

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

David Hajjar, Ph.D., CCC-SLP; Julia Cohen, B.S.; & Isabelle Michaud, B.S.

Department of Speech-Language Pathology and Audiology

Background

Research in augmentative and alternative communication (AAC) has focused on a range of 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 recreation and how this area can positively impact individuals with complex communication needs who use AAC. Previous research in the areas of AAC and recreation have focused on barriers to passive recreation (e.g., board games, attending sporting events, going to the movies) reported by individuals with cerebral palsy (Dattilo, et al., 2008). Dattilo et al., 2008, found that lack of facilitator skills and knowledge, accessibility, and negative societal attitudes were common issues for people who use AAC in recreational activities. Recreational settings provide many opportunities for communication and socialization with dedicated communication partners who share common interests. Since individuals with complex communication needs may have limited social networks, this can lead to feelings of loneliness and isolation (Ballin & Baladin, 2007). This cycle of loneliness can then lead to less community engagement. However, when individuals share common interests and participate in motivating community based recreational activities, additional opportunities for communication and social interaction may occur (McAvoy, Smith, & Rynders, 2006).

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).

Methods

This qualitative research study was conducted to gain a better understanding of the experiences and perceptions of active recreation from individuals with developmental disabilities who use AAC. Five individuals who use AAC from the United States were recruited to participate in an online focus group over the course of 7-weeks. The participants included two individuals with cerebral palsy, two individuals with autism spectrum disorder, and one individual with Rett syndrome. The focus group was moderated by the principal investigator, who posted topics with discussion questions each week. All participants responded asynchronously to the discussion questions by posting their perspectives and experiences with active recreation and competitive team sports. Some of the participants responded with support of a caregiver or family member and others responded independently. Data was collected using a password-protected forum created specifically for the purpose of this research.

Activity

Hiking

Skiing

Biking

Kayaking

Swimming

Water skiing

Parasailing

Basketball

Power soccer

of Participants

Activity

Baseball

Ziplining

Shooting

Camping

Pilates

Snowshoeing

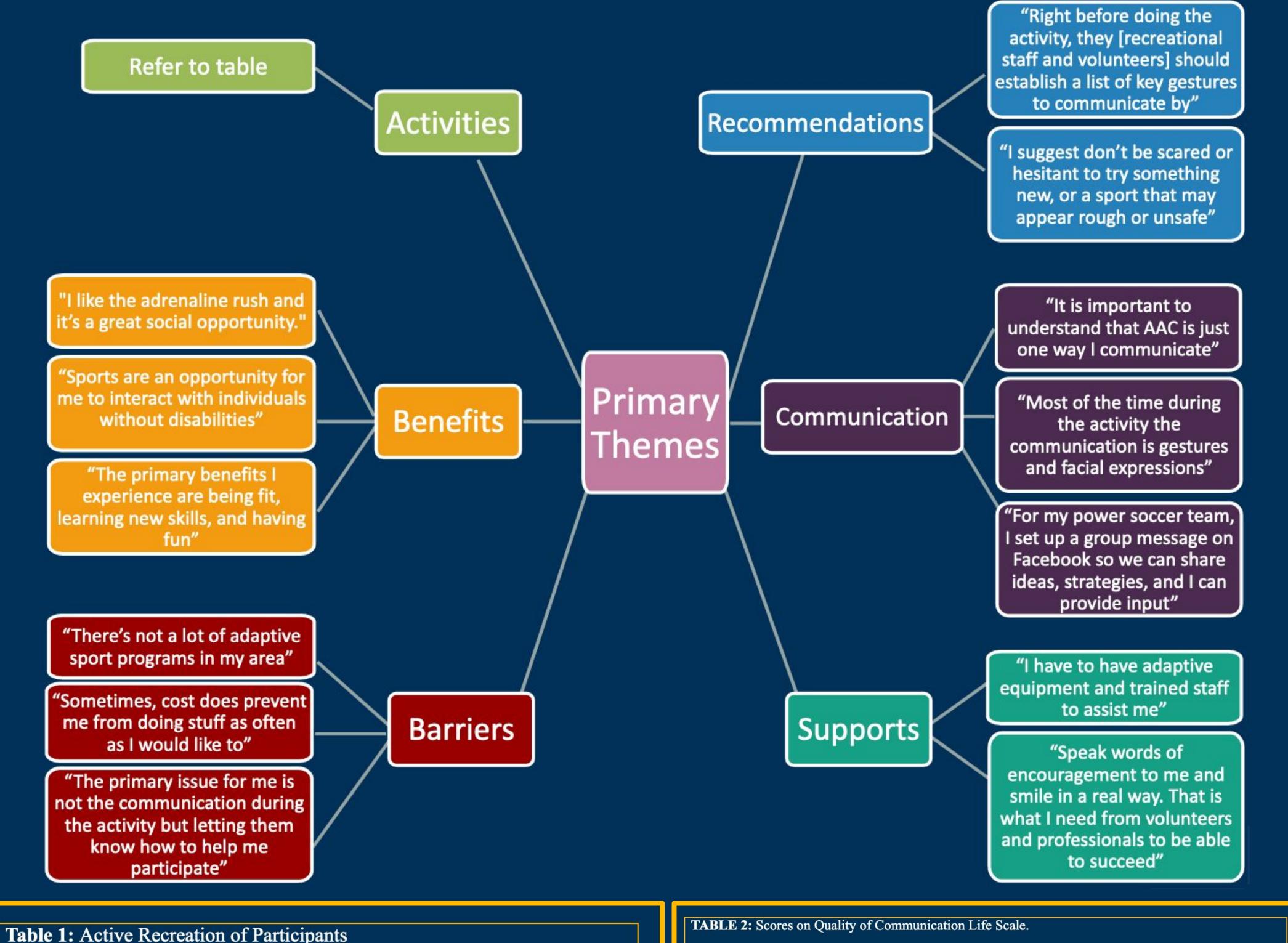
Personal trainer

Gymnastics

Results

The 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. 4/5 individuals rated their quality of communication life with a score of 3 or more, and one individual rated their quality of communication life with a score of 1.

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 research team identified 173 thought units from the focus group data across 6 themes. The themes that emerged were (1) Supports, (2) Barriers,(3) Activities, (4) Communication, (5) Benefits, and (6) Recommendations. A graduate student not familiar with the data independently reviewed and coded 47 thought units across the 6 themes which was 25% of the total thought units. Cohen's Kappa was used to determine inter-rater reliability and yielded a level deemed to be highly acceptable at 90% agreement.



of Participants

Name Total # Answered Total Points Average Score "Quality of Life Good?" GARY 19/19 80 4.4 5 NICK 19/19 83 4.7 3 DEREK 19/19 82 4.5 5 JEFF 19/19 48 2.8 1 GINNY 19/19 72 4 4 Note: Participants responded using a scale from 1-5. 1 = lowest score and 5 = highest score. The last item on the Quality of Communication Life Scale (Paul et al., 2005) is "In general my quality of life is good";

this value does not get calculated into the average score.

Discussion

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 of 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, educators, and healthcare professionals will learn about the value of recreation for people who use AAC and the types of barriers that exist. Participants in this study provided valuable recommendations for how communication partners can effectively support their recreational endeavors. Findings from this study reveal that partners are critical supports who provide resources, transportation, and time to make recreational experiences happen. In regard to overall communication in the recreational setting, participants discussed using both aided and unaided methods. Multimodal communication (e.g., tablets, gestures, facial expressions) was reported as a frequent method for expressing basic wants and needs as well as enhancing social interactions across the experience. Also, the participants reported many benefits as a result of participating in recreational activities. Both intrinsic and extrinsic types were reported, while participants specifically mentioned benefits in the following areas; physical/wellness, social-emotional, and psychosocial. Overall, perspectives gathered in this study indicate that recreation and related professionals can improve and enhance adaptive sport programs by providing more focused communication training to caregivers, staff and volunteers who support people who use AAC.

Selected References

- Ballin, L., & Balandin, S. (2007). An exploration of loneliness: Communication and the social networks of older people with cerebral palsy. *Augmentative and Alternative Communication*, 32(4),
- Creswell, J. (2007). Qualitative inquiry and research design: Choosing among five traditions.
 Thousand Oaks, CA: Sage.
- Dattilo, J., Estrella, G., Estrella, L.J., Light, J., McNaughton, D., and Seabury, M. (2008). "I have chosen to live life abundantly": Perceptions of leisure by adults who use augmentative and alternative communication. *Augmentative and Alternative Communication, 24*, 16-28.
- Hajjar, D., McCarthy, J., Benigno, J., & Chabot J. (2016). "You get more than you give": Experiences of community partners in facilitating active recreation with individuals who have complex communication needs. Augmentative and Alternative Communication, 32, 131-142.
- Hajjar, D., & McCarthy, J. (2016, November). Participation in active recreation: Experiences of adults with acquired conditions who use AAC. Poster presentation. American Speech-Language and Hearing Association Annual Convention, Philadelphia, PA
- Kent-Walsh, J., & Light, J. C. (2003). General education teachers' experiences with inclusion of students who use augmentative and alternative communication. Augmentative and Alternative Communication, 19, 104-124. https://doi.org/10.1080/0743461031000112043
- Lundberg, N., Bennet, J., & Smith, S. (2011). Outcomes of adaptive sport and recreation participation among veterans returning from combat with acquired disability. *Therapeutic Recreation Journal*, 45, 105-120.
- McAvoy, L., Smith, J. G., & Rynders, J. E. (2006). Outdoor adventure programming for individuals with cognitive disabilities who present serious accommodation challenges. *Therapeutic Recreation Journal*, 40, 182-199.
- McNaughton, D., Light, J., & Gulla, S. (2003). Opening up a "whole new world": Employer and co-worker perspectives on working with individuals who use augmentative and alternative communication, 19, 235-253.
- Mirenda, P. (2014). Revisiting the Mosaic of Supports Required for Including People with Severe Intellectual or Developmental Disabilities in their Communities. *Augmentative and Alternative Communication*, 30, 19-27.

Selected References

- Ballin, L., & Balandin, S. (2007). An exploration of loneliness: Communication and the social networks of older people with cerebral palsy. *Augmentative and Alternative Communication*, 32(4), 315-326.
- Creswell, J. (2007). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage.
- Dattilo, J., Estrella, G., Estrella, L.J., Light, J., McNaughton, D., and Seabury, M. (2008). "I have chosen to live life abundantly": Perceptions of leisure by adults who use augmentative and alternative communication. *Augmentative and Alternative Communication, 24*, 16-28.
- Hajjar, D., McCarthy, J., Benigno, J., & Chabot J. (2016). "You get more than you give": Experiences of community partners in facilitating active recreation with individuals who have complex communication needs. *Augmentative and Alternative Communication*, 32, 131-142. https://doi.org/10.3109/07434618.2015.1136686
- Kent-Walsh, J., & Light, J. C. (2003). General education teachers' experiences with inclusion of students who use augmentative and alternative communication. Augmentative and Alternative Communication, 19, 104-124. https://doi.org/10.1080/0743461031000112043
- Lundberg, N., Bennet, J., & Smith, S. (2011). Outcomes of adaptive sport and recreation participation among veterans returning from combat with acquired disability. *Therapeutic Recreation Journal, 45*, 105-120.
- McAvoy, L., Smith, J. G., & Rynders, J. E. (2006). Outdoor adventure programming for individuals with cognitive disabilities who present serious accommodation challenges. *Therapeutic Recreation Journal*, 40, 182-199.
- McNaughton, D., Light, J., & Gulla, S. (2003). Opening up a "whole new world": Employer and co-worker perspectives on working with individuals who use augmentative and alternative communication.

 Augmentative and Alternative Communication, 19, 235-253.

 https://doi.org/10.1080/07434610310001595669
- Mirenda, P. (2014). Revisiting the Mosaic of Supports Required for Including People with Severe Intellectual or Developmental Disabilities in their Communities. *Augmentative and Alternative Communication,* 30, 19-27.