Research in Developmental Disabilities 115 (2021) 103998

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

"There's nothing here": Perspectives from rural parents promoting safe active recreation for children living with autism spectrum disorders

Crystal A. Shannon [a,c,*], Lise L. Olsen [a,c,b], Rachelle Hole [a,b,d], Kathy L. Rush [a,c]

[a] University of British Columbia, Okanagan, 3333 University Way, Kelowna, BC, V1V 1V7, Canada
[b] Canadian Institute for Inclusion and Citizenship, 1147 Research Road, Kelowna, BC, V1V 1V7, Canada
[c] School of Nursing, University of British Columbia, Okanagan, Canada
[d] School of Social Work, University of British Columbia, Okanagan, Canada

ARTICLE INFO

Number of reviews completed is 3

Keywords:
Autism spectrum disorder (ASD)
Recreation participation
Parents
Safety
Rural

ABSTRACT

Background: Children with autism spectrum disorder (ASD) and their families experience challenges and barriers at multiple levels that influence their activity participation. The purpose of this study was to develop understanding about factors influencing how families can promote safe, active recreation for their children 3–12 years living with ASD across rural settings and how supports for these families can be enhanced.
Methods: This qualitative study used an interpretive descriptive approach. Twelve in-depth, semi-structured interviews with parents of children with ASD were conducted. Data was analyzed thematically.
Results: Four main themes emerged: 1) ASD specific child vulnerabilities impeding safe recreation. 2) Importance of safe outdoor spaces in rural settings for children with ASD. 3) Diverse parent strategies to address risks and needs. 4) Perceived needs for training of recreation providers.
Conclusion: Findings highlight family-centred priority issues including parental safety concerns related to elopement and risk of injury linked to environmental and outdoor hazards prominent in rural settings. Autism awareness and recreational training is needed and could incorporate collaborative development of child specific safety plans to foster inclusive opportunities. Program planners can use this information to encourage policy making to aid families' safe activity participation.

1. Introduction

Autism is a complex spectrum disorder, characterized by significant deficits in social communication, social interactions, and behavioral challenges (Li, Larsen, Yang, Zhai, & Sullivan, 2019). Compared with their typical peers, children with ASD have also been reported to have lower physical activity and fitness levels (Borremans, Rintala, & McCubbin, 2010; Tyler, MacDonald, & Menear, 2014). Furthermore, evidence indicates that they engage in more sedentary behaviors and are more likely to be obese than their typically developing peers (Corvey, Menear, Preskitt, Goldfarb, & Menachemi, 2016; Curtin, Anderson, Must, & Bandini, 2010). Additionally, rural youth are at even greater risk than urban youth for obesity and recreational inactivity (Yousefian, Ziller, Swartz, &

* Corresponding author at: University of British Columbia, Okanagan, 3333 University Way, Kelowna, BC, Canada.
E-mail address: crystal.shannon@ubc.ca (C.A. Shannon).

https://doi.org/10.1016/j.ridd.2021.103998
Received 13 March 2020; Received in revised form 2 May 2021; Accepted 12 May 2021
Available online 7 June 2021
0891-4222/© 2021 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Hartley, 2009), thus children living with ASD in rural settings are at particular risk for poor health due to inactivity.

It is important that children with ASD participate in recreational activities to improve their health, fitness, and quality of life. Involvement in recreation also plays an important role in the emotional well-being and development of children (Krauss et al., 2012). However, studies comparing children with high functioning autism with typically developing children indicate that those with autism engage in fewer activities, take part in a more limited range of activities and in less varied environments (Hilton, Crouch, & Israel, 2008; Hochhauser & Engel-Yeger, 2010). Moreover, families with children with autism experience barriers at child, family, and community levels that may influence their full participation. For example, in a qualitative study with adolescents with ASD researchers found that physical activity participation was shaped by complex factors and relationships reflecting individual (biological and psychological) as well as social dimensions (Jachyra, Renwick, Gladstone, Anagnostou, & Gibson, 2020). Greater barriers to recreational opportunities have also been noted for families living in rural communities (Moore et al., 2010), highlighting the need for research related to the experiences of families living with ASD outside of larger centres. In one study conducted in a rural US state, authors reported that children with high functioning autism participated in fewer physical activities than their typically developing peers (Potvin, Snider, Prelock, Kehayia, & Wood-Dauphinee, 2013).

Furthermore, in a review by Potvin et al. (2008), the authors highlighted a lack of meaningful inclusive activities available for children due to the frequent social, communication, and behavioral challenges associated with ASD. Similarly, in a study using online focus groups, parents identified a lack of community activity programs or locations to engage in safe participation for children with ASD, along with the lack of adequately trained staff (Obrusnikova & Miccinello, 2012). In a mixed methods study by Ayvazoglu et al. (2015), it was also identified that caregivers highlighted a lack of awareness and understanding about ASD in community settings. These authors argued that unique developmental considerations for each individual child living with ASD must be taken into account when looking at factors affecting recreational participation. Further, in a qualitative investigation, parents emphasized ASD-related developmental delays, such as difficulty managing frustration, rigidity, sensory issues, poor coordination, and reduced reaction time as factors related to their children's abilities to engage with physical activities (Polfuss et al., 2016). In other research addressing rural caregivers' views of overall services available for their children living with ASD, parental reports identified that rural communities "had less of everything" (Hoogsteen & Woodgate, 2013). This was consistent with Mello, Goldman, Urbano, and Hodap (2016) who found decreased access to services for children with ASD in rural communities when compared to non-rural settings, a finding which likely holds relevance for recreational programs and services.

Safety is a significant concern amongst caregivers of children living with ASD because of developmental challenges their children often experience and potential for lack of supports within programs (Polfuss et al., 2016; Schleien, Miller, Walton, & Pruett, 2014). Researchers also report how parents may perceive it to be unsafe for their children with autism to engage in outdoor activities due to their children becoming easily distracted or preoccupied (Obrusnikova & Miccinello, 2012) or because of coordination issues that may impact their ability to participate safety (Ayvazoglu, Kozub, Butera, & Murray, 2015). Furthermore, children with ASD have been reported to experience a higher incidence of injuries than their typically developing peers (Jain et al., 2014; Lee, Harrington, Chang, & Connors, 2008). Evidence also shows that parents of children with intellectual and related developmental disabilities value community recreation as an important aspect of their children's quality of life; however, they had safety concerns due to underprepared program staff (Schleien et al., 2014). Similarly, other research findings have indicated parental concerns about inadequately trained staff can create safety related barriers for children's participation (Gregor et al., 2018; Obrusnikova & Miccinello, 2012). Further, parents of youth with ASD were found to worry about their children's vulnerability to bullying, (both physical and verbal), resulting in parents engaging in protective actions that could result in lower activity involvement (Gregor et al., 2018). Thus, safety-related factors at the child, parent, and community levels form important influences on recreation participation of children with ASD; however, the ways in which these factors are experienced by parents in rural settings specifically has not been studied.

In terms of general services for children with ASD, parents in a recent rural study reported needing to engage in constant advocacy for their children with ASD for inclusive programming in rural settings due to lack of understanding and knowledge among community members about the array of spectrum impairments (Hoogsteen & Woodgate, 2013). This study, however, did not address the extent to which parental safety considerations for their children with ASD may be linked to such efforts.

This current study was undertaken to explore the factors associated with rural living and ASD-related safety considerations, along with experiences of parents regarding their child's recreation participation. Three research questions were addressed: 1) What are the experiences of parents living in rural communities with engaging their children with ASD in safe and active recreation? 2) What factors are associated with their efforts to engage their children with recreation? 3) What needs do parents identify that would better support their efforts to help their children participate?

Children with ASD require supports to participate in recreation in meaningful ways (Potvin, Prelock, & Snider, 2008). New understandings about parent experiences and perceived needs for supporting children can help to inform community and recreation services and programming in smaller centres and rural areas. Addressing children's safety needs may help parents in rural areas with aiding their children with ASD to engage more fully in recreation opportunities.

2. Methods

2.1. Study design

This study used interpretive description (ID) for the research design (Thorne, 2016). The research focused on rural parents' experiences and factors influencing their ability to engage their children with ASD in safe recreation participation. ID as a research methodology was well-suited to understand this complex phenomenon through developing rich descriptions and fuller understanding

of parent perspectives as well as their perceived needs for improved community-based supports for their children's recreation participation. This qualitative approach allowed a rigorous analytic process for the interpretation of the data to provide new insights into the phenomenon under study and generate ideas relevant for applications to practice (Thorne, Kirkham, & O'Flynn-Magee, 2004).

2.2. Participants and sample

Caregivers of children ages 3–12 years with a clinical diagnosis of ASD and living in rural settings were recruited initially using convenience sampling. Recruitment of this sample was conducted through contact with a regional community-based organization that provided services to families of children with ASD. This was followed by a purposive approach to recruit fathers and diversify the sample. Recruitment of fathers was done by advertising the study using the social media channel of a family support organization that served the region under study.

This sample was recruited from rural areas and small population centres in British Columbia's interior. According to Statistics Canada (2016a, 2016b), the medium population centres are comprised of 30,000–99,999 residents while large urban centres are comprised of 100,000 or more. For this study, small population centres and rural areas outside of these medium and large centres formed the focus for recruitment. Participants included biological parents (mothers and fathers) and adoptive parents, a single parent, and blended families. All respondents were the legal guardians of the children. Thorne (2008) indicates ID can be conducted with almost any sample size; however, the majority of studies employing this approach tends to fall within a sample range of 5–30 participants. For the purpose of this study, to obtain a rich data set that recognized the issues of concern for the rural population, 12 caregivers were interviewed on one occasion and interviews lasted from 45−60 min each.

Informed consent was obtained from the study participants and ethics approval was obtained from the University of British Columbia, Okanagan. The certificate number is H18−00854-A001. All efforts were made to uphold participant confidentiality.

2.3. Data collection

Data were collected using a combination of open-ended and semi-structured interview questions using a parent interview guide (See Table 1). While being mindful not to direct the dialogue, probing questions were used to encourage and guide the participants' expansion of details within each interview. This enhanced clarity of information and helped keep the interview focused close to the caregivers' lived experiences and opinions related to recreational activities and safety for their children living with ASD.

Following consent, interviews were conducted in participants' homes, or in a safe public place private enough to ensure confidentiality in the local community, such as a restaurant or café of the family's choice. Participants completed a demographic information form prior to the interview.

2.4. Data analysis

The interviews were digitally recorded and transcribed verbatim. Transcripts were double checked against the recordings for accuracy. The steps for data analysis were guided by Braun and Clarke's (2006) approach to thematic analysis. To start, the interview transcripts were closely read and reviewed. The first author (CS) then conducted broad-based coding on all transcripts with CS and LO (second author) coding the first four transcripts together (Thorne, 2016) that resulted in an initial list of 29 codes that reflected parent experiences promoting safe and active recreation for their children living with ASD. The initial codes were then grouped into categories and potential themes. With ongoing analysis of interviews, themes were refined, and example extracts selected from the data. Selected excerpts were those that clearly illustrated the main idea of the theme and represented a pattern common across the data.

Table 1
Parent Interview Guide.

1	Can you tell me a bit about your child?
2	Can you explain some of the ways your child engages in recreational or physical activities?
	a What types of indoor or outdoor activities do they enjoy doing?
	b What types of play or recreational areas are available for your child to active in your rural community?
	c What organized or structured community activities are they involved in?
	d What makes it easier for them to engage in your mentioned activities?
	e What makes it more difficult?
3	Do you have any concerns about your child's physical or emotional safety when they are being active?
	a When you think about your child's safety; what concerns you the most?
	b What are some things that make it easier for your child to stay safe during recreational or physical activities?
	c What are some of the things that make it more difficult for your child to be safe?
4	What are some ways that you feel supported in your community to help your child be active?
	- What are some improvements that you feel are needed in your community to help your child be active?
5	What suggestions do you have for ways to improve opportunities for families in rural communities to help their children with ASD experience safe and active recreation and play on a regular basis?
	a What kinds of services are needed?
	b What kinds of recreational or activity options would you like to see?

Analysis was not a linear process but required engaging with the data in a back-and-forth manner throughout the interpretive research process, reflecting both inductive and deductive reasoning processes. To support the rigor of analysis, the first and second author reviewed and discussed coding, and all authors were involved in the development of themes, interpretation, and presentation of findings and themes. Consistent with ID (Thorne, 2016), CS completed field notes after each interview, kept a reflexive journal with analytic memos and open-ended reflections, and developed mapping diagrams to aid in the development of themes and interpretation of findings. Confidence in the saturation of themes was gained when new interviews did not yield substantial information that further informed theme development. However, acknowledging the diversity of the ASD spectrum and family situations, it may be that further interviews could have produced new and varied information, a consideration consistent with Thorne (2020) who argues that claiming full saturation can sometimes be problematic for applied health research.

3. Results

Twelve parents (10 mothers, 2 fathers) of children living with ASD participated in the study. Most of the parents were between 25–44 years (75 %). The majority of parents held a trade school or college diploma (58 %), while 25 % had completed a university degree. Approximately 17 % of the sample of parents had some high school or post-secondary education. The children (11 boys, 2 girls) of the caregivers (n = 13) were between the ages 3 and 12 years old. Just over half of the sample of children (54 %) were less than 10 years old, while the remainder (46 %) were between 10 and 12 years old. One participant was a parent of 2 children with ASD and in 9 of the families, the child with ASD had one or more siblings. According to Statistics Canada (2016a, 2016b), the population size of the communities where participants resided ranged from 1203 to 11,615. The proximity of the participants' residence to the largest urban centre, of approximately 150,000 ranged from 25 to 135 km.

Analysis of the data regarding parents' experiences promoting safe and active recreation for their children living with ASD in rural BC settings revealed four main themes. These included: ASD specific child vulnerabilities impeding safe recreation; importance of safe outdoor spaces in rural settings for children with ASD; diverse parent strategies to address risks and needs; and perceived needs for training of recreation providers. These themes are explored from the perspective of parents who are raising children living with ASD in rural settings while making efforts to promote their safe recreation experiences. Parent safety concerns specifically for their children with ASD are highlighted, along with importance of safe outdoor environments and the varied strategies used by parents to ensure safe recreation experiences for their children. Lastly, how community professionals and programs can better meet parent needs for access and trust in recreation options for their children is addressed.

3.1. ASD specific child vulnerabilities impeding safe recreation

Parents in the study described several different ways that they considered their children vulnerable to safety risks when engaged in recreational activities. These concerns included compulsive and impulsive behaviors that could threaten children's physical safety as well as social vulnerabilities that could compromise their ability to safely take part in community programs.

Children with ASD often develop an intense focus or preoccupation with special interests, which are unique to the child and can result in compulsive and, at times, dangerous behaviors. For example, one mother with a child with ASD shared, "He loves water. There's a lot of risk and he would just open the door and go" [Participant 05]. These types of intense focussed interests among children could pose substantial dangers especially for families who lived in areas with many lakes and rivers in proximity.

Parents also expressed significant concerns about their children's elopement behaviors. Many parents described how this type of unpredictable bolting behavior during recreational activity was sometimes compounded by children's impaired sense of danger and risk, and thus exposed them to hazardous circumstances. Parents described this as an alarming behavioral response often resulting from sensory overload, triggering the child to bolt to get away from a situation. One mother described, "His ability to bolt…Fight or flight. [*Child*] would certainly bolt whether because he misunderstands something or because he thinks somebody laughed at him or he's just so overwhelmed. If you're not prepared for it, BANG! That kid's gone" [Participant 06]. Thus, parents expressed fears that their child could suddenly run away or wander off if they did not have sufficient supervision during recreational activities. These concerns influenced their decisions about the types and locations of recreational activities that they considered safe for their child.

Many families also expressed concerns about socially oriented vulnerabilities that related to their child's ability to understand and respond appropriately to complex social situations that could impact their ability to safely participate in recreation activities in the community. Parents concerns included their child being emotionally bullied or taken advantage of by peers or others. For example, one mother explained, "He tends to get picked on. He tends to be almost targeted" [Participant 02]. Another mother reflected on how her child could be easily manipulated, "He wants friends so bad that if someone tells him to do something, he will actually do it; …he wants to belong" [Participant 03]. Parents were reluctant to have their children participate in recreation activities where they could be exposed to these types of social harms.

Some parents also expressed their fears about their children possibly approaching or being approached by strangers, children being over trusting of others, misreading social cues, or if they were non-verbal, fears that they might be unable to call for help when in danger. As one mother described, "She is outgoing … her talking to strangers. What if she talks to the wrong stranger one day …and she's gone" [Participant 1]?

Therefore, a sense of danger from behavioral, physical, and social factors were evident in parents' descriptions of their safety concerns for their children living with ASD. Many of these concerns were exacerbated by some of the clinical characteristics associated with ASD, and others were exacerbated by the qualities of the rural settings. While most parents described how safety risks could be amplified in rural communities, for example, with proximity to hazards, others pointed how in smaller communities they believed their

children were safer from a social perspective. For example, one parent stated, "A lot of people in the community know us or know him… It's good to know that people know who he is and who he belongs to. It makes me feel better that I know he's safe" [Participant 04]. Thus, there was a tension noted between these perceptions of safety risks described by parents that related to raising their child with ASD and accessing recreation activities in rural communities.

3.2. Importance of safe outdoor spaces in rural settings for children with ASD

Many of the concerns that parents had about child risky behaviors such as elopement were heightened in a rural context because of additional exposure and proximity to environmental hazards such as ponds and waterways. Parents also voiced concerns about threats from wildlife in their rural communities that could pose a potential risk to the well-being of their children living with ASD pursuing outdoor recreation. For example, one mother stressed her concerns about wildlife in their rural area, "The unpredictability of wildlife! … We have deer in the yard, we have coyotes, there's bears" [Participant 05]. These parental concerns reflected unique aspects of the rural environments which when coupled with children's elopement and other risk behaviors affected parent decisions about their child's recreational activities.

As a result of these perceived risks related to outdoor hazards and wildlife, in combination with children's tendencies to engage in riskier, impulsive types of behaviors, many of the parents voiced a desire for their children to have access to safe and enclosed play areas with play equipment appropriate for their child's needs. Across the interviews, parents expressed the importance of providing safe physical spaces to promote their children's activity and play. Two parents of children with ASD expressed their desire for fencing in their community's public playgrounds to help reduce the risks to their children who had unpredictable elopement behaviors. For example, one mother expressed how her small town would probably have been a safer place for her child if the playground had been enclosed. Parents also referred to the safety risks posed by some of the playground structures that were available for children for outdoor play. For example, a mother shared, "I just think that the actual environment isn't as set up. Even the playgrounds here. There's some I can't even take him to because the fall is like an 8 – foot drop" [Participant 08].

Other parents recommended provision of inclusive playground equipment or "autism friendly" options in their local communities to increase safe play opportunities for their children. For example, a mother identified this need in her rural area and suggested, "Improving the playground equipment to make it more autism friendly" [Participant 02]. Another parent emphasized, "We don't have the big things or the simple things that the other communities might have or as many. Parks with like, swings that have proper special needs swings or special needs equipment" [Participant 11]. As illustrated, parents expressed how creating more play areas for children secured by fencing as well as improvements such as "autism-friendly" equipment options would help promote safe recreation participation opportunities for their children in their rural communities and help to create outdoor opportunities to enhance their children's recreation participation.

3.3. Diverse parent strategies to address risks and needs

3.3.1. Safety planning

One specific strategy that some families used to promote safe, active recreation was the development and rehearsal of proactive family safety plans. This included having a safety plan in place and rehearsing safe responses with their children in the case of unforeseen circumstances and involving trusted members of the community to assist with carrying out the plans. For example, one parent stated,

> [*Children with ASD*] get lost easy. They get overwhelmed easily. Disorientated easily. So, you have to think about what the possible outcomes could be …and the default position is, if you get lost or you gotta go to the bathroom, or there's something wrong; go to the pastor's house. [Participant 10]

Parents developed concrete safety plans that provided their children with specific directions and guidance for unexpected situations. Parents also involved their extended and trusted community network contacts to assist with carrying out the safety plans. Thus, use of safety plans was a strategy used by parents to facilitate children's engagement in recreation activities but also reflected parental trust in other members of their rural communities.

Use of technology was another safety strategy used, but only mentioned by two parents. As one parent [Participant 10] explained, "All our phones are tracked. So, if you [*child*] take a phone, I know where you are" [Participant 10].

3.3.2. Addressing lack of access and trust in program options

Parents expressed having a lack of access to local recreation programs in their rural communities that they felt comfortable taking their children to. Issues included a lack of options for their children as well as a focus on organized sports, which their children did not often enjoy or fit with their needs. For example, one father described the lack of fit between mainstream organized sports and his child's needs: "He needs the freedom, independence, and space to succeed and to fail. You put all his peers around him, throwing balls at him, he can't catch them or throw it as hard; it shuts the whole thing down" [Participant 10]. This same parent described how soccer was an option that his child had access to but that "we wouldn't go more than once and it wouldn't work for [him]. So, technically there is nothing." Seven of the 12 participants in the study reported their experience of there being no suitable recreation options for their child in their rural community with five parents directly stating, "There's nothing here."

Closely linked to these parent perceptions that their communities lacked suitable recreation opportunities for their children with ASD were the varied efforts that parents made to ensure that their children did have opportunities to take part in activities that parents

trusted would be safe and well-supervised experiences for their children. For some parents, this reflected an intensive level of involvement in the child's activities. For example, among families who had access to organized sport opportunities, some parents joined the organizations as leaders so they could be closely involved and provide one-on-one support as a trusted party who was available to monitor and maximize their child's safe activity participation within the team and group environment. For example, one mother (Participant 11) described how her husband's involvement in sport with their child, who had differing abilities and communication challenges, contributed to their son's successful participation, "[*Child*]'s dad has been coaching hockey with him, so he's allowed to be out there [*on the ice*] with him. So, that has taken him a long way to have the one-on-one [*support*] out there."

For others, this strategy of active involvement included constant supervision in children's recreation activities. As one mother explained, "I'm always there on the sidelines. I always have to be there to make sure [*child is*] not playing this way …not touching this …staying in this one spot" [Participant 04]. This type of intensive level of constant supervision was described by another parent as not only taking place for the protection of the child with ASD but also to protect other children from their child's behavior. For example, a mother stated, "I feel like I can't ever really put him in programs without me being there … I worry about his safety, and I worry about, sometimes, other kids – not because he's a violent person but just because he's not aware" [Participant 08]. Such safety precautions utilized by these parents reflected the intensive ways they felt they needed to become involved in order to trust that their child's experience would be positive, safe, and adequately supervised for their own child as well as other children.

In contrast, several other parents, who lacked access to organized or inclusive activity options described a variety of nature-based activities they did with their children living with autism in their rural communities. As stated by a single mother, "It's just me ensuring that he's active. There are no programs for him to join as of now, so it's all on myself to ensure he's getting out, going to the park, going for hikes" [Participant 09]. This parent's experience reflected both the lack of activity program options for her child, along with her feelings of being solely responsible to assist him with being active in the outdoors. Thus, while the rural context afforded families with opportunities to seek recreation outdoors, it necessitated very close supervision by parents due to environmental hazards or risky child behaviors and reflected the overall lack of access to suitable recreation options that parents felt they could trust.

3.4. Perceived needs for training of recreation providers

Parents offered many suggestions that they believed would help facilitate recreational participation for children living with ASD to meet their diverse needs in their rural communities while attending to children's safety-related risks and fostering confidence and trust. Parents expressed their desire for increased options for inclusive programming designed to meet individual child needs. For such programming, they also expressed a particularly strong desire for well-trained personnel to support their children's safe and inclusive recreation participation.

Parents voiced that there was a need to increase awareness about autism among recreation leaders and enhance their qualifications to promote a safe, inclusive instruction style for children with ASD in rural community programs. For example, one mother expressed her view that "[a] lot of people don't even know about autism here, even the people that do the recreation programs" [Participant 09]. She further suggested that it would be helpful if "there were more people educated in the topic or more people that have careers in autism." Another parent further emphasized how without trained support her children with ASD would experience difficulty with safe participation in sport. She explained, "They won't understand what you're supposed to do. They don't have the instincts to pick up a bat and swing it the proper way and be safe" [Participant 11]. Similarly, another parent (participant 06) emphasized the need for recreational leaders to have adequate safety awareness when teaching her child with autism, while also being physically prepared to perform physical activities with him. She explained,

> I need somebody that is qualified to handle his behaviors or his reactions, and [*who is*] in shape enough to go hiking or take him stand up paddle boarding or kayaking or any of those things that are readily available [in rural community] but there isn't somebody who is qualified in both autism and the physical part of instructing it. [Participant 06]

She further perceived that her son would benefit from a coaching approach that focused more on individual scaffolding and instruction techniques to help him succeed. "If [*recreational leaders*] can't show him how to do it and break it down into the steps ahead of time, he can't keep up with the other kids" [Participant 06]. These parents perceived that recreational coaches and instructors often lacked experience in facilitating the inclusion of children on the autism spectrum in ways that adapted to the children's unique presentation of ASD.

Parents viewed benefits of community training for recreation workers and support staff not only for their children but for themselves in providing a peace of mind that their children would be in competent and trusted hands. They anticipated this would make them feel comfortable leaving their children for the duration of the group activity. For example, one mother thoughtfully reflected, "Wouldn't it be nice for someone to start something or do something where you could just drop your child off and know that they are going to be taken care of" [Participant 07]?

Parents expressed a strong desire that recreational leaders should be experienced and/or certified with instructing children living with neurodevelopmental differences. Parents also highlighted the need for such leaders to have the physical skills to engage with children in outdoor pursuits in rural settings and to be able to anticipate and meet children's safety needs. Access to qualified and trained personnel was also viewed by parents as providing opportunities for respite knowing their children with ASD were actively engaged and supervised in a healthy and safety promoting manner.

4. Discussion

4.1. Key findings and implications

The findings of this study highlight how parents experienced wide-ranging safety concerns related to their children's special interests, risky behaviors, social vulnerabilities, and the presence of hazards prominent in rural settings. Thus, parents feared recreational participation could place their children with ASD in harms way due to their unique autism related characteristics and challenges as well as the particular hazards present in outdoor areas. These hazards and risks present in their rural communities accentuated their concerns and parents expressed a range of solutions to mitigate these concerns.

Among the parent concerns, child elopement caused particular worry due to the seriousness of the potential consequences and resulted in the curtailment of children's recreation activities. These findings are consistent with a US study that reported the occurrence of elopement amongst close to half of children with ASD (49 %) in the sample. Of those that eloped, 26 % were in situations that caused parent concern, with 24 % and 65 % reported in danger of drowning or being injured in traffic (respectively) (Anderson et al., 2012). In the current study, parents voiced strong fears about child elopement that could result from inadequate supervision during organized recreational activities and that could seriously jeopardize their children's safety. These concerns of caregivers in rural settings were found to be related to unique features of rural settings such as proximity to major highways and abundance of bodies of water, concerns that are justified given the substantial risk to children with ASD for bodily harm from traffic injury, drowning, or even death (Anderson et al., 2012). Parents' elopement concerns were closely linked to their expressed desire for adequate monitoring and supervision by recreation personnel of their children while taking part in organized programs and also to their wishes for access to enclosed and secure play spaces for their children. These suggestions from parents warrant consideration of educational strategies to ensure that those working with children with ASD in recreation settings complete training on working with this vulnerable population. Future research studies should address elopement behavior among children with ASD. This is a topic on which numerous clinically-based studies exist, but there is little research on strategies that can be implemented by families in community-based settings. Furthermore, strategies to ensure safe design of play spaces could include policy directions for community spaces to include secure areas where children with ASD can play without parents enduring constant fears about their elopement behaviors. A further suggestion for research is for study on the use of inclusive design principles to promote recreation activity for children with disabilities including ASD (Fernelius, 2017). Finally, participatory strategies have been used for the design of products for children with ASD (Benton & Johnson, 2014) and may hold potential for the design for safe and inclusive play space.

Parents in this study were also concerned about their children's possible interactions with wildlife in rural areas. There were no specific solutions suggested by parents to address this concern, however, further research on this topic may be fruitful to assess the learning needs that parents have about wildlife in their communities, and how community organizations might develop wildlife education programs to address such concerns and adapt this material to suit children with ASD.

Parents in the study also described how children's social vulnerabilities comprised additional barriers to recreation participation. Children with ASD often display social interactions and communication difficulties with disruptive behaviors. This is similar to findings that social interaction challenges are important for recreation participation for children with ASD (Little, Sideris, Ausderau, & Baranek, 2014; Obrusnikova & Miccinello, 2012). Parents voiced their perceptions that a general societal lack of awareness and understanding of ASD often resulted in their children's autism behaviors being misunderstood and this left families feeling unsupported and excluded by other community members. These findings resonate with other qualitative study findings reporting challenges with lack of support and exclusion faced by parents with children with ASD (Ludlow, Skelly, & Rohleder, 2012). In contrast, parents also reported how they believed that their rural communities comprised a safe place for their children since people in the community knew each other. This reflected a tension whereby parents described both social fears from strangers in the community as well social support and a sense of safety from those they knew and could trust as part of their safety planning. As Valentine (1997) argues, conceptions of childhood play in rural areas can be construed by parents as both safe and carefree as well as being a place of danger and vulnerability. Valentine (1997) suggests these conceptions can co-exist and reflect multiple meanings about parenting in rural settings. The findings of this study reflect these complex notions and point to the need to acknowledge that parents may have contradictory views that may be reflected in in their restrictions or encouragement of children's recreation participation.

The findings also highlighted the varied strategies and adaptations that parents/families used to take charge and promote their child's safe recreation participation. Parents described their oftentimes intensive involvement with their children's activities that helped to integrate their children more effectively in recreational activities while providing them familiar one-to-one support and high levels of supervision. Similarly, Gregor et al. (2018) report in their Canadian study focused on physical activity participation among adolescents with ASD living in urban settings that organized recreational activities required parents to hire private supports to allow their child's participation, which was only possible if families could afford to take such measures. In our study, parents who had enrolled their children in programming highlighted the lack of access to trained or qualified personnel to effectively address their children's needs suggesting needs for practice and policy changes in community programs. For example, recreation department policy could address appropriate ratios for children in their programs, as well as mandated training for personnel who work with children with ASD. Having high ratios of coaches to participants is important for supporting individualized approaches to participation for those with ASD (Rosso, 2016) and access to support and training for coaches is also critical (Ohrberg, 2013; Rosso, 2016). Furthermore, online training programs hold promise for building knowledge and skills among qualified personnel across various disciplines (e.g. recreation, ASD therapy providers) and can also address cost and accessibility barriers (McNamara, Bittner, & Healy, 2020).

The findings also showed that some parents promoted their child's outdoor independence through the development and rehearsal of individualized proactive safety plans that were consistent with their perceptions of their rural communities as safe places with

strong and familiar social networks. Practice implications for this finding is that health, recreation, and service providers could work more closely with families to develop child-specific safety plans that promote the child's independence and inclusive recreational participation. Murphy and Carbone (2008) recommend the need to implement strategies through pre-participation evaluation and activity adaptation prior to activity participation to minimize the risk of injury to children with various disabilities. Solomon and Lawlor (2013) also suggest training for practitioners to recognize parents' descriptions of children's elopement behavior and triggers so tailored advice may be promptly provided. This advice could focus specifically on the importance of safety planning. Autism Speaks (2019), an American leading national organization, currently offers online resources on summer recreation safety and creating safety plans. This approach could be adapted for the Canadian context with rurality as a priority due to some of particular risks associated with hazards and outdoor environments identified in this study. Implementation of collaborative safety planning between families and recreational providers to promote activity participation would also enhance the broader rural community's awareness and understanding of ASD.

4.2. Limitations and future directions

This study builds on the limited existing body of literature on parents' perspectives of recreational participation amongst children living with ASD in rural settings. This study provides useful and unique insights about parental safety-related experiences with facilitating recreation for their children along with their perspectives about needed practical changes in the community settings to address their needs. These contributions are consistent with the practical implications that an approach using interpretive description can provide.

Some limitations of this study include that the majority of study participants were Caucasian; given this, future research with greater cultural and ethnic diversity including Indigenous caregivers would be valuable. Secondly, only two fathers participated in this study, and therefore future studies should include broader considerations of gendered perspectives. Also, given the qualitative nature of the study with the small sample size of 12 participants, comparisons across the target children and their diverse spectrum of needs related to ASD were not included. Moreover, in this study we did not classify children according to the severity of their autism symptoms and functioning. Ascertaining this in future studies with a validated tool to complement qualitative data collection would be a helpful strategy to use.

Future research should include studies that consider the diversity of support needs for children/youth with ASD and consist of larger more varied samples of participants reflecting different levels of ASD severity. A mixed methods study that includes parents' experiences promoting safe and active recreation along with objective findings of their children's functional status and individual needs would provide additional insights. Furthermore, studies that focus on training and educational interventions for recreation providers should assess the barriers and facilitators to implementing in-person programs in rural settings for children with ASD. Due to the likely higher costs associated with in-person program delivery and to recognize the recent restrictions for in-person programming due the COVID-19 pandemic, it is also critical to develop and evaluate distance-based or online strategies that could provide needed resources for both providers and parents.

5. Conclusion

This study highlights parental experiences and expressed needs for promoting safe recreation participation for their children living with ASD in rural settings. Practical strategies for addressing these needs that can be implemented at community and recreation program levels have been suggested. This research offers new understanding of parents' perspectives and the unique safety concerns surrounding recreational participation for their children with autism in rural contexts. Moreover, this study represents a family-centred voice reflecting rural perspectives and provides a novel contribution to the literature. These findings provide an important foundation for future program and policy development to support families and children living with ASD to engage in recreation and sport in their communities. Improved participation in recreation can contribute to the health, safety, and quality of life of children with ASD and their families. Future directions for research are also suggested. Children living with ASD should have opportunities to experience safe inclusive recreation no matter their differing abilities, needs, or settings in which they live.

Author statement

CS conceptualized the study with assistance from LO. CS was responsible for data collection and management. Formal analysis was conducted by CS with assistance from LO, RH, and KR. Funding was secured by LO. Initial writing was completed by CS with input from LO, RH, and KR. Review and editing was completed by all authors.

Declaration of Competing Interest

The authors of this manuscript report no actual or potential conflicts of interest.

Acknowledgements

The authors would like to thank the rural parent participants for their time and contributions. The Social Sciences and Humanities Research Council of Canada provided funding for this study.

References

Anderson, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics, 130*(1), 870–877. https://doi.org/10.1542/peds.2012-0762.

Autism Speaks. (2019). *Creating safety plans for people with autism*. Retrieved from https://www.autismspeaks.org/creating-safety-plans-people-autism?utmsource=email&utm_medium=text-link&utm_campaign=espeaks.

Ayvazoglu, N., Kozub, F., Butera, G., & Murray, M. (2015). Determinants and challenges in physical activity participation in families with children with high functioning autism spectrum disorders from a family systems perspective. *Research in Developmental Disabilities, 47*(1), 93–105. https://doi.org/10.1016/j.ridd.2015.08.015.

Benton, L., & Johnson, H. (2014). Structured approaches to participatory design for children: Can targeting the needs of children with autism? *Instructional Science, 42*(1), 47–65. https://doi.org/10.1007/s11251-013-9297-y.

Borremans, E., Rintala, P., & McCubbin, J. A. (2010). Physical fitness and physical activity in adolescents with Asperger syndrome: A comparative study. *Adapted Physical Activity Quarterly, 27*(4), 308–320. https://doi.org/10.1123/apaq.27.4.308.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(1), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Corvey, K., Menear, K. S., Preskitt, J., Goldfarb, S., & Menachemi, N. (2016). Obesity, physical activity and sedentary behaviors in children with an autism spectrum disorder. *Maternal and Child Health Journal, 20*(2), 466–476. https://doi.org/10.1007/s10995-015-1844-5.

Curtin, C., Anderson, S. E., Must, A., & Bandini, L. (2010). The prevalence of obesity in children with autism: A data analysis using nationally representative data from the national survey of children's health. *BMC Pediatrics, 10*(1). https://doi.org/10.1186/1471-2431-10-11, 11-11.

Fernelius, C. L. (2017). *Evidence-based practices for the design of inclusive playgrounds that support peer interactions among children with all abilities* [Master's thesis, Utah State University], All Graduate Theses and Dissertations. 6809. Retrieved from https://digitalcommons.usu.edu/etd/6809.

Gregor, S., Bruni, N., Grkinic, P., Schwartz, L., McDonald, A., Thille, P., … Jachyra, P. (2018). Parents' perspectives of physical activity participation among Canadian adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders, 48*(1), 53–62. https://doi.org/10.1016/j.rasd.2018.01.007.

Hilton, C. L., Crouch, M. C., & Israel, H. (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *American Journal of Occupational Therapy, 62*(5), 554–563. https://doi.org/10.5014/ajot.62.5.554.

Hochhauser, M., & Engel-Yeger, B. (2010). Sensory processing abilities and their relation to participation in leisure activities among children with high-functioning autism spectrum disorder (HFASD). *Research in Autism Spectrum Disorders, 4*(4), 746–754. https://doi.org/10.1016/j.rasd.2010.01.015.

Hoogsteen, L., & Woodgate, R. L. (2013). Embracing autism in Canadian rural communities. *The Australian Journal of Rural Health, 21*(3), 178–182. https://doi.org/10.1111/ajr.12030.

Jachyra, P., Renwick, R., Gladstone, B., Anagnostou, E., & Gibson, B. E. (2020). Physical activity participation among adolescents with autism spectrum disorder. *Autism, 25*(3), 1–14. https://doi.org/10.1177/1362361320949344.

Jain, A., Spencer, D., Yang, W., Kelly, J. P., Newschaffer, C. J., Johnson, J., … Dennen, T. (2014). Injuries among children with autism spectrum disorder. *Academic Pediatrics, 14*(4), 390–397. https://doi.org/10.1016/j.acap.2014.03.012.

Krauss, H., Buraczynska-Andrzejewska, B., Piatek, J., Sosnowski, P., Mikrut, K., Glowacki, M., … Zwolinski, J. (2012). Occurrence of neurotic and anxiety disorders in rural schoolchildren and the role of physical exercise as a method to support their treatment. *Annals of Agricultural and Environmental Medicine, 19*(3), 351–356.

Lee, L., Harrington, R. A., Chang, J. J., & Connors, S. L. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities, 29*(3), 247–255. doi:10.1016éj.ridd.2007.05.002.

Li, D., Larsen, L., Yang, Y., Zhai, Y., & Sullivan, W. C. (2019). Exposure to nature for children with autism spectrum disorder: Benefits, caveats, and barriers. *Health & Place, 55*, 71–79. doi:10.1016éj.healthplace.2018.11.005.

Little, L. M., Sideris, J., Ausderau, K., & Baranek, G. T. (2014). Activity participation among children with autism spectrum disorder. *American Journal of Occupational Therapy, 68*(2), 177–185. https://doi.org/10.5014/ajot.2014.009894.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 15*(5), 702–711. https://doi.org/10.1177/1359105311422955.

McNamara, S., Bittner, M., & Healy, S. (2020). Online training for physical activity practitioners on evidence-based practices for clients with autism. *Advances in Autism*. https://doi.org/10.1108/AIA-04-2020-0026. Advance online publication.

Mello, M. P., Goldman, S. E., Urbano, R. C., & Hodap, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural with non-rural communities. *Education and Training in Autism and Developmental Disabilities, 51*(4), 355–365.

Moore, J., Jilcott, S., Shores, K., Evenson, K., Brownson, R., & Novick, L. (2010). A qualitative examination of perceived barriers and facilitators of physical activity for urban and rural youth. *Health Education Research, 25*(2), 355–367. https://doi.org/10.1093/her/cyq004.

Murphy, N. A., & Carbone, P. S. (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *American Academy of Pediatrics, 121*(5), 1057–1061. https://doi.org/10.1542/peds.2008-0566.

Obrusnikova, I., & Miccinello, D. L. (2012). Parent perceptions of factors influencing after school physical activity of children with autism spectrum disorders. *Adapted Physical Activity Quarterly, 29*(1), 63–80. https://doi.org/10.1123/apaq.29.1.63.

Ohrberg, N. J. (2013). Autism spectrum disorder and youth sports: The role of the sports manager and coach. *Journal of Physical Education, Recreation & Dance, 84*(9), 52–56. https://doi.org/10.1080/07303084.2013.838118.

Polfuss, M., Johnson, N., Bonis, S., Hovis, S., Apollon, F., & Sawin, K. (2016). Autism spectrum disorder and the child's weight-related behaviors: A parents' perspective. *Journal of Pediatric Nursing, 31*(6), 598–607. https://doi.org/10.1016/j.pedn.2016.05.006.

Potvin, M., Prelock, P. A., & Snider, L. (2008). Collaborating to support meaningful participation in recreational activities of children with autism spectrum disorder. *Topics in Language Disorders, 28*(4), 365–374. https://doi.org/10.1097/01.TLD.0000341129.01158.bb.

Potvin, M., Snider, L., Prelock, P., Kehayia, E., & Wood-Dauphinee, S. (2013). Recreation participation of children with high functioning autism. *Journal of Autism and Developmental Disorders, 43*, 445–457. https://doi.org/10.1007/s10803-012-1589-6.

Rosso, E. G. F. (2016). Brief report: Coaching adolescents with autism spectrum disorder in a school based multisport program. *Journal of Autism and Developmental Disorders, 46*(7), 2526–2531. https://doi.org/10.1007/s108003-016-2759-8.

Schleien, S., Miller, K., Walton, G., & Pruett, S. (2014). Parent perspectives of barriers to child participation in recreational activities. *Therapeutic Recreation Journal, 47*(1), 61–73.

Solomon, O., & Lawlor, M. C. (2013). "And I look down and he is gone": Narrating autism, elopement and wandering in Los Angeles. *Social Science & Medicine, 94*(1), 106–114. https://doi.org/10.1016/j.socscimed.2013.06.034.

Statistics Canada. (2016a). *Census profile*. Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E.

Statistics Canada. (2016b). *Population centre*. Retrieved from http://www12.statcan.gc.ca/census-recensement/2011/ref/dict/geo049a-eng.cfm.

Thorne, S. (2020). The great saturation debate: What the 'S word' means and doesn't mean in qualitative research reporting. *Canadian Journal of Nursing Research, 52*(1), 3–5. https://doi.org/10.1177/0844562119898554.

Thorne, S. (2008). *Interpretive description, Walnut Creek: California*. Left Coast Press.

Thorne, S. (2016). *Interpretive description* (2nd ed.). New York: New York. Routledge.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1–11. https://doi.org/10.1177/160940690400300101.

Tyler, K., MacDonald, M., & Menear, K. (2014). Physical activity and physical fitness of school-aged children and youth with autism spectrum disorders. *Autism Research and Treatment, 2014*(2014), 312163–312166. https://doi.org/10.1155/2014/312163.

Valentine, G. (1997). A safe place to grow up? Parenting, perceptions of children's safety and the rural idyll. *Journal of Rural Studies, 13*(2), 137–148. https://doi.org/10.1016/S0743-0167(97)83094-X.

Yousefian, A., Ziller, E., Swartz, J., & Hartley, D. (2009). Active living for rural youth: Addressing physical inactivity in rural communities. *Journal of Public Health Management and Practice, 15*(3), 223–231. https://doi.org/10.1097/PHH.0b013e3181a11822.