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Exploring Community Recreation and Leisure of Young Adults with Autism

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Introduction

- Adults with autism participate less in the community compared to adults with other diagnoses (e.g., intellectual disability, emotional disturbance, and learning disabilities) (Myers et al., 2015; Orsmond et al., 2013).
- Quantitative studies have shown the benefits of participating in recreation and leisure activities for young adults with autism (Bishop-Fitzpatrick et al., 2017; Garcia-Villamizar & Dattilo, 2010; Stacey et al., 2019).
- The use of qualitative research has been recommended to offer a deeper understanding (Stacey et al., 2019).
- The lack of opportunity for young adults with autism to share their experiences and opinions can lead to a misunderstanding and mistreatment of adults with autism (Lam et al., 2020).
- Their perspectives are valuable for families, professionals, and the quality of life for adults with autism (Hurlbutt & Chalmers, 2002).

PURPOSE: This qualitative inquiry explored the experience of community recreation and leisure activities from the perspective of young adults with autism.

AIM 1: Describe the dimensions of participation with community recreation and leisure activities from the perspective of young adults with autism.

AIM 2: Describe the determinants of participation with community recreation and leisure activities from the perspective of young adults with autism.

Methods:

Data Collection:

- This qualitative inquiry was approved through the Thomas Jefferson University Institutional Review Board.
- An interview guide was created based on the conceptual model of optimal participation (Kang et al., 2014).
- -17 main interview questions & 41 probe questions were developed.
- Participants were recruited through autism organizations, universities with autism programming, social media, & professional networks.
- Eight semi-structured interviews were completed with young adults with autism using Zoom phone call audio.

Theoretical Framework: Model of Optimal Participation (Kang et al., 2014).

Dimensions of Participation:

- **Physical:** entails the actual involvement in the activity
- **Social:** interpersonal interactions that occur during the activity when feeling included
- **Self:** the enjoyment, self-determination, and self-understanding that develops from the activity

Determinants of Participation:

- **Person:** attributes such as age, sex, preferences for activities or experiences, and physical functioning
- **Family:** family's socioeconomic status, family interaction and functioning, and activity orientation
- **Environment:** access to community and transportation system, social supports, supportive services, and attitude of others

Data Analysis:

- Interviews were analyzed using the four stages of content analysis described by Bengtsson et al. (2016) (Figure 1).
- Data were coded under each of the six dimensions and determinants of participation using NVIVO software (QSR International, 2021).

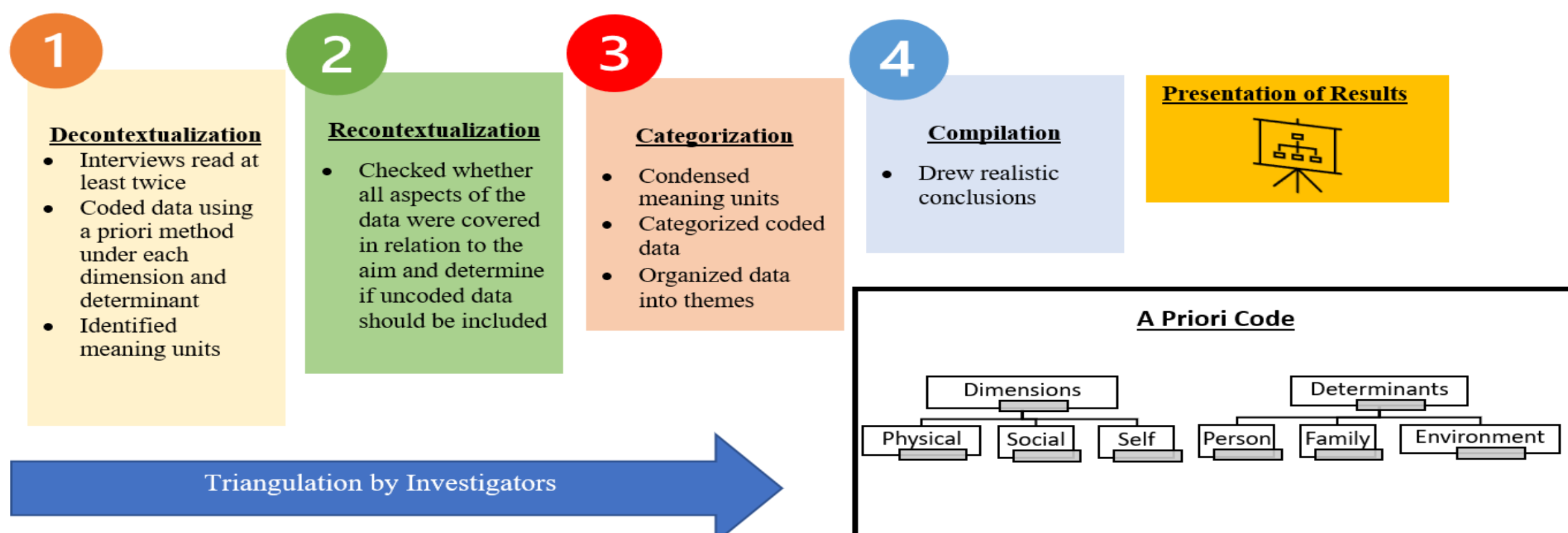


Figure 1. An overview of the four stages of content analysis adapted from Bengtsson et al. (2016).

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Results:

Demographics:

- Eight young adults with autism completed the semi-structured interviews (Figure 2).
- Five participants preferred the term “adult with autism,” two participants preferred “autistic adult,” and one participant preferred “just adult.”
- All eight young adults that started the interview completed it; no participants dropped out.

Themes:

Themes were organized using the dimensions and determinants of participation (Figure 3).

Figure 2: Demographic information of the participants.

| | Number | | Number |
|--------------------|--------|---------------------------|--------|
| Gender | | State of Residence | |
| Male | 6 | Virginia | 3 |
| Female | 2 | Pennsylvania | 2 |
| | | Maryland | 1 |
| Age | | District of Columbia | 1 |
| 18-21 | 3 | Texas | 1 |
| 22-25 | 1 | | |
| 26-28 | 4 | Living Situation | |
| Ethnicity | | Resides with family | 8 |
| White or Caucasian | 4 | Alone | 0 |
| Black or African | 2 | | |
| American | 1 | Education | |
| Asian American | 1 | Some High School | 1 |
| Hispanic | | High School Diploma or | 3 |
| | | GED | 2 |
| | | Some College | 2 |
| | | College Degree | |

Figure 3: Themes from semi-structured interviews.

| Physical | Social | Self |
|--|--|---|
| <p>Interviewees:</p> <ul style="list-style-type: none"> • Participate in activities common to young adults “Movies” & “Video games” • Participate in organized groups <ul style="list-style-type: none"> • Peers with autism and disabilities “Special Olympics” • Neurotypical peers “Young adult writers’ group” | <p>Interviewees:</p> <ul style="list-style-type: none"> • Socialize “Hang out with my friends” • Share common interests with others “Computer guys like me” • Have difficulty finding others “Not always for people in my age group” • Females preferred to doing activities with less social interaction “Enjoy without having to interact” | <p>Interviewees:</p> <ul style="list-style-type: none"> • Expressed goals & aspirations “Get published professionally” • Desire to help others “Be that kind of support to somebody else” • Self-Identified characteristics that help participation “That attention to details helps me” |
| Person | Family | Environment |
| <ul style="list-style-type: none"> • Symptoms of autism impact participation “I have social anxiety” “I’m not as good as like dealing with the sensory part of things” “Nervous about conversations” • Use coping skills to help “Just breathing” • Practice and persevere “Continuing to work” & “Practice” | <ul style="list-style-type: none"> • Family supports physically and emotionally “Parents drive me there” • Parent Guardianship “They say like, I can’t hang out with these certain people” • Relationship with family member impacts participation “Good at helping to accommodate me” | <ul style="list-style-type: none"> • Driving facilitates ability to participate in activity “Drive my own vehicle and go” • Traffic and weather are barriers, but activities close by help “Traffic” • Professionals help with access “Send me stuff” & “Helped me with the whole getting round” |
| Stress & Quality of Life | Participants’ responses to open ended questions | Participants’ recommendations to the community: |
| <ul style="list-style-type: none"> • Participation decrease stress “I feel like they decrease my stress” “Yeah, I mean, it definitely decreases my stress” • Participation increases quality of life “Increases my quality of life because I know more about things” • Participation is beneficial and stressful “It’s something that I get stressed out about if I don’t give it a try. And so, but at the same time if I’m if I try it, and it doesn’t go quite the way I want it, then then I can get stressed too.” | <ul style="list-style-type: none"> • “Some people take the caregivers who are helpful, but they ask for their opinions more than the people with autism themselves” • “I’m just glad I could share my own insights.” • “I liked that you guys put an emphasis on what can be done for us. That is very important. Because I feel like a lot of times, it’s just people just want to see what our deficits are. And that’s very interesting, but we have needs that need to be met. It’s not always about how cool a science experiment we can be. It’s nice that you guys are willing to try to see what can be done to help us.” | <ul style="list-style-type: none"> • Having better points of contact • Announcing more events will help them access more activities they are interested in • Quieter and adult-only events • More education and to be accepting of individuals with autism. |

Conclusions:

Dimensions of Participations:

- Young adults with autism can participate in community recreation and leisure activities associated with their specific interests.
- Physical and social engagement in community recreation activities can have an impact on self understanding of young adults with autism (e.g., identify strengths, goals and aspirations).

Determinants of Participations:

- Young adults with autism may experience barriers (e.g., anxiety, traffic, and weather) and have facilitators (e.g., family and perseverance) when participating in community recreation and leisure activities.

Stress and Quality of Life:

- While community recreation and leisure activities can decrease stress and increase quality of life for young adults with autism, recreation and leisure activities can be stressful.

Implications:

Occupational therapists can support young adults with autism participation in community recreation and leisure activities by:

- Recognizing they have valuable perspectives and can provide rich insights into their unique participation.
- Supporting them to articulate their needs and desires for their participation.
- Providing interventions (e.g., coping skills) to minimize anxiety to promote participation.
- Championing their ability to be powerful decision makers about their participation.
- Addressing barriers such as transportation, sensory concerns, communication, and limited availability of activities.
- Including their powerful voices and supporting advocacy for change at the community level.

Young adults with autism appreciated the opportunity to express their own views. Occupational therapists gaining their perspective directly can have a positive impact on outcomes and provide valuable information for others who support young adults with autism.

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