Autism and Physical Health Across the Lifespan

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Physical activity participation among adolescents with autism spectrum disorder

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Abstract

Adolescents with autism spectrum disorder are less physically active compared with their age-related peers. Despite the many benefits of physical activity, little is known about why they are predominantly inactive. To date, research has rarely included adolescent's perspectives, and little is known about how wider social, systemic, and policy forces shape physical activity. The purpose of this study was to explore the perceptions, meanings, and role of physical activity in the lives of adolescents with autism spectrum disorder, and draw on their experiences to examine how social and cultural processes shaped their participation. Ten adolescent boys with autism spectrum disorder created individual digital stories, and participated in two interviews. Thematic analysis was informed by a critical social science approach. The results highlight that bullying, challenges in community programs, and the prioritization of therapeutic interventions limited participation. Participation was maximized when physical activity generated meaning, purpose, a sense of identity, and affective pleasures. The study findings illuminate the complexity of physical activity participation which has not previously been described in the literature. The findings suggest potential value in promoting the affective pleasures of movement, along with facilitating social and systemic pathways to enhance physical activity participation.

Lay abstract

Adolescents with autism spectrum disorder are less likely to be physically active compared to their age-related peers. Despite the lower levels of physical activity observed among adolescents with autism spectrum disorder, it is unknown why they are predominantly inactive. Much of the research so far has focused on understanding how biological aspects influence physical activity participation. But there is little research that has examined how social and cultural components influence their physical activity participation. There is also little research that has sought the perspectives and experiences of adolescents with autism spectrum disorder. In this study, 10 adolescent boys with autism spectrum disorder created a digital story, and also participated in two face-to-face interviews. The purpose of the study was to examine how individual, social, and cultural forces influenced physical activity participation. Analysis of the data highlight that bullying, challenges in community programs, and the prioritization of therapeutic interventions limited participation. On the contrary, participants were more likely to be active when physical activity generated meaning, purpose, a sense of identity, and affective pleasures. The findings add new knowledge suggesting that adolescents with autism spectrum disorder are not simply unmotivated. Rather, physical activity participation was shaped by wider social experiences, norms, values, and practices in which they were immersed. The findings suggest a need for directed efforts to create policies and practices which are individualized and reflective of the needs and abilities of adolescents with autism spectrum disorder to promote physical activity participation and potentially enhance physical health and wellbeing.

Keywords

autism spectrum disorder, physical activity, adolescents, physical health, qualitative research, digital storytelling

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Introduction

Research consistently suggests that physical activity (PA) participation for children and adolescents (hereafter adolescents) with autism spectrum disorders (ASD)[1] can present a number of physical, psychological, and social benefits. In this vein, intervention research suggests that PA can improve motor skills and motor control (Ketcheson et al., 2018), enhance overall fitness and physical health (Lang et al., 2010), and improvements in sleep quality (Tse et al., 2019). In addition, PA participation can also contribute to psychological wellbeing with observed reductions in stress and anxiety (Lochbaum & Crews, 2003), and decreases in self-injurious (Sowa & Meulenbroek, 2012) and self-stimulating behaviors (Sorensen & Zarrett, 2014). Finally, PA has been associated with improving social and communication skills (Dillon et al., 2016), along with facilitating inclusion in the community (Gregor et al., 2018).

Despite the many benefits of PA, research suggests that children with ASD are predominantly inactive (Healy et al., 2017; Pan et al., 2016). In this vein, children with ASD often do not meet the recommended guidelines (Bandini et al., 2013) of 60 min of daily participation, and become even less active during adolescence (Pitchford et al., 2013). Compared with their age-related peers, McCoy et al (2016) highlighted that adolescents with ASD were 60% less likely to participate in PA, and 74% less likely to participate in an organized sport. Not only are adolescents with ASD less likely to benefit from the many positive aspects of activity described above, but inactivity can also potentially contribute to negative physical health outcomes observed in the general population such as increased risks for obesity, cardiovascular disease (Biddle & Asare, 2011), diabetes, pain, and musculoskeletal disorders (Jansen & LeBlanc, 2010). Although inactivity in isolation does not causally confer poor health, lower levels of PA among individuals with ASD in particular can potentially be problematic as they are at increased risks for co-occurring physical health and psychiatric illnesses (Hwang et al., 2019) and their sequelae across the lifespan. Given the numerous benefits of PA outlined above, there is a need therefore to understand why adolescents with ASD are predominantly inactive, and to understand how to facilitate their participation.

To date, much of the PA research among adolescents with ASD has focused on PA measurement, along with the characteristic impairments of ASD that influence participation (MacDonald et al., 2011). To this end, research has predominantly focused on examining how somato-motor (balance, gait, postural stability, and joint flexibility) and behavioral (motivation, perceived skill competence, interest, and hyperactivity) dimensions influence PA (Eversole et al., 2016; Loprinzi et al., 2015; Ostfeld-Etzion et al., 2016). While the aforementioned research is important in its aims of enhancing PA, qualitative investigations of adolescents' perceptions toward PA is a significantly neglected area of inquiry. Yet, there is a pressing need for this research as little is known about the role, meanings, and processes that shape PA participation. Directly engaging and partnering with adolescents with ASD has the potential to generate rich insights informing how to design interventions, programs, supports, and policies that are reflective of their lives, needs, and abilities.

Not only is there a lack of research that has examined the perspectives of PA among adolescents with ASD, but research that has examined how PA is influenced beyond the level of individual physical impairments (gross-motor deficits and sensory factors) also is sparse. Apart from our own preliminary work (Campos et al., 2019; Jachyra, 2020), there is a dearth of research that has critically theorized, and examined how broader social, cultural, community, and public policy forces (hereafter socio-behavioral processes) influence PA. However, examining how socio-behavioral processes shape participation can elicit novel and original insights to understand how wider social and cultural processes converge with biological and psychological dimensions to shape PA participation. Recognizing that PA participation among adolescents with ASD is complex and requires addressing barriers at individual, environmental, and systemic levels (Jachyra, 2020), there is a need for this work to examine the complexity of physical (in)activity.

Given the knowledge gaps described above, the purpose of this qualitative study was to explore (a) the attitudes, beliefs, conceptualizations, and experiences of PA participation among adolescents with ASD and (b) draw on their experiences to examine how socio-behavioral processes enhance, shape, and/or curtail their participation.

Study design

Sampling and recruitment. The research described in this article is a part of a series of studies exploring how to best support PA participation among adolescents with ASD by directly working with adolescents (Jachyra, 2020), caregivers (Gregor et al., 2018), and healthcare providers (Campos et al., 2019). In this study, adolescents with ASD were recruited from a major urban Canadian city. Adolescents were invited to participate in the study if they (a) had a diagnosis of ASD as per the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) criteria (American Psychiatric Association, 2013), supported by the Autism Diagnostic Observation Schedule (Lord et al., 2012); (b) were aged 12–19 years; (c) demonstrated verbal proficiency in English by utilizing language as understood by strangers; (d) were capable of taking turns during a discussion and had the ability to participate in a discussion to share their thoughts; and (e) demonstrated the capacity to provide consent to participate in the study.

Each prospective participant was initially screened with their caregiver through a telephone conversation to ensure eligibility, and to assess whether participants would be

comfortable participating in the interview components of the study. To assess verbal proficiency, prospective participants were asked to describe whether they had a favorite activity or interest of any sort, and also were asked to describe any activities they engaged in on that particular day. Throughout these extended conversations, question starters such as "what did you do today" or "do you have any pets at home" were used as needed to facilitate discussion with prospective participants. To support participants as best as possible, the primary author spoke with the caregiver of each prospective participant prior to the screening phone call to establish any communication preferences, styles, and modes of communication that might help facilitate discussion with the participant. With these supports in place, prospective participants who met the study inclusion criteria, and were able to engage in extended discussions were invited to participate in the study. Suitability to participate in the study was reassessed during the first in-person meeting, and consent was sought from each participant who agreed to participate. The research study was approved by the Research Ethics Board at the hospital where recruitment took place, and the associated university health sciences research ethics board. The results of this work are reported elsewhere (see Jachyra, 2020).

Conceptual framework. The study utilized a qualitative design and was driven by a critical social science approach. Critical approaches examine the interplay between personal and environmental forces, examining how individual (behaviors, perceptions, and experiences) and microlevel interpersonal factors (social networks) are contoured by broader macrolevel (social, institutional, community, and public policy) forces. In this vein, critical approaches acknowledge interdependent recursive relationships between the micro and macrolevel (Eakin et al., 1996), and this dialectical approach seeks to examine how social structures, and social norms influence people's daily lives, what people think and do, and what they imagine is possible (Kincheloe & McLaren, 2005). A critical approach was adopted in this study to move beyond merely describing the barriers and facilitators of participation. By adopting a critical approach, we sought to examine how microlevel, or individual PA perceptions/experiences interconnect with macrolevel social structures, values, and beliefs at the social systems level to shape PA participation (Jachyra & Fusco, 2016).

Methodology and methods. In total, 10 adolescents (see Table 1 for participant characteristics) participated in the creation of digital stories, and two face-to-face semi-structured interviews (see Jachyra, 2020 for an in-depth description of research methods). Reflecting the heterogeneity of ASD, the strengths, needs, interests, and abilities among participants varied greatly. Eight participants had an intelligence quotient (IQ) score of above 70, and two participants had an IQ score below 70. Among the study participants, some adolescents possessed highly advanced vocabularies and technical skills, and did not outwardly experience challenges when participating in the creation of digital stories. Other variations in abilities were observed during the interviews, where some participants required little support to participate in the discussions, while others benefited from prompting, further explanations, and/or breakdown of interview questions.

Table 1. Participant characteristics.

Name	Age	Self-described PA status	PA frequency per week
Manuel	15	Highly active	3–4 times/week
Malcolm	18	Predominantly inactive	1–2 times/week
Mark	17	Highly active	5–6 times/week
Allan	12	Predominantly inactive	0–2 times/week
Seper	14	Highly active	3–4 times/week
Daniel	13	Highly active	3–4 times/week
Miguel	18	Predominantly inactive	1–2 times/week
Jas	12	Predominantly inactive	0–2 times/week
Guido	15	Predominantly inactive	0–2 times/week
Romeo	13	Predominantly inactive	1–2 times/week

PA: physical activity.

In this study, each participant created a digital story. Digital storytelling combines first-person audio narration, music, video clips, artwork, photographs, text, and drawings to create short, evocative, and engaging stories (Gladstone & Staslius, 2019). Digital storytelling was strategically selected for several reasons. First, it provided participants with a mode of expression (in the form of a visual medium) that creatively captured their everyday lives, meanings, practices, and PA experiences. Second, given the highly participatory nature of creating digital stories, digital storytelling was selected as we sought to provide participants with an opportunity to potentially develop new strengths, interests, insights, and skills. Third, digital storytelling was selected as a tool to build rapport given the multiple participant interactions over a significant period of time. By creating rapport, we sought to facilitate the creation of rich data in a safe and enjoyable manner. Fourth, digital storytelling was selected as a tool to generate a form of analyzable data to meet the study objectives. Fifth and finally, digital storytelling was selected as it was a flexible research method that could be tailored to the diverse needs and abilities of adolescents with ASD. For example, when creating digital stories, some participants were highly independent and did not require much support from the workshop facilitators or the primary author. Other participants experienced challenges with verbal and nonverbal communication and interactions, challenges with restricted/repetitive interests, and benefited from additional support such as assistance with conceptualizing or writing the script for the digital story, and/or implementing the technical aspects associated with digital storytelling. The flexibility of the

method, however, enabled the primary author to offer support where and when needed, and his role varied greatly throughout the workshop. For example, at times, the primary author was simply off to the side observing the interactions among participants and facilitators. At other times, the primary author was directly working together with participants to co-construct their story board, and/or write out their scripts for the voiceover narration. The flexibility in roles highlights the importance of using flexible methodological approaches and adaptions that are reflective of, and suitable to the diverse needs and abilities of adolescents with ASD.

Digital stories were created at a digital storytelling center, and were guided by expert digital storytelling facilitators. Digital stories were created over the course of three workshops. Each workshop was 5 h in duration, and the three workshops were held over a 6-week period. Prior to the first workshop, participants were asked to take photos, videos, and go through existing personal archives (photos, drawings) to find artifacts that remind them of PA, and they were asked to bring these artifacts to the first workshop. The first workshop commenced with a story circle in which the facilitators introduced the history of digital storytelling, and explained the principles of digital storytelling developed by the Centre for Digital Storytelling in Berkeley, California (see Burgess et al., 2010). During this workshop, workshop facilitators also played a few sample digital stories to help participants conceptualize the type of story they would be interested in creating. The first workshop culminated with participants working with workshop facilitators to brainstorm what sort of story they sought to tell.

During the second workshop, participants further brainstormed the story they were interested in producing, and worked to determine which pictures and videos they would include in their digital story. After selecting the different mediums to be used, they worked with workshop facilitators to create a visual storyboard that outlined the order in which these visual mediums would fit into their digital stories. Over the course of the second workshop, participants also wrote out a script that would narrate and accompany the visual and digital elements of their story. For the third and final workshop, participants used computer software to add the voiceover narration to the story along with music and sound effects. As part of the editing processes, adolescents adjusted the timing of all visual (pictures/videos) and nonvisual (voiceover narration and sound effects) elements to ensure that all elements were synchronized. The final workshop concluded with a story circle in which participants shared their stories, and discussed their enjoyment and experience of participating in the workshops.

To capture the primary author's fluid and evolving participation in the digital storytelling workshops, detailed field notes were written by the primary author. These field notes captured the interactions observed among participants, workshop facilitators, and the researcher (Jachyra et al., 2018). Field notes in turn added more depth, breath, context, and nuance to the observed interactions, and were used as a data source as part of the analysis (Jachyra et al., 2019).

In addition to creating digital stories, each participant engaged in two face-to-face in-depth interviews ($n=20$ interviews). Interviews were conducted prior to, and after producing the digital stories, and were conducted at a location of their choosing. In an effort to reduce potential stress and anxiety of the interview, participants had the option of including their parents in the interview as support persons. For one participant, including his mother in the interview helped to calm him down such that the participant seemed to be initially very anxious as he was very restless, and also was very soft spoken with a quiver in his voice. The initial trepidation of the interview changed, however, as soon as his mother sat down beside him where he seemed to be more relaxed as he sat still, and his voice transitioned into a more relaxed tenor. In addition to relieving anxiety, including parents as support persons also helped facilitate the recall of life events and experiences. During our interview, one parent helped facilitate discussion using verbal prompts such as "Tell Patrick about the time when you went bike riding with your dad" and "What activities did you do last week." These prompts in turn helped ease this particular participant into the interview, and also served as a point of departure for further discussion. In total, 2 of 10 parents (all mothers) were present during both interviews, and the remainder of participants (8 of 10) were interviewed independently. Notably, however, parents were not considered as participants in the study.

The first interview with each participant was designed to build rapport, and to learn about the intricacies of their everyday lives both within, and beyond the PA context. Questions were guided by a semi-structured interview guide (See Appendix A) which was designed to elicit discussion about daily and weekly routines, interests in activities/hobbies. The guide was used as a tool to guide conversations (Jachyra, Atkinson, & Washiya, 2015), and the interviews were between 60-90 minutes in duration. As suggested by Jachyra et al. (2014), the interview guide was adapted to each participant's interests, but was not used rigidly. Field notes were immediately written following each interview to detail the interview setting; tone of language, interactions with participants, and reflexive notes were also written which captured initial analytical insights.

The second interview was created after the creation of digital stories, and the interviews were 90-120 minutes in duration. Interviews commenced by watching the digital story created by each participant who was then asked to describe why they included particular images/videos in his digital story. This initial discussion also focused on discussing the personal meaning(s) of the digital story. This interviewing approach served as an elicitation technique to generate rich discussions about perceptions, meanings, experiences, and the role of PA in their lives. Whereas each

method generated novel and original insights into PA participation, combining these methods revealed complexity, contradiction, and insights into the daily lives of adolescents with ASD that would likely have not been gleaned by solely interviewing participants alone. The combination of digital stories and interviews in turn enabled an in-depth analysis of how interdependent macrolevel and microlevel forces interacted to enhance, shape, and curtail PA participation.

Data analysis

All qualitative data (verbatim interview transcripts ($n=20$) digital stories ($n=10$) field notes from each interview ($n=20$) and field notes from each digital story ($n=3$) workshop) were analyzed thematically. Analysis was driven by techniques described by Miles and Huberman (1994). Analysis was led by the primary author (who was a doctoral candidate and a former physical education teacher), and supported by the research team with expertise in childhood neurology, autism research, qualitative methodology, intellectual disability, occupational therapy, and critical disability studies. An analytic guide derived from the research questions, aims of the study, and the overarching critical social science approach was used to guide data analysis and interpretation.

Analysis commenced by repeatedly viewing each digital story created by participants. Analysis of the digital stories was guided by Gibson's (2005) procedures for analyzing video accounts to help examine how each digital story was constructed. Five analytic questions were used to gain a better understanding of participants' daily lives both within, and beyond PA:

> What audience is the digital story directed to? How are identities being portrayed by participants? Who was involved in directing the video, and what does this reveal about the participant and/or his relationship? What role(s) does the participant express or perform? What was not included in the digital story, and why? (Gibson, 2005)

When reflecting on these five analytic questions, field notes from the three digital storytelling workshops were also read several times to add more context, depth, and breadth to the process of analysis and interpretation. Preliminary thoughts from analysis of the digital stories and field notes were captured in a narrative summary written for each participant.

After analyzing the digital stories, interview transcripts from the two interviews, and field notes from each interview were read multiple times to develop a sense of the whole (Sandelowski, 1995). While reading the transcripts and field notes for each participant, inductive coding was used to analyze the frequency, location of activities, type of PA participation; beliefs and representations of PA; structure of their daily lives; family interactions; and whether they participated in group based or independent settings. Codes generated from each participant's data were clustered together to create larger thematic categories. Overarching thematic categories were then integrated into the individual narrative summaries written during analysis of digital stories. Narrative summaries written during analysis of digital stories and interviews described the perceptions, meanings, and role of PA for each participant, which addressed the first purpose of the study. To analyze how sociocultural processes enhanced, shaped, and curtailed PA participation (second purpose of the study), analysis continued by noting patterns, contradictions, and postulations within each participant summary. Narrative summaries were then compared and contrasted with those of the other participants (cross-analysis) to provide new ways of seeing and analyzing the data and to take data in fertile and unexpected directions (Smith & Sparkes, 2016). Multiple cross-analysis cycles (Jachyra, Atkinson, & Bandiera, 2015) were conducted to identify recurring patterns, contradictions, and relationships to examine how the confluence of macro and microlevel forces shaped PA participation. Analysis was considered complete when the two main themes were established.

Results

The analysis generated two overarching themes: *learning to be inactive* and the *pleasures of movement. Learning to be inactive* highlights how exclusion and bullying, challenges in community programs, and how the prioritization of therapeutic interventions curtailed PA participation. Whereas these socio-behavioral processes dissuaded participation, the second theme illustrates the forces that enhanced participation. *Pleasures of movement* illustrates how affective dimensions of PA, and PA as a quest for excitement increased predilection for participation. Notably, these dimensions of PA were shaped by one's family identity and PA experiences. These interconnections are described below. Similar to the wide-ranging abilities, participants engaged in a wide range of activities throughout their lives and engaged in various individual and group-based activities. For example, some participants engaged in gardening, walking, riding a bike, sports, and swimming. Others engaged in yoga, dancing, or fitness exercises such as lifting weights or jogging. Notably, PA was not deployed as a therapeutic modality among study participants. As described in the results below, their participation varied greatly throughout their lives. To protect the identity of participants, pseudonyms selected by participants are used.

Learning to be inactive

Exclusion and bullying

Narratives of exclusion and bullying recurrently came to the "fore" in participant interviews. For seven participants, exclusion and bullying occurred predominantly in

school-based health and physical education class (HPE), and was most pervasive in secondary school (14–18 years of age). Across the accounts were stories of both covert and overt forms of exclusion. Covert forms of exclusion were subtle in nature such as being selected last by their peers when teams were being formed for class scrimmages. For instance, Guido noted that he is "usually one of the last guys in the draft, and have never been chosen first in my life." Some adolescents also experienced overt exclusion, where at times, peers would preclude their participation by substituting adolescents with ASD for another player, or they would not be substituted into activities at all. Not only did covert and overt forms of exclusion limit participation, exclusion was tied into physical forms of bullying. Seven participants described being hit in the face or groin when playing dodgeball, or being deliberately tripped when participating in class warm-up activities. Other forms of physical bullying included being "body checked to the ground when playing ball hockey" (Allan). Although teachers often intervened and reminded peers that physical body contact was prohibited, relief from bullying often was temporary as bullying was a recurring issue. Given these repeated experiences, perhaps it is unsurprising that participants described feeling as if they were proverbial outsiders in class, and at times felt that they did not belong in HPE. Highlighting the impacts of exclusion and bullying, Guido noted:

> Teachers tell them (peers) to aim below the waist, but they do what they want anyway. It's hard to like gym when you feel like an alien on the wrong planet, like you feel as if you do not belong in gym class, and feel like you are being targeted. Gym just sucks and I hate it.

Physical bullying was often accompanied by verbal taunting, belittlement, and jeers. Although the magnitude and frequency of verbal bullying in HPE varied across participants, seven participants noted that jeers occurred mostly frequently when there were no teachers in the immediate surroundings. These adolescents were often derided about their (in)ability to execute physical skills and drills in HPE. Derision at times was relatively subtle. For example, Allan recalled one of his peers laughing at him and saying that he "throws like a girl, and plays soccer with two left feet." At other times, however, derision was much more poignant, and was especially pronounced if study participants made a performance error that contributed to their team losing an activity. With recollections of HPE experiences from participants suggesting that there was an emphasis on competition, winning, and excellence in physical skills, HPE at times served as a breeding ground for taunting and belittlement. Recollecting a time when he did not score a goal on an empty net and contributed to his team losing in the final game of the class soccer tournament, Romeo's narrative highlights how these particular participants did not fit into these traditional HPE systemic structures and experienced bullying:

> One of the guys came up to me and said that I'm a retard, and a waste of space and am good for nothing. All because I did not score.

Problematically, the data suggest that repeated exclusion, bullying, and derision negatively impacted their enjoyment and experience of HPE. Across the seven participant accounts, participants described a general distaste toward HPE. To avoid exclusion, bullying, and derision, Romeo and Jas remarked that at times they would deliberately forget their HPE uniforms when the bullying was "really bad" (Jas) during the previous class. Moreover, Miguel noted that he would book meetings with his guidance counselor and special education teacher in order to avoid HPE class. Loathing HPE, Miguel and Guido described that at times when the bullying was no longer bearable, they had meltdowns to avoid going to school altogether. Therefore, exclusion and bullying had not only limited opportunities to be active, but also had debilitating impacts in other aspects of their daily lives. Lamenting his HPE experiences, and highlighting the impact of bullying on engagement, Allan noted:

> It's hard to enjoy being active when you're always being picked on. You just learn to hate activity. Like there is no point in going to class if all I get out of it is getting hurt.

Whereas a debilitating social climate in HPE negatively impacted participation, as illustrated below, the interaction of broader macrolevel social forces (such as availability of programs) interacted with microlevel processes (such as instructional approaches used in community-based PA activities) also contributed to inactivity.

Challenges in community programs

In discussing their PA participation from childhood to adolescence, study participants described difficulty locating adapted community-based activities that were responsive to their needs and abilities. Although participants generally engaged in integrated PA settings, the structure, design, and instructional methods employed at times dissuaded participation. For example, four participants described that PA activities predominantly focused on executing repetitive skills and drills such as dribbling a soccer or a basketball around pylons, or running laps around a gymnasium. Despite the potential value of teaching movement skills through repeated exposure, these four participants described that they were often bored and disengaged, as they spent more time waiting in line to perform these repetitive skills than time engaged in the activity. In addition to the use of autocratic coaching styles emphasizing skills and drills, the predominant use of verbal instructional strategies added an additional layer of

complexity for participants. Across the accounts, participants described difficulty comprehending large amounts of verbal instructions often shared at one time. Without breaking down the requisite movement patterns into a series of progressions, some study participants experienced what Miguel called "information overload" and had a very difficult time understanding, assembling, and then implementing instructions into movement patterns. When activities and methods of instruction were not adapted accordingly, PA was perceived to be "overwhelming" (Jas), "stressful" (Malcolm), and "unenjoyable" (Allan). Given these challenges, the combination of these forces in turn dissuaded participation. Highlighting how these contingencies impacted his participation, Jas noted:

> When I was a kid and did t-ball, the coach told me to keep my eye on the ball, so I put my actual eye on the ball. Turns out, that's not what he meant. I find activity overwhelming sometimes because there is so much new info, so much to remember, all at the same time. It's hard to find an activity and a place where I am comfortable with the activity, the teachers and can understand what they want me to do. I keep trying new activities, but keep quitting because they don't work for me.

Limited availability of PA programs was further complicated by policies from some service providers which mandated that personal support workers (PSWs, such as siblings, parents, or hired professionals such as behavior therapists, or recreation therapists) accompany adolescents. For example, despite locating an activity they were interested in, three study participants were withdrawn from community PA activities as service providers mandated that they be accompanied by a PSW. Although the reasons why these participants could not secure a PSW were manifold (such as cost, or trouble locating a PSW responsive to their needs), mandating external supports at the macrolevel of policy shaped their daily lives at the microlevel, by excluding them from participating. Although limited community opportunities and policy considerations in turn dissuaded their involvement, participation was also shaped by a recursive relationship between family values, and the prioritization of therapeutic interventions. It is to this discussion that we now turn.

Prioritization of therapeutic interventions

Across the accounts, participants highlighted that living with ASD presented unique strengths, opportunities, challenges, and additional activities such as participating in therapeutic interventions. In recollecting their childhoods, they noted that they had spent a substantial amount of their time during engaged in therapeutic interventions. From behavior therapy and occupational therapy, through to speech language pathology, participants described that their families (re) directed substantial amounts of their time and resources toward therapy during childhood. For six participants, therapy was ascribed social and familial priority such that participating in therapeutic interventions took precedence over other life activities, including PA. For example, Jas, Allan, Seper, and Daniel noted that they missed organized PA activities to attend therapy. Other participants noted that they were late, or left PA activities early in order to maximize the amount of time engaged in therapy. The accounts suggest that PA was not merely driven as an individual based behaviour, but rather individual dispositions interconnected with broader social determinants and family contexts such that caregivers were balancing multiple competing demands, family interests, and values. Capturing this complexity, Miguel remarked:

> As a kid, I did a lot of therapy, but not a lot of physical activity. Sometimes we would plan to do active things, but then my mom would tell me that the OT [occupational therapist] was coming. So then physical activity like always was just pushed off to the side. Not like once or twice, like all the time. It seemed like there never was enough time to do active things because therapy always got in the way and was more important.

With a predominant focus on intervention during childhood, there was often less time to develop sustained PA interests, habits, and patterns of participation. Given these time constraints, there was little consistency in their participation. Six participants described that participation entailed many starts, stops, and diversions as they were often withdrawn from PA to accommodate therapy, especially of government-funded therapies. Highlighting the complexity of and (sometimes unintended) privileging of therapeutic interventions, Guido's quote illustrates the complexity of inactivity:

> My parents put me in swimming, basketball, soccer, and t-ball. I would start activities for a few weeks but then they pulled me out as soon as they got me off the therapy waitlist. I never really developed an interest in anything, never really had the time or a chance to do so. Now, I am too afraid to try new things.

The theme learning to be inactive highlights that PA participation was a multifaceted and complex issue. As illustrated by the subthemes of exclusion and bullying, challenges in community-based PA, and the prioritization of therapy over activities, PA participation was shaped by socio-behavioral mechanisms interconnected at the macro and microlevel. Whereas the socio-behavioral processes described above dissuaded participation, the analysis suggests that the pleasures of movement drew adolescents toward PA. It is to this second theme that we now turn.

The pleasures of movement

Affective pleasures of movement

In analyzing perceptions and experiences of PA, the concept of pleasure recurrently came to the fore, and was multidimensional in nature. Affect and pleasure were not

dichotomous, but fundamentally interconnected, as participants noted that PA participation elicited a sense of joy, amusement, and made them "feel alive" (Miguel). When individual abilities aligned with social environments that met their needs, PA contributed to a spirit of fun and could elicit a sense of connectedness and belonging. For five participants, these affective dimensions contributed to both immediate and prolonged gratification, and shaped dispositions toward activity as they sought to (re)create these experiences in subsequent PA engagements. The interconnected nature of PA, and emotions, was illustrated in Allan's account:

> I had nothing until I found swimming. I felt like a complete misfit. When I found swimming that all changed. Swimming gives me a focus that I've never had, it is fun and it feels so good having the water on my skin. I feel tired after swimming, but that feeling also is what gets me coming back to the pool. I don't know what I would do without it now.

Further to these affective dimensions, PA also created an aura of exciting significance and served as a controlled form of emotional release. For some participants, PA provided an outlet from their relatively predictable, structured, repetitive, and prescriptive lives which often featured attending school, completing school/homework, and then doing it "all over again, the next day" (Seper). Although some adolescents found solace and comfort in structure and routine, the controlled decontrolling of emotions elicited by PA attracted participants toward participation. Participation in PA enabled participants to temporarily disengage from the monotony of everyday life, and was particularly experienced in non-sport activities such as going for walks and/or completing home/garden work. For these particular study participants, PA offered temporary freedom from the mundane features of daily life, and enabled them to (re) create their lives in other, and some times, more exciting ways. Seper's narrative highlights how PA was shaped by the interaction of affect and broader macro (daily structures such as attending school) and micro (affect and pleasure) level forces:

> I do the same thing every single day. Being active is the only time where I feel free. Free from always been told what to do, how to do it, when to do it. Free from teachers, therapists, and parents telling me how to live my life. Free from doing the same routine of school, home, doing homework, being a loner, getting beat up. Going for walks with my dog gets me to my happy place. Being active just allows me to be, me.

Not only did affective dimensions invite and incite participation, the affective pleasures of movement also contributed to management of externally imposed life rhythms that at times were anxiety producing or overwhelming. For some participants, PA provided a dedicated time and space to detach from difficult features of life such as broader experiences of bullying, or isolation. For three adolescents in particular, PA was an outlet to "take a break from pretending to be normal" (Daniel) in social situations, as they drew on coping strategies and techniques to camouflage what they perceived to be "abnormal behaviours." Whereas participants described that the success of pretending to be normal was physically and emotionally exhausting, PA provided an opportunity to loosen habits of self-restraint and a temporary space to move beyond normative social expectations. Although detachment from these features of life was fleeting, PA provided a sense of tranquility that at times was absent in other aspects of their lives. These aspects of PA drew adolescents closer to participation. Therefore, participation in PA not only included physical aspects, which influenced participation, but also included psychological ones, which helped maintain wellbeing. Highlighting how emotions and pleasures of movement shaped his participation, Daniel said:

> I try so hard and spend so much time and energy trying to fit in to be normal. I can't help myself from rocking back and forth, or times when I start banging my head against the wall. I've tried mindfulness, deep breathing and behaviour therapy to find some calm in my life but none of those worked. Doing taekwondo allows me to be me, and even if I start rocking or head banging, I don't feel like I am always being judged by people because they just get it.

The pleasures of movement were also shaped by broader processes such as family identity. It is to this discussion that we now turn.

Family identity

Family identities played an important role in shaping PA interests, habits, and patterns of participation. By identity, we mean the shared habits, values, and preferences of a family in relation to activity. Family identity in turn shaped how families devoted their time, efforts, and resources such as engaging in PA. Some study participants noted that their parents, siblings and family unit did not engage in PA during their leisure time. For example, Jas noted that he does not come from a "sporty family" as his family spent much of their leisure time attending museums, learning about history, and learning about ancient artifacts. Whether it was spending time with the family at home, cooking, or attending music, theater, or the arts, some study participants and their families devoted their leisure time to pursuits other than PA.

Whereas some participants and their families engaged in other pursuits, for others PA participation was an integral component of family life. For these particular adolescents, PA was a central component of their family life, and was a part of the social fabric of their family identity. From

participating in weekly family activities such as walks to the park, and family bike rides, through to hiring PSWs in community settings, some families invested significant time and resources to facilitate PA participation. Perhaps unsurprisingly, study participants from families that valorized PA adopted and reproduced self-identity as "physically active." A physically active self-identity was a resource used to make sense of their lives, interactions with others, and with the world. For example, four participants took pride in being physically active and noted that PA contributed to a sense of responsibility (such as taking neighborhood dogs for a walk to the dog park (Seper)). When analyzing participants' accounts, adolescents who were active were also praised by teachers, families, and peers alike. For three adolescents, participation in PA also elicited social status, and they used this social status to distinguish themselves from other adolescents with ASD who were not physically active. For example, in his digital story, Mark featured four photos of himself without his shirt on, and included one photo in which he flexed his arm, chest, and abdominal muscles. When asked in his interview about his decision to include those photos, Mark's narrative illustrates how these self-representations and a physically active identity were central to his sense of self, and facilitated participation:

> I tried to show that kids with autism also can be fit and active. I work hard for this body and its something that I am damn proud of. Plus, I am known as the muscle guy at school, around my family and my friend. You might as well flaunt it if you have it. Keeping this body is what keeps bringing me back to doing active things.

As illustrated across the two key themes, PA participation was enhanced, shaped, and curtailed through highly interdependent macro and microlevel forces. These interdependent socio-behavioral processes shaped PA in numerous ways, and illustrate the complexity of participation.

Discussion

In this study, our analysis demonstrates that this particular group of adolescent males with ASD had both negative and positive experiences in PA. Importantly, their experiences and nature of participation were shaped by interdependent relationships between individual (pleasure and emotions), family (values, prioritization of therapy, and identity), and social processes (bullying, availability of programs, and policy). Despite research suggesting that adolescents with ASD tend to be less active than their peers (Curtin et al., 2013), and participate in higher levels of sedentary activities (Must et al., 2013), the findings suggest that PA participation was not merely an individual behaviour determined by cognitive forces such as volition, motivation, or self-efficacy. Rather, PA was shaped relationally, where interdependent relationships between biological, psychological, and socio-behavioral dimensions converged to enhance, shape, and/or curtail PA. This relational understanding described in this study highlights the complexity of participation which heretofore has not been described in the literature. In addition to calls for research and interventions oriented at enhancing biological and psychological dimensions of PA (microlevel) (Lloyd et al., 2013), findings suggest that efforts at the social, cultural, and systemic level (macrolevel) are also required to potentially enhance PA, and the physical health of adolescents with ASD. The findings of this study serve as a point of departure in mapping out the possible ways forward on how to enhance PA participation among adolescents with ASD.

Our exploration of PA participation among adolescents with ASD revealed that exclusion and bullying (especially in HPE class) was rampant and a shared experience. Despite the large corpus of research studying bullying among children and adolescents with ASD (see Maiano et al., 2015), curiously, research on exclusion and bullying in PA curiously have been absent. Apart from two studies that briefly identified bullying in PA (Ayvazoglu et al., 2015; Healy et al., 2013), bullying has been overlooked as a mechanism that can shape PA participation. However, the findings highlight that repeated exclusion and bullying experiences can have a deleterious impact on the enjoyment and experience of PA. Whereas exclusion and bullying dissuaded PA participation in the short term, research among youth (Jachyra, 2014, 2016; Jachyra & Gibson, 2016) and adults (Ladwig et al., 2018) without ASD suggests that negative experiences such as bullying can potentially dissuade predilection to be active during adulthood. Although associations between negative experiences and decreased PA participation in adulthood appear to be modest (Jachyra, 2013), our findings suggest that there is a need to minimize bullying in an effort to potentially enhance the enjoyment and experience of PA participation.

In addition to efforts directed at mitigating bullying as a potential vehicle to enhance participation, our findings suggest that there may be potential benefit to implement new pedagogical approaches that may be better suited to the needs and abilities of adolescents with ASD. In our study, participants expressed a disdain for completing drills during school and community-based PA, were dissuaded from participation when they were picked last by peers, and experienced difficulty following complex sets of instructions. These particular participants in turn experienced difficulty when engaging in traditional PA pedagogies. Given this complexity, we suggest that there is a need to move beyond traditional HPE pedagogies which predominantly focus on technical skills, reproducing isolated drills, and participating in class scrimmages (Hopper et al., 2009). For example, a possible alternative model for PA and HPE for adolescents with ASD is adventure-based

learning (ABL). ABL utilizes highly structured physical activities coupled with periods of group debriefing to promote social and personal development. Drawing on cooperative activities, ABL seeks to develop interpersonal and intrapersonal relationship skills to build a sense of community among students and teachers (Stuhr et al., 2018). ABL may also be well-suited to needs of children with ASD as it provides high amounts of opportunities to participate in PA at their own skill level and pace, without incessant pressure of competition and winning. With one study suggesting that ABL can potentially decrease bullying and facilitate participation (Battey & Ebbeck, 2013), further exploration of ABL among adolescents with ASD is warranted.

A lack of community programs, challenges with instructional methods, and policy issues also curtailed PA participation. Consistent with Ayvazoglu et al. (2015), our findings suggest that there were difficulties in locating PA opportunities that were responsive to the diverse needs and abilities of children with ASD. Whether it was difficulties adapting and explaining activities to the diverse needs of participants, or policies mandating external support workers, study findings suggest that adolescents with ASD were not simply drawn to sedentary activities as has been reported in previous research (Obrusnikova & Miccinello, 2012). Rather, individual needs, preferences, and abilities interacted with broader socio-behavioral processes (instructional methods, policy) to curtail participation. In light of research suggesting that children with ASD participate in fewer recreation programs than their peers (Solish et al., 2010), our study highlights the need for training and policy efforts implemented to potentially enhance their participation. With research suggesting that PA participation can potentially be a modifiable risk factor that can potentially influence physical health outcomes (Healy et al., 2018) such as sleep patterns (Tse et al., 2019), overweight, and obesity (Healy et al., 2018), we suggest that there is a need to develop funding mechanisms to support PA. Supports at the level of policy and practice such as access to recreation activities and support mechanisms (such as clinicians, support workers, and training programs for schools and community) to facilitate PA participation can be a part of a holistic approach to facilitating physical health and wellbeing across the lifespan.

In this study, our analysis highlights that the pleasures and affective dimensions of movement centrally influenced PA. From generating meaning and identity, through to experiencing emotional pleasures, the findings contribute new knowledge regarding the pleasurable and affective dimensions of PA. Although the concept of pleasure is underresearched and undertheorized in PA (Nichols et al., 2018; Phoenix & Orr, 2014) and health-related research more broadly (Coveney & Bunton, 2003), the affective dimensions of PA elicited in this study highlighted new ways of thinking about PA promotion for adolescents with ASD. As such, our findings suggest potential value in recognizing and promoting the affective pleasures of PA alongside physical health and functional outcomes where PA can elicit the dimension of the human experience such as experiencing freedom, creativity, spontaneity, adventure, and risk. In addition to promoting the physical health benefits of PA such as the potential reduction of cardiovascular disease or diabetes, our findings highlight that there is also merit in promoting fun, joy, tranquility, satisfaction, and participation in all forms of PA.

The findings highlight that PA was also shaped by family dynamics, values, and identities. The qualitative methodology employed in this study elicited the complexity of participation, which has not been described in the literature. Whereas previous research suggests that familial forces such as parental education, employment, family income, and family size/number of siblings influence PA (Jones et al., 2018), our findings highlight that these familial variables and physical (in)activity did not exist in isolation. Rather, PA participation was shaped relationally. From competing family interests such as prioritizing therapy (macrolevel), through to family identity (e.g. "sporty family") (microlevel), these novel findings highlight how negotiating the multiple demands of living with ASD shaped PA participation in numerous ways. In our study, families valorized therapeutic interventions such that PA was often substituted for more time engaged in therapy. The predominant focus on intervention during childhood, however, adversely impacted PA for some participants, as there was less time and exposure to develop sustained PA interests, habits, and patterns of participation. Our intent is not to criticize parents for prioritizing therapeutic interventions over PA, nor to downplay the widely documented benefits of various therapeutic interventions for children with ASD (Lai et al., 2018). Rather, the findings prompt us to reflect on, and bring attention to, thinking about how we can maximize therapeutic, developmental, and physical health outcomes without losing sight of other aspects of life such as PA participation. Taken together, our study findings suggest that there is a need to reflect on how therapeutic interventions can potentially be balanced with other aspects of life in order to support the physical health and development of the "whole" person.

Limitations and future directions

Despite the many strengths of this research, the study limitations present opportunities for future research. First, the study sample was limited to the perspectives and experiences of adolescent boys with ASD. In light of emerging research suggesting that girls with ASD are underdiagnosed and underrepresented in the ASD literature (Lai et al., 2011), future work needs to include girls and women to understand potential gender differences. Conducting this work is crucial to understanding how to optimize their participation in PA. Second, the sample only included

participants with verbal conversational skills (albeit in a wide range). Future research with non-speaking adolescents, along with enhancing ethno-cultural diversity (age, and socioeconomic status) is needed to examine how to best support their needs. Third, our findings suggest that future research is needed to explore whether ABL would be an amenable pedagogy to teach HPE and PA for children and adolescents with ASD. Fourth and finally, the integrated use of digital storytelling and interviews serves as a point of departure to engage and co-create research data among individuals with ASD. Recognizing the heterogeneity of ASD, the integrated use of these methods presents an opportunity to potentially engage participants who communicate in channels (or modes) other than speech. Although our study only included participants who demonstrated verbal proficiency, we suggest that methodological work that develops these methods for use with non-speaking participants would be of great value.

Conclusion

This study examined the perspectives, meanings, and experiences of PA, along with the socio-behavioral mechanisms that enhance, shape, and curtail PA participation for adolescent with ASD. Given the scarce knowledge in this area, the study findings provide an innovative and original contribution to the understanding of physical (in) activity. The findings illuminate the complexity of PA, and highlight the need to identify pathways at the social and systemic levels to facilitate participation.

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Note

1. In this article, we use person-first language (adolescents with ASD) as this was the preferred terminology expressed by the study participants. We acknowledge and respect that others may prefer identity-first language (autistic person).

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Appendix 1

Interview guide-visit one

Preamble: Today, I'd like to get to know you a little bit. Together, you will also get to know me a little bit better as well. We are going to talk about some of your favorite activities and physical activities outside of school time.

1. Tell me about yourself.
    - Who is in your family? Probe re: extended family and friends, pets, caregivers?
    - What kinds of things do you really like to do? Do you have any activities or interests that you really like? What are you really good at? Which activities make you feel really good about yourself?
2. What are some of the activities you do on a weekday and weekend? Ok, now let's talk about what a school day usually look like for you.
    - Probe getting up and ready for school, including timing, school location, transportation, social and communication networks at school, classroom type, assistance/support at school, fieldtrips, clubs or extracurricular activities, school peers/friends/helpers, favorite/least favorite subjects, general accessibility issues.
    - What do you usually do after school—typical evening routines and activities, with who, where in home, tightly structured care routines versus variable and relaxed, time for leisure.
    - Now let's think about a usual week—are there differences between the days of the week?
3. When you think of physical activity, what do you think about?
4. How often do you usually do physical activities?
5. After you finish doing physical activities, how do you usually feel?
6. Does anyone else in your family do physical activities?
7. What are the things that make you enjoy physical activity?
8. What are some of the things that do not make you like physical activity?
9. End with review of next session—remind participant about attendance at digital storytelling workshop.

Interview guide-visit two

Individualized according to the digital story data generated by the participant

1. You took a lot of videos and photos inside and outside of your home when doing physical activity.
    - How did you choose which parts of your home you wanted to include in the film?
    - How did you choose which photos you wanted to take inside of your home? Can you tell me about your home?
2. Can you tell me about the physical activity you did with your younger sister and her friend?

- Imagine being back with your sister and her friend. Think about what it would have felt like. What should the title be for this part of the digital story if you were to give it a title? [*show participant a couple of generic captioned photos of youth like the example below to explain the concept if needed*]
- What are some good things about the place, group, or activity in the photo? What are some "not so good" things that you feel?

3. You included a long part of the digital story showing you doing yoga in a park alone. Can you tell me about this part of the digital story?
   - What made you choose yoga to show you being physically active?
   - Where did you learn to do yoga?
   - Why that particular park? What is in that surrounding environment that makes you comfortable to do yoga there?
   - How do you feel after doing yoga? Physically (relaxed) and emotionally (grounded)?
   - How does yoga fit in your daily life? When do you usually do it—before school or after school?
   - Is physical activity important to you? Why?
   - If a friend asked you to suggest a physical activity to them, what would that be?

General questions

- What or who is potentially missing?
- Are there ideas in these digital stories that you would want to share with other people? What are the most important things that these digital stories tell about? How would you change the story told in your digital story to make it better for YOU?
- Are there things in the digital story (or part of your life but not in the digital story) that you wish you could change? Can you tell me about that?
- Is there anything else that we haven't talked about today that you think I should know about?