people with disabilities have equal rights to others to participate in social relationships and acknowledges the additional barriers they face. Often the disability sector focuses on daily living skills and employment outcomes, neglecting sexuality and intimacy needs (Valvano et al., 2014). Research acknowledges that people with congenital disabilities need a whole of life approach to exploring sexuality and intimate relationships (Wiegerink, Roebroek, Bender, Stam, & Cohen-Kettenis, 2011). Augmentative and Alternative Communication (AAC) literature discusses many of the identified issues, yet has a strong focus on sexual abuse protection (Collier, McGhie-Richmond, Odette, & Pyne, 2006; Light & McNaughton, 2015), and also calls for improved sex education and ongoing relationship support (Collier et al., 2006). A recent systematic review ascertained that little is known about the lived experiences of people with complex communication needs in developing romantic or sexual relationships (Sellwood, Raghavendra, & Jewell, 2017).

AIM

Hence, this research asks:

What are the lived experiences of people with complex communication needs in developing romantic or sexual relationships?

What are the barriers and facilitators to developing romantic or sexual relationships for people with complex communication needs?

METHOD

This research deliberately sought lived experiences and perspectives in an area that is seldom discussed openly, and uses a Critical Hermeneutics phenomenological approach to provide a deeper understanding of experiences. The methodology used is in-depth interviews. Following ethics approval, recruitment was conducted internationally, through social media and listservs, the snowball method using e-mail, and direct approach. The inclusion criteria were that participants: had to be 21 or older; have had a physical and communication disability since childhood; and use AAC. The interviews began with demographic questions then explored participants' social life and romantic or sexual experiences. These questions were based on the International Classification of Functioning, Disability and Health (ICF). Interview transcripts were analysed using NVivo, a qualitative research application.

RESULTS

Nine participants, aged from 21 to 70+, were interviewed. Their AAC strategies included dedicated AAC devices, mainstream technology and unaided strategies. The six female and three male participants discussed a total of 21 experiences of relationships. Analysis of these experiences identified an approximately equal number of barriers and facilitators which impacted on the relationships. Some, such as the role of communication devices, was identified as both a barrier and a facilitator. Three themes emerged: personal attributes; interpersonal communication; and the power of others.

CONCLUSION

The research suggests that people with complex communication needs can develop romantic and sexual relationships. Yet, the main factors that can impact relationships are attitudes of others (e.g., family members, friends,

support staff, potential partners and strangers), their own attitudes and the ability to communicate when being intimate. The findings offer new insights into the lives of adults with complex communication needs. These could have implications for professionals supporting people with complex communication needs to enhance intimate relationships.

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Evidence Area: AACcess diversity, AACcess culture, AACcess relationships, AACcess social media

Content Focus Area: Research Evidence