

The influence of motor abilities in children with autism spectrum disorder on caregiver experiences: A pilot study

Sara M. Scharoun^{1*}, Roula A. Markoulakis², Paula C. Fletcher³, Pamela J. Bryden³

1 Department of Kinesiology, University of Waterloo, Waterloo, ON, Canada 2 Centre for Addition and Mental Health, Social Aetiology of Mental Illness (SAMI), University of Toronto, Toronto, ON, Canada 3 Department of Kinesiology and Physical Education, Wilfrid Laurier University, Waterloo, ON, Canada

Abstract

Background: Parents of children with Autism Spectrum Disorders (ASD), particularly mothers, experience a unique caregiving demand. Although benefits do exist, caregivers often report a burden due to children's lack of social interaction and ability to self-care. Development of motor skills employed in these activities is often delayed in children with ASD; however, possible links between motor skills and the experiences of their caregivers is not clearly understood. This pilot study explored caregivers' descriptions of the functioning of children with ASD in relation to their children's motor abilities.

Methods: Five children (two male, three female, ages 6–8) with ASD participated in the following tasks to assess lateral preference and performance: the WatHand Cabinet Test, involving a series of unimanual tasks; the Large and Small Grooved Pegboards test, which time the placement of pegs into key-shaped holes; Eyedness Tasks, such as looking through a tube with one eye; and Footedness Tasks, such as kicking a ball. The five married female primary caregivers (ages 35–46) of these children participated in one-on-one, semi-structured interviews regarding their view of their children's functioning, and costs and benefits of their experiences.

Results: Overall, parents of children who displayed weaker lateralization described their children's motor abilities in ways that were indicative of greater difficulties with social interaction and age-appropriate self-care.

Conclusions: Implications exist for intervention planning, where service providers should be cognizant of the motor difficulties experienced by children with ASD, and plan interventions that promote functional gains.

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* Email: sscharou@uwaterloo.ca

Introduction

One in every 68 children is diagnosed with Autism Spectrum Disorder (ASD), making ASD one of the most common neurodevelopmental disorders [1]. Characterized by atypical language and social skills, speech development ranges from a complete absence, to that which may appear typical, albeit lacking the pragmatic (i.e. social) element of language [2]. In particular, children with ASD display impairments in coordination of speech with eye contact, showing a genuine interest in the thoughts and opinions of



others, and recognizing when to initiate and conclude conversation [3, 4]. Patterned and repetitive behaviors are also considered a hallmark of ASD, where these manifestations are seen to overlap with obsessivecompulsive disorder [5–7].

Considering the aforementioned behavioral manifestations, parents of children with ASD experience a unique caregiving demand that can present negative effects with respect to aspects of finances, social life, health and family life [8-11]. This caregiving demand is generally understood to arise from impairments in the children's social and communication skills; namely inappropriate behaviors, the children's inability to care for themselves, aggressive actions, language deficits, and a lack of eye contact or affection [10–13]. There is also evidence that the severity of the children's social impairment can predict the level of stress associated with parenting [14]. Such negative effects tend to be burdensome for mothers, who are typically more involved in daily childcare tasks than fathers [10, 15, 16]. Nevertheless, mothers of children with ASD describe benefits arising from the caregiving role, including personal growth [17].

It is generally understood that, in typical development, a child's motor skills can provide an important foundation for the development of social skills. More specifically, elements of praxis can be of use in social imitation and goal-directed motor skills [18] that are employed in social, play and self-care activities. In ASD, a lag in motor development is evident as early as infancy [19]. Recent reports indicate that motor impairments are a core but variable feature of ASD [20–22], where prevalence rates have been reported between 21 and 100% [22–26].

Research with children with ASD has consistently shown atypical development of lateral preference and performance of motor skills. Children with ASD tend to display decreased laterality and inconsistent handedness [27–29]. There is also inconsistency between motor preference and performance, where for instance, the preferred hand may not be the more skilled hand [27]. Such differences have been attributed to inconsistent cerebral lateralization, leading to less well-established outward lateral preference [28, 30]. In addition to inconsistencies in lateral preference and performance, children with ASD also experience difficulties with manual dexterity, balance skills, motor planning and overall motor skills [22, 31]. Furthermore, Hilton et al. [31] noted a correlation between motor impairments and social reciprocity, suggesting a relationship between motor delay and the development of social skills, or vice versa. A recent review of motor abilities in ASD poses the question, of "how motor difficulties relate to social difficulties-are they independent or do underlying motor issues cause the social characteristics?" [22, p. 340]. Clearly, further investigation is warranted.

Overall, evidence indicates that the characteristics of children with ASD, particularly in terms of their lack of social interaction and the ability to care for themselves, are associated with caregiver burden and stress [15]. Despite the link between social and motor development, no studies to date have explored the possible role of children's motor abilities in those behaviors that function as known predictors of stress experienced by caregivers. As such, the aim of this study was to explore caregiver descriptions of the functioning and behavior of children with ASD, particularly self-care and social skills, in light of the children's motor abilities, as evidenced through lateral preference and performance. As this was a pilot study, the preliminary nature of the investigation was meant to establish a basis for continued research in this field.

Methods

Participants

A total of 10 participants took part in this study. Participants were recruited from local childhood disability support organizations. Five children (two males, three females, aged 6–8 years, self/caregiverreported right-handers) diagnosed with ASD participated in the motor tasks, and the five mothers (married, female primary caregivers, aged 35–46 years) of those children participated in the interview portion of the study. See Table 1 for participant caregiver and child pairs. Participants in this study comprise a subset of the participants in two larger studies of motor dominance in children with ASD [32] and the costs and benefits of caring for children with ASD [9, 17]. The Research Ethics Board at Wilfrid Laurier University approved all recruitment and testing procedures, and informed consent was obtained from all caregivers for themselves and on behalf of their children. All children also provided verbal assent prior to participating.

 Table 1. Caregiver/child pairs

Caregiver	А	В	С	D	Е
Age	46	35	37	40	42
Child					
Cillia					
Age	8	7	6	6	7
Gender	М	F	F	F	М



performance on all handedness, footedness and eyedness tasks (Table 2).

Table 2. Overall lateralization

Р	Handedness	Eyedness	Footedness
А	Right	Strong Right	Right
В	Mixed	Weak Right	Mixed/Weak Right
С	Mixed	Strong Right	Mixed
D	Mixed	Left	Mixed/Weak Left
Е	Right	Mixed	Right

Prior to

Qualitative tools

Quantitative tools

All children completed the handedness (WatHand Cabinet Test and Grooved Pegboards) and footedness tasks described by Markoulakis et al [32]. All tasks were analyzed as described in the paper detailing the larger study [32] and provided information on both the lateral preference and lateral performance of the children's hands and feet. In addition, eyedness was explored in this study to obtain an additional indicator of dominance. The eyedness tasks involved asking the participant to look, with one eye, through a tube with colored tissue paper on one end and tell the experimenter what color was seen. The first tube was mounted on the table at eye-level to the participant, and the participant was required to move forward to look through the tube. This task was completed three times, and the eye used to look through the tube was recorded. The next task involved a smaller tube, which the participant would bring up to one eye, using one hand. This task was completed three times, and both the hand and eve used on each occasion was recorded. Eye preference was determined by observation of the eye selected across the three trials for each task. All of the tasks were performed in a randomized order with each child participant. Motor dominance was ascertained by summating the frequency of right or left-dominant preference and

Prior to the interview, all caregivers completed a The questionnaire background questionnaire. contained items pertaining to 1) demographic information, 2) the child's diagnosis, 3) the caregiver's wellbeing, and 4) any supports and services accessed. This questionnaire aided in providing context for the subsequent interview. All caregivers participated in a one-on-one, semistructured interview, which was recorded and transcribed verbatim. Participants discussed the costs and benefits of their experiences, as well as the child's functioning and behavior, and the caregiving routine. Results pertaining specifically to caregiver accounts of the child's functioning and behavior, a subset of the whole interview, will be presented in this paper. Theoretical saturation was reached through these five interviews, as "new sources [led] to redundancy", and additional interview data would not contribute to data quality [33]. All participants were also given the opportunity to participate in a member check, where they could add, clarify or omit information from their transcripts, and offer feedback on overall study findings [34]. Additionally, data and researcher triangulation were employed. Data triangulation was accomplished by obtaining numerous data sources for all participants through the quantitative and qualitative tools described above. Researcher triangulation involved two researchers independently analyzing the qualitative data, and then discussing points of agreement or dissent in order to strengthen the credibility of findings.



Data treatment

A phenomenological orientation was applied to aid in the understanding of the lived experiences of married female primary caregivers to children with ASD, as they pertain to the caregiving routine and the child's functioning and behavior [35]. See Markoulakis et al. [17] for a description of the analysis of qualitative data. In particular, data pertaining to the child's functioning and behavior was used to explore the possible relationship between these caregiver descriptions and the child's motor dominance. Children's motor dominance was determined by grouping findings from each of the quantitative tools. Right or left hand, foot, or eye dominance was determined if the majority of trials were performed on one side; otherwise, dominance was determined to be mixed.

Results

Although all children were originally classified as right-handed according to their caregiver or by selfreport, handedness measures revealed that only two children (A and E) were indeed right-handed. Closer examination of other lateral preferences revealed that child A displayed right handedness, footedness and eyedness. In comparison, the four other children displayed mixed preferences in terms of handedness, footedness and eyedness (Table 2). In many cases, mixed hand, foot, and/or eye preference in the child were accompanied by caregiver descriptions of difficulties with skill development, particularly in cases where the skills described involved a motor component. The following will outline caregiver accounts of their children's behaviors.

Caregiver A expressed concerns regarding her child's speech, social skills, and – to some extent – motor abilities. Minor difficulties were noted in the fine motor ability required for typing, for which an occupational therapist had provided a typing program. There were also some motor difficulties that persisted in the child's self-care routines, for which both parents provided assistance.

"He gets up, he gets dressed... Sometimes I-I have to help him with buttons. We still have problems with buttons." "H-he bathes on his own, um, my husband's job is to give him, to wash his hair. So he does that, and then, he's now washing his body by himself."

Caregiver A also spoke of the improvements achieved through access to services, mainly around social interaction. Improved social interaction afforded opportunities for motor play, with Lego blocks or activities such as karate, as well as social interaction using a computer.

"Uh, well, first of all he-he, um, he now will play games. He will interact. His imag... he plays imaginary, you know, games, um, with his little... hihis imagination is just boundless. Um, but when he's playing with others he speaks, he offers input. Um, there's a couple little girls they have Webkins, and so they're... they even go on the computer and play Webkins."

She also frequently described her child's helpfulness or independence, through skills that required a level of motor ability and some learning.

"But um, and he's trying to, he offers to help. I get him to shovel the walk. I just need t-to sometimes help him along with stuff, right? With instructions, and um, he's a helpful kid, he's a very giving kid and I'm-I'm teaching him how to make scrambled eggs and stuff like that, much more than his brother. He loves to do that stuff. Uh, I get him to start the washing machine for me. So I'm, I'm trying to learn to let him help, 'cause it's really important for him. But with you know, supervision."

Interventions such as occupational therapy had been accessed for many concerns, and Child A had access to an educational assistant at school. Caregiver A mentioned that there had been a great deal of improvement in her son's abilities over time. Child A was right-lateralized for his handedness, footedness and eyedness measures (Table 2), which may have been related to his general comfort with motor tasks and willingness to learn and help with household duties.

Child B did not display the strength of lateralization observed in Child A, and her mother described early difficulties with socialization and self-care skills. Caregiver B discussed her daughter's initial lack of talk and her disinterest in social interaction. Her social skills have improved, however, and she now



actively engages in games with other children and tries to make sure everyone is involved.

"Um, she's, she's um (laughs) very, very empathetic. If she sees, if there's another child in the room who is, um, on the periphery she will go and she will take that child by the hand and bring them into, uh, activities."

She also had some difficulty learning self-care skills, but was described as having caught up to her age group.

"She-she's fine, um, she's about her age range for, for like, toileting and getting herself dressed and giving herself a bath an-and, you know, personal hygiene like brushing her hair and brushing her teeth and stuff like that, so... Um, yeah none of that is, is an issue. She was, she was a little bit slower learning it but she's fine now, she's caught up."

Caregiver B also mentioned that her daughter has a great deal of confidence in her skills and in taking part in the same activities as other children her age. She mentioned that the therapy her daughter has received has been very instrumental in ensuring she is not self-conscious of her differences, and is confident in her skills.

"She has learned that she can do what every other child her age does, like skate, go to camp, go down the block to the park by herself, go visit her friend by herself. I think that if we hadn't received so much therapy and help for her then she would be much more self conscious of her differences, and I would be over-protective of her. She sees her friends at school doing activities and has had nothing but encouragement to try them too."

Child B had difficulties with fine motor skills when she was younger, and received occupational therapy for these concerns.

Caregiver C described considerable concern over delays in her daughter's skill development, particularly around self-care and socialization. Caregiver C discussed how her daughter's development was behind that of her peers, but was slowly improving. Child C enjoyed playing on the computer and with a video game system. Socially, Child C's play behaviors were not very interactive, and she often preferred to play alone. She was described as not very interactive in her play, but was slowly showing more interaction with others.

"Well she um, is definitely behind her peers. She, um, is starting to react with or, you know, interact with them as opposed to reacting to them or um, playing beside them so, but that's still very far behind what they are. Um, she seems to be further ahead than she was, you know, two or three years ago with that, so she is definitely progressing but um, it's just slower, a slower development, I think."

There was some initial delay in her daughter's selfcare skill development. Early delays in toileting had improved, but had taken much more time than expected.

"Um, well, her toileting habits were delayed, they're fine now. But um, she, it w..., I think it was last year before she, yeah, it was last summer um, that she was able to go at night without having a Pull-Up on – that she was six before she was fully independent toileting."

Sometimes, delays in Child C's development were of concern for Caregiver C.

"I kind of see her size and I see her age and see what other kids are doing and sometimes I might get a little frustrated because she's not doing maybe what some of the other kids can."

Caregiver C also mentioned that services such as speech therapy, occupational therapy and a special education teacher are being accessed through her daughter's school, but no external services are being accessed.

Caregiver D described her daughter's avoidance of social situations at a young age, but mentioned that she has become very social and very confident in her abilities. Caregiver D was very happy that her daughter enjoys taking part in these activities, but expressed concern over her daughter's distress when her skills do not match her expectations.

"She believes that she can play every sport, every instrument. She's a very, very confident kid, very uninhibited, and so why, she has no, no concept of something she might not be able to do. So she will try anything: swimming, soccer, golf, dance – she just wants to do it all. And that's great, I love that she is, has come so far. Um, the adverse side of that is that



when she tries something that she believes she can do well from day one, she gets very frustrated that she can't, and so the fact that she, that there might be some skills that she might not develop in life, or the fact that she really needs to work hard to refine some of them, cause her frustration...she can get very aggressive and very loud and um, she'll yell at herself or she'll yell at people, or she'll burst into tears and have [pause]... her emotional responses are very dramatic compared to what the situation actually is."

Caregiver D also indicated that with increasing comfort with play and social scenarios, Child D's peer interactions had improved.

"Um, she [pause] loves to do lots of dramatic play, again in complete contrast to when she was little. Now she has a great imagination, imaginary thing comes to her head and can, she's really good at that. So I think that her interactions with peers now are, are very, very good, providing that they're in an environment that she's comfortable with."

There were minor issues described with self-care, namely with dressing herself following bathroom use, and with toileting, which had been resolved.

"Um, toileting, uh, was a big challenge when she was probably well over three when she got that figured out in her head. Um, and today she can do it independently (pause) - I wouldn't necessarily say always effectively [laughs], but she can do it."

Caregiver D indicated that Child D had access to an educational assistant at school, and had also accessed occupational, physical and speech therapy. Caregiver D also indicated that her daughter's skills had shown improvement over time, particularly in terms of selfcare and social play behaviors. She mentioned that her daughter enjoyed trying new activities, but that she had to work a lot harder than her peers to develop certain skills. Although she was described as righthanded, Child D's handedness was found to be mixed, along with inconsistency in eye and foot dominance.

Caregiver E described her son as unsociable when he was younger, but said he had progressed a lot and was interested in playing and socializing with other children. He was considered very pleasant and well liked. Caregiver E described her son's improvements in fine motor skills over time, and attributed these gains to his play behaviors; his favorite play activity was to build using Legos. He used small pieces, which his mother felt had helped his fine motor skills. The Grooved Pegboard tasks indicated that some minor difficulties persisted with fine motor skills, but overall hand dominance was consistent. He did still have difficulty with coordination, and was described as 'clumsy'.

"Just things like he's, his uh, co-ordination isn't great. I mean he still, on his bi- on his bicycle, I mean he's seven and he still has his training wheels on – he can't quite get that, you know, coordinated. And uh, his fine motor skills, I dunno, he plays with Lego a lot, with the little tiny pieces, and we think – we hope, anyway – that's really helped him."

When he was younger and had even greater coordination difficulties, he would get frustrated when he was not able to manipulate the pieces of a train set. His parents accommodated his abilities and prevented frustration by modifying the toy.

"We had a train table set up and it would, he would, he could never play with it when we set the tracks up because he would always knock them over and he was, he was just a little clumsy, like not co-ordinated. And uh, [my spouse] ended up actually nailing everything down. W-we did a really cool set up for him and then we nailed it to the train table so that [Child E] could play with it without getting frustrated."

Caregiver E indicated minor issues with self-care, namely around dressing.

"You know, he'll go and uh, pretty mu- he gets himself ready pretty much. Sometimes he's got things on backwards, like he puts his underpants on backwards and socks on upside down, you know, with the, you know, the heel part over his toes and stuff like that. But he's pretty, pretty, you know, efficient at getting himself dressed."

Child E also had access to an occupational therapist and educational assistant through his school. His mother mentioned that he takes part in extracurricular activities such as swimming, soccer and karate.

Finally, although unexplored in the quantitative assessment of children's skills, it is worth noting that



in the interviews, caregivers described their children's speech as a major initial indicator to seek help before they were aware of their children's diagnosis. Parents noted that their children had not been talking enough or at all, or did not display any interactive speech.

"Um, he was uh, about three years old and uh, we had noticed some behaviors and the fact that he wasn't talking at all. Um, so we decided to look into it. And somebody at [music lessons] had also uh, told us that um [organization], would be a great place to get some feedback." – Caregiver A

"Our family doctor, when [Child C] wasn't speaking at oh, about fifteen months, he decided we should get on the wait list for speech therapy at [organization]...the speech therapist is actually the one who noticed that she wasn't doing other things maybe the way that other children her age should be doing them. So we got into occupational therapy and from there physiotherapy, and um, and with all of that we got uh, what do you call them, child psychologist, who ultimately made the diagnosis of autism." – Caregiver C

By seeking assistance for this concern, parents and children were directed to organizations and professionals that led them to a diagnosis of ASD and the needed services and supports.

Discussion

The purpose of this pilot study was to aid in the understanding of the lived experiences of five primary caregivers of children with ASD. More specifically, we wanted to investigate descriptions of the functioning and behaviors of these children, particularly in terms of self-care and social skills, and in light of the children's motor abilities, as evidenced through lateral preference and performance. Considering the preliminary nature of this investigation, the results serve as a basis for future investigations, thus must be interpreted in light of the small sample size. Nevertheless, it is clear that knowledge of the costs and benefits to caregivers of children with ASD is important for the team of professionals involved in education, support, and care [17].

Taking the aforementioned into consideration. children's accounts detailed caregiver their functioning and behaviors, and were reflective of their children's motor abilities. Comparisons of caregiver accounts to children's motor abilities provides preliminary evidence to support the idea that parents with children who displayed weaker lateralization described their children's motor abilities in ways that were indicative of greater motor delays. This is evidenced by descriptions of play behaviors, social interaction and age-appropriate self-care skills such as dressing and basic hygiene.

Children displaying strong lateralization were described by their caregivers as generally comfortable with motor tasks, and as willing to learn and help with household duties. It has been noted that motor skills are essential for the attainment of skills in other domains [18]. As such, these results provide preliminary evidence that comfort with motor skills translates to engagement in household tasks and opportunities for positive interactions.

It is possible that the presentation of novel motor tasks allowed us to observe discrepancies in lateralization (i.e. right hand preference for the WatHand Cabinet Test and small Grooved Pegboard, and left hand preference for the large Grooved Pegboard) that are not an issue in the children's nowfamiliar everyday skills. This supports suggestions that children with ASD can overcome motor difficulties through practice and adaptation to familiar tasks [22], and may also explain why some caregivers described initial displays of frustration when their children attempted novel motor tasks, which improved with time. Furthermore, it has been suggested [36] that a lack of consistency in dominance can lead to difficulty in novel skill development for children with autism. This was evidenced in parents' descriptions of their children's novel skill development, which may also have contributed to past experiences of frustration described by caregivers. Conversely, parents of children with mixed lateralization described caregiving stress related to their children's delays, and difficulties in the attainment of motor skills. Tomanik and colleagues [12] similarly found that mothers of children with ASD who were more socially withdrawn and less able to take care of themselves experienced greater stress than mothers of



children with ASD for whom these were not concerns.

Although the sample size was limited, there were numerous instances where motor skill deficits added a level of stress to caregivers by increasing parenting demand. Motor abilities are linked to social skills, which - for parents of children with ASD - are strongly related to parenting stress [15, 18]. For mothers in particular, a child's compromised self-care skills are also a considerable stressor [15]. Development of motor abilities has the potential to have a positive effect on a child's social skills, which may in turn alleviate a considerable predictor of parental stress. It is unclear whether improvements in motor abilities were linked to improvements in selfcare skills or social skills over time; however, all caregivers spoke highly of the services they were able to access, and the positive implications for their children's functioning.

There are certain limitations to the conclusions that can be drawn from this work. Firstly, although the motor ability findings broadly concur with studies of children with ASD, this was an exploratory pilot study with a small sample size. Further work is necessary to fully comprehend the relationship between lateralization and factors such as access to services, parents' caregiving roles and children's functioning and behavior. Secondly, the children included in this study were determined to be high functioning, with an IQ of 80 or above. Therefore, these findings cannot be generalized to all children with ASD, since those who are lower functioning may display greater maladaptive behaviors and/or motor difficulties that can lead to greater negative effects for caregivers.

Conclusions

The findings from this exploratory pilot work provide preliminary support for a potential relationship between the motor dominance of children with ASD and the experiences of their caregivers. Caregivers' descriptions of their children's functioning and behavior were indicative of delays in self-care and social skill development in a manner linked with the children's motor abilities. The trajectory of the development of these skills appears to have played a role in caregiver stress. Future work in this area might make use of mixed methods to further explore caregivers' accounts of children's motor abilities and effects on their functioning and ability.

Identification of the appropriate treatment or intervention for a child with ASD can be complex, and often requires a team approach [37]. When planning interventions for these children and their families, it is important that service providers are cognizant of the implications of motor difficulties among children with ASD, and to plan interventions in an individualized manner that promotes functional gains [18]. Not only will this aid in the treatment of children with ASD, but will contribute to caregivers' and families' coping strategies and realization of benefits in their experiences [17]. Knowledgeable professionals should be prepared and mindful of appropriate interventions for motor difficulties, the effects of these difficulties on children's abilities and behaviors, and the effects these abilities, or related social and self-care skills, may have on caregivers' experiences in turn.

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