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Title: Participation in Active Recreation: Perspectives of Adults with Developmental Disabilities who use Augmentative and Alternative Communication

1. Background:

Previous research in augmentative and alternative communication (AAC) has focused on a range of passive settings including education, employment, and community integration (Kent-Walsh & Light, 2003; McNaughton, Light & Gulla, 2003; Mirenda, 2014); however, less attention has been paid to engagement in active recreation and how this area can positively impact individuals with complex communication needs who use AAC. The primary research question that was explored in this study was: What are the lived experiences and perceptions of individuals with developmental disabilities who use AAC and participate in active recreation?

Active recreational participation (e.g., skiing, paddling) can have extensive benefits for adults with disabilities who use AAC (Hajjar et al. 2016; Hajjar & McCarthy, 2016) as these types of activities can reduce behavioral and emotional distress, build social networks, and improve physical health (Lundberg et al., 2011). The infrastructure of adaptive recreational programs supports the process of developing relationships, increasing engagement, and fostering independence through teaching new skills (Lundberg et al., 2011).

2. Methods:

This study, which was approved by the Institutional Review Board at Ithaca College, used a qualitative research design involving an online focus group spanning over the course of seven weeks. This methodology was used to gain a better understanding of the lived experiences of people with developmental disabilities who use AAC and participate in active recreation and sport. Focus groups have been used in previous research to explore new phenomena and understand the perceptions of people who use AAC (Caron & Light, 2015; McNaughton, Light, & Groszyk, 2001).

Five individuals who use AAC were recruited from around the United States to participate in the online focus group. If individuals met all the inclusionary criteria, they completed the consent form, screening questionnaire, and the Quality of Communication Life Scale (Paul et al., 2004). The focus group participants included; two individuals with cerebral palsy, two individuals with autism spectrum disorder, and one person with Rett syndrome.

The focus group was moderated by the principal investigator and each week topics were posted with discussion questions. Some participants responded independently and others required a moderate level of support from a caregiver or family member. Participants were encouraged to post their perspectives and experiences, while also responding to each other's comments in the focus group.

3. Results:

Findings from the thematic analysis (Creswell, 2007) of the qualitative data indicated that active recreational pursuits provide meaningful opportunities for people who use AAC to engage and communicate with both familiar and unfamiliar communication partners. The five participants posted responses for all 7 topics during the focus group. Upon reviewing the data, individual units of analysis were identified based on the smallest amount of information that could stand alone. Next, coding themes with corresponding operational definitions were developed post-hoc based on the discussion topics and participants' written responses. The six primary themes that emerged from the focus group data were, (a) types of recreational activities, (b) barriers, (c) supports, (d) benefits, (e) communication, and (f) recommendations.

4. Discussion and Conclusions:

This research is important for people who use AAC, their communication partners, speech-language pathologists, and recreational professionals. Overall, the results from this study indicate that active recreation has strong value and is often a defining feature in the lives of people who use AAC. With greater awareness about active recreation, individuals who use AAC may increase participation and be interested in trying different types of activities available in their local and regional communities. Also, as a result of this research, communication partners will learn about the value of recreation for people who use AAC and what types of barriers exist. Findings from this study reveal that partners are critical supports who provide resources, transportation, and time to make recreational experiences happen. Lastly, outcomes from this study are important for recreational and related professionals as they work to improve and enhance adaptive sport programs by providing more focused communication training to staff and volunteers who support people who use AAC.

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