

**Parents' Perspectives of the Secondary Effects of an Early Motor Skill Intervention for
Their Four Year-Old Children with Autism Spectrum Disorder**

by

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A thesis submitted to the
School of Graduate and Postdoctoral Studies in partial
fulfillment of the requirements for the degree of

Master of Health Sciences in Kinesiology

The Faculty of Health Sciences
University of Ontario Institute of Technology
Oshawa, Ontario, Canada

April 2019

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THESIS EXAMINATION INFORMATION

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Master of Health Sciences in Kinesiology

Thesis title: Parents' Perspectives of the Secondary Effects of an Early Motor Skill Intervention for Their Four Year-Old Children with Autism Spectrum Disorder
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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

Parents' Perspectives of the Secondary Effects of an Early Motor Skill Intervention for Their Four Year-Old Children with Autism Spectrum Disorder

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ABSTRACT

This qualitative study was grounded in interpretive phenomenology to elicit rich descriptions of parents' (N=8) experiences with an early motor skill intervention for their four year-old children with Autism Spectrum Disorder (ASD). The results of this study suggest that motor skill interventions have several child and parent-level benefits. Key child-level benefits include improvements with: motor skills, social skills, listening skills, turn-taking skills, and transition skills. Key parent-level benefits include: observing their children succeed, learning strategies to address challenging behaviours, developing a greater appreciation for the motor domain as an important part of child development, and meeting other children with ASD as well as their parents. Parents also described how these child and parent-level benefits extended to their family unit; ultimately reducing parental stress and improving family quality of life. These findings indicate that early motor skill interventions have several meaningful secondary effects that can benefit families of children with ASD.

Keywords: Autism Spectrum Disorder; early motor skill intervention; secondary effects

AUTHOR'S DECLARATION

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Leanne Elliott

STATEMENT OF CONTRIBUTIONS

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

ACKNOWLEDGMENTS

Thank you to my amazing supervisor Dr. Meghann Lloyd for your valuable feedback and unwavering support throughout this journey. I truly cannot thank you enough for your incredible mentorship. I could not have asked for a better supervisor and I am forever grateful for all that you have done for me. You are the reason for a great deal of my success, in academia and research, and I hope to one day be as influential to my students as you were to me.

Thank you to Dr. Jonathan Weiss for all of the time and effort you have dedicated to assisting me with this research project. I feel very lucky to have been able to learn from you and have you as one of my committee members.

Thank you to Aaron Ibbitson for being an incredible and reliable research assistant and friend throughout this experience. I could not have carried out this study without you volunteering your time (on evenings and weekends no less!) to provide childcare for my participants' children while I conducted interviews at the lab. I can't wait to see what the future holds for you!

Thank you to Tayler Runge for volunteering your time to provide childcare and conduct interrater reliability tests with me. I appreciate your support and positive attitude; you were a pleasure to be around!

Thank you to my parents for your continued love and support... and for the free lunches at Hot Rocks- forever grateful for those.

Thank you to my brothers and sister-in-law for pretending to be interested in my research and for reminding me that there's more to life than studying.

Finally, thank you to my rock, Adam, for always making me laugh, and for your unconditional love.

This thesis was partially funded by the Canadian Institutes of Health Research.

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LIST OF ABBREVIATIONS USED

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
DD	Developmental Delay
GAD	Generalized Anxiety Disorder
SPD	Sensory Processing Disorder

OVERVIEW

This thesis is divided into six sections:

1. Introduction
2. Literature Review
3. Manuscript 1
4. Manuscript 2
5. Conclusions
6. Appendices

SECTION 1: INTRODUCTION

Introduction to Thesis

Overview of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder resulting in impairments in communication skills, language, and social interactions in addition to restricted and repetitive behaviours or interests (American Psychiatric Association, 2013). The prevalence rate of ASD in Canada is estimated to be approximately 1 in every 66 children (Public Health Agency of Canada, 2018); similar rates have been estimated by the Centers for Disease Control and Prevention in the United States (Christensen et al., 2016). ASD is typically detected in early childhood and it is approximately five times more frequent among boys compared to girls (Christensen et al., 2016; Public Health Agency of Canada, 2018). ASD is a life-long, pervasive disorder and its effects extend beyond those diagnosed, to their families and the greater community (Public Health Agency of Canada, 2018).

There is a vast range of characteristics associated with ASD that are variable with regards to their time of onset and level of severity (Masi, DeMayo, Glozier, & Guastella, 2017). Those with ASD often have difficulty initiating social interactions and responding appropriately to verbal and nonverbal cues (American Psychiatric Association, 2013). As well, a lack of flexibility in behaviour often interferes with his or her ability to function successfully in daily life (American Psychiatric Association, 2013). For example, it is common for people living with ASD to have a difficult time transitioning between activities, coping with change, or switching his or her focus/ attention (American Psychiatric Association, 2013). Difficulties with planning and organization can also

negatively impact independence (American Psychiatric Association, 2013). In addition to the core deficits experienced by people with ASD - centered around social communication and interaction as well as restrictive and repetitive patterns of behaviour - they often experience challenges in other domains, including motor development (Lloyd, MacDonald, & Lord, 2013).

Early interventions for children with ASD often target the hallmark characteristics of the disorder. For example, the Ontario Autism Program funds early Intensive Behavioural Intervention (often called IBI therapy) which uses the principles of applied behavioural analysis in varying levels of intensity, to target multiple areas of children's development, including speech and language, social, motor, and adaptive skills via repetition, rewards, and goal adjustment (Harris & Weiss, 1998; Piccininni & Penner, 2016). These programs are effective, and are considered the gold-standard for ASD treatment (Butter, Wynn, & Mulick, 2003); however, government-funded interventions have been associated with long wait times, and private services are costly (Jones, Bremer, & Lloyd, 2017; Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006). There is a need for cost-effective, early interventions that benefit the families in addition to the children with ASD, in order to promote best outcomes for all.

ASD and the Family

The direct and indirect impacts of ASD span several sectors, including social services, education, and healthcare, with great economic costs across the lifespan which are often carried by families (Buescher, Cidav, Knapp, & Mandell, 2014; Ganz, 2007; Leigh & Du, 2015; Masi et al., 2017). In addition to the financial burden commonly

experienced by families of children with ASD, parents also face many other unique challenges as they navigate the world of ASD services (Jones et al., 2017; Karst & Van Hecke, 2012). For example, the time period immediately following a child's diagnosis has been identified as a particularly sensitive time for parents (Stuart & McGrew, 2009), yet children with ASD are often left with few intervention options during this period due to long waitlists and expensive services (Piccininni & Penner, 2016). This leaves families in a state of limbo where they may not have the skills to manage their child's challenging behaviours, and lack the knowledge required to promote best developmental outcomes; leading to increased stress on the whole family (Jones et al., 2017).

As a result of the challenges associated with caring for a child with ASD, parents have consistently reported increased levels of stress and lower levels of family quality of life compared to parents of children with typical development, and compared to parents of children with other developmental disabilities (Karst & Van Hecke, 2012). These outcomes have been shown to negatively, and reciprocally, influence the child and reduce the positive effects of interventions and services for ASD (Karst & Van Hecke, 2012; Osborne, McHugh, Saunders, & Reed, 2008). Parents of children with ASD often act as the support coordinators for the children and it is important that their needs are also being addressed (Karst & Van Hecke, 2012).

Most interventions for children with ASD only evaluate the direct effects of the service; those pertaining to the individual the intervention was targeted at (Karst & Van Hecke, 2012). However, there is a need for child-centered interventions for ASD to

investigate the secondary effects, or indirect effects, of said interventions; effects pertaining to the parents and families of those receiving the intervention.

Understanding how different types of interventions for ASD can affect parents and families will provide valuable information for policy development as well as service delivery and design, and ultimately enhance the short and long-term outcomes for the children and their loved ones (Wang & Brown, 2009).

Two constructs that should be considered important secondary outcomes of child-centered interventions, include 1) parental stress, and 2) family quality of life. High parental stress levels have been shown to hamper the progress of children with disabilities (Lessenberry & Rehfeldt, 2004), and low family quality of life scores indicate that the needs of the family are not being fully met (Hu, Summers, Turnbull, & Zuna, 2011). Since parents of children with ASD have consistently reported high levels of stress and low levels of family quality of life (Karst & Van Hecke, 2012), interventions for children should aim to improve these family outcomes. There is a need for researchers to measure these outcomes more frequently following child-centered interventions in order to gain a better understanding of the effects of different types of services, in a wider context.

Early Motor Skill Interventions and Family Outcomes

As previously mentioned, behavioural interventions spanning several aspects of children's development are regarded as the gold-standard for ASD treatment, but, wait times for these services are notoriously long (Butter et al., 2003; Harris & Weiss, 1998; Piccininni & Penner, 2016). This is unfortunate since earlier access to intervention is

associated with better outcomes, including, but not limited to: language gains, acceleration of developmental rates, improved social behaviour, and an overall reduction in the symptoms of ASD (Corsello, 2005; Piccininni & Penner, 2016; Rogers, 1996; Rogers & Vismara, 2008). We hypothesize that the experience of an early motor intervention, between the time of diagnosis and access to gold-standard ASD treatments, may influence parental stress levels and family quality of life.

Poor motor skills are considered to be a core symptom of ASD by many (Dziuk et al., 2007; Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Liu, 2012). Unfortunately, the motor domain is often overlooked by clinicians and parents as an important part of the child's development since these children also experience delays in multiple other domains, including social skill development, communication, and emotional regulation (Gregor et al., 2018). In other words, the maladaptive behaviours most obviously impacting the daily lives of these families tend to overshadow the importance of motor skill *development* among children with ASD (Gregor et al., 2018).

Fundamental motor skills are the movement patterns (running, jumping, throwing, catching etc.) considered to be the building blocks for more advanced movements and sport specific skills (Clark & Metcalfe, 2002; Robinson & Goodway, 2009; Seefeldt, 1980). Thus, a certain level of motor skill proficiency is required for children to be able to successfully engage in active play and sport (Mandigo, Francis, Lodewyk, & Lopez, 2009). Early motor interventions may improve the movement proficiency of some children with ASD to a level where they are able to successfully participate in active play and sport. As a result, parents may perceive an improvement in their family quality of

life since the ability to engage in recreational activities, together as a family, is important to many parents (Jones et al., 2017). This is one possible mechanism through which an early motor skill intervention may influence family outcomes.

Leisure and recreational activities often include an active component, thus, in order to participate fully in such experiences, one must acquire an appropriate level of physical literacy to do so (Ketcheson, 2014). These types of activities provide plenty of opportunities for socialization and inclusion which are a high-priorities for individuals with ASD as poor social skills are a key characteristic of the disorder (American Psychiatric Association, 2013). Individuals with developmental disabilities who have participated in sport via Special Olympics, have reported several positive outcomes, including improved social competence and more positive feelings about themselves and their abilities (Harada, Siperstein, Parker, & Lenox, 2011). The benefits of such experiences have also been found to extend to athletes' family members (Harada et al., 2011). Family members of Special Olympics athletes have reported improvements in the quality of their family's interactions during activities of daily living, and improvements in sibling relationships (Harada et al., 2011). Thus, given the similarities between organized sport and group-based motor interventions, children's perceptions of themselves may change as a result of their participation in an early motor skill intervention and that these changes could influence their family members via "flow on" effects – where the effects experienced by the child, positive or negative, are carried on to their family members (Tan & Simmonds, 2018). This is another potential mechanism through which

family outcomes such as parental stress and family quality of life could be affected by a child's participation in an early motor skill intervention.

In addition to the opportunities for socialization that early motor skill interventions provide for children with ASD, they also provide opportunities for parents of different children, with the same disability, to interact with one another. Parents of children with ASD have reported that their social networks including their family, friends, and community members, influence their stress levels (Altiere & von Kluge, 2009). These parents have reported that their friendships often become compromised due to the fact that they have less time for social activities, and because their friends who have children with typical development often express discomfort when the child with ASD exhibits challenging behaviours (Altiere & von Kluge, 2009). Shared waiting rooms for parents of children with ASD may provide a comfortable setting for them to ask each other questions, share insights, and develop friendships; thus, building their social networks (Kutash & Northrop, 2007). This process explains yet another mechanism through which family outcomes, for example parental stress, may be affected as a result of a child's participation in an early motor skill intervention.

The challenging behaviours often expressed by children with ASD have been identified as a major contributor to parental stress levels (Bonis, 2016; Rao & Beidel, 2009; Shawler & Sullivan, 2017). Thus, not surprisingly, improving the behaviour of children with ASD is a common goal of many interventions and services (Howlin, Magiati, & Charman, 2009). Although the primary purpose of motor skill interventions is to assist the child with their motor development, motor proficiency has also been

positively correlated with behaviour in children with ASD (Papadopoulos et al., 2012). Therefore, early motor interventions may indirectly have a positive effect on children's behaviour and mitigate parental stress.

There are many possible mechanisms through which the experience of an early motor skill intervention for children with ASD could impact parental stress and family quality of life. Although this review has identified several ways that early motor interventions could have a positive influence on family outcomes, it is also possible that some parents may perceive some negative effects. For example, although not reported in the current literature, it is possible that some parents may perceive the burden of participating (time, travel, etc.) as outweighing the benefits of participating. Whatever the case, it is important that parents' perceptions are understood as to how early interventions for children with ASD effect the family unit. This information could inform best practices for program and intervention design and delivery, guide policy development, and support or refute the notion that there is a need for interventions – such as early motor skill interventions – between the time of diagnosis and access to traditional behavioural interventions, both for the wellbeing of the child, and their family members.

Gap in the Literature

A comprehensive review of the literature (Chapter 2) has revealed a gap concerning the indirect effects of interventions for children with ASD. Most research concerning early interventions for children with ASD has focused on child outcomes post therapy and virtually ignored family outcomes (Howlin et al., 2009; Peters-Scheffer,

Did den, Korzilius, & Sturme y, 2011). Some occupational therapy interventions have investigated their effects on families, however most only focused on parental stress as an outcome measure and quantitative methods were used as the predominant means for inquiry (Gika et al., 2012; Reed et al., 2009; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). Additionally, most, if not all, interventions that have considered family outcomes are not child-centered, meaning the intervention actually targeted the parents and/or families and measured family outcomes afterwards (Gika et al., 2012; Okuno et al., 2011; Reed et al., 2009). Qualitative inquiry provides an opportunity to gain rich insight into the perspectives of parents whose children are receiving interventions for ASD. Parents' perceptions of the intervention's effect on their family quality of life and stress levels will provide a more complete picture of the intervention's impact (Kuhaneck, Madonna, Novak, & Pearson, 2015). There is a need for researchers to understand parents' perspectives on family outcomes, using qualitative approaches, following children's participation in early interventions for ASD. To our knowledge, there have been no studies that have investigated parents' perceptions of their child's experience with an early motor skill intervention, and how this experience influenced their family's quality of life and parental stress levels.

Research Questions

1. How is parental stress and family quality of life affected by the experience of an early motor skill intervention for children with ASD?
2. What motivates parents to enroll their child with ASD in an early motor skill intervention?

Impact and Significance

Parental stress and family quality of life are well documented areas of concern among families of children with ASD and there is a clear need for further investigation into the effects of child-centered interventions on family outcomes (Bonis, 2016; Brown, MacAdam–Crisp, Wang, & Iarocci, 2006). This will be the first qualitative study to consider parents' perceptions on the effects of an early motor skill intervention, with a particular focus on changes in parental stress levels and family quality of life. As a secondary focus, this research aims to investigate parents' motivations for enrolling their child in an early motor intervention. We anticipate the findings of the proposed study will provide insight as to how clinicians and researchers can better meet the needs of families who have a child with ASD and help to guide policy development, service design and delivery, and enhance the outcomes of these children and their family members. This research will fill the current gap in the literature and ultimately improve the wellbeing of this population.

Purpose

The purpose of the proposed study is to help us understand how early motor skill interventions influence parental stress and family quality of life, from the parents' perspectives. The secondary purpose of this study is to shed light on parents' motivations for enrolling their child in an early motor skill intervention.

Theoretical Framework: Family Systems Theory

Recent recommendations within the ASD family literature have called for future research to be grounded in a family systems approach (Cridland, Jones, Magee, &

Caputi, 2014; Gardiner & Iarocci, 2015; Tint & Weiss, 2016). This approach is based on general systems theories that emphasize the interplay between elements within a larger system (Von Bertalanffy, 1968). The family systems perspective says that family members mutually and dynamically affect one another (Cox & Paley, 1997). Thus, based on this view, interventions for children with ASD will indirectly affect their family members if the intervention affects the child in any way; whether it be positive or negative.

Researchers have suggested that healthcare professionals and educators need to understand relationships between family members in order to promote optimal outcomes for children with disabilities (Ayvazoglu, Kozub, Butera, & Murray, 2015; Turnbull, Turnbull, Wehmeyer, & Shogren, 2012). Functional skills enhance children's independence in daily life, thus, affecting family dynamics (Ayvazoglu et al., 2015). Motor skill development in particular has great potential to influence the lives of individuals with disabilities- within their homes and in the community (Ayvazoglu et al., 2015). This explains why motor skill development and physical activity engagement among individuals with disabilities have previously been linked to family functioning and family wellness using systems based principles (Kozub, Oh, & Rider, 2005; Tint & Weiss, 2016). Furthermore, the fact that children with ASD are often dependent on their parents well into adulthood, accentuates the need for programming that is sensitive to the needs of the parents to facilitate best outcomes for all (Kozub et al., 2005; Tint & Weiss, 2016).

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SECTION 2: LITERATURE REVIEW

Literature Review

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong, pervasive developmental disorder marked by difficulties with social interaction and communication, and restricted/repetitive patterns of behaviour, interests, or activities, beginning in the first few years of life (American Psychiatric Association, 2013). Some common behaviours expressed by children with ASD include eye contact avoidance, poor emotional control, difficulty understanding others' emotions, motor stereotypies (ex. hand flapping), echolalia, adverse responses to certain noises or textures, and intense attachments to unusual objects, to name a few (American Psychiatric Association, 2013). The wide-ranging challenges associated with ASD have large implications for families, education, social services, and the healthcare systems.

ASD is a multi-factorial disorder that emerges as a result of many genetic and non-genetic risk factor interactions (Currenti, 2010; Kim & Leventhal, 2015; Park et al., 2016; Yuen et al., 2017). Some non-genetic risk factors include advanced parental age, prenatal exposure to toxins, and perinatal complications (multiple birth, meconium aspiration, low birthweight, etc.) (Kim & Leventhal, 2015; Wu et al., 2017). More research is needed to better understand the etiology of the disorder considering there has been a significant increase the prevalence of ASD, in North America, over the last few decades (Christensen et al., 2016; Public Health Agency of Canada, 2018). Greater public awareness, better case detection, and a change in the DSM-5 diagnostic criteria account for some of the change in ASD prevalence (Hansen, Schendel, & Parner, 2015;

Kim & Leventhal, 2015). The National Autism Spectrum Disorder Surveillance System recently released their 2018 report on autism prevalence in Canada which estimated that 1 in 66 children are currently diagnosed with ASD (Public Health Agency of Canada, 2018); similar rates have been reported by the Centers for Disease Control and Prevention in the United States (Christensen et al., 2016). Furthermore, ASD is approximately five times more common among boys compared to girls (Christensen et al., 2016; Public Health Agency of Canada, 2018), and it is likely that a greater number of parents to male children are available to participate in studies, such as this, focusing on parents' perspectives.

The literature suggests that early signs of the disorder may appear by the child's first birthday (Park et al., 2016; Zwaigenbaum et al., 2005). Some of these early behavioural signs include poor motor control, elevated emotional reactivity, language delays, and abnormal visual attention (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Ketcheson, Hauck, & Ulrich, 2017; Maestro et al., 2005; Zwaigenbaum et al., 2005). Early interventions for children with ASD have been shown to lead to better functional outcomes including significant language gains, acceleration of developmental rates, improved social behaviour, and an overall reduction in the symptoms of ASD (Corsello, 2005; Rogers, 1996; Rogers & Vismara, 2008). Although large scale interventions targeting multiple areas of children's development (such as Applied Behaviour Analysis and Intensive Behavioural Intervention) are optimal, waitlists for these types of government-funded programs are long and private services are costly (Butter, Wynn, &

Mulick, 2003; Jones, Bremer, & Lloyd, 2017; Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006).

The Ontario Autism Program funds behavioural interventions for children affected by ASD in Ontario (Canada), and although the program is currently in flux, in previous years children have waited an average of 2.7 years from the time they applied for services to the time they received the services (Piccininni & Penner, 2016). This is concerning since earlier access to services for ASD is associated with better outcomes (Corsello, 2005; Piccininni & Penner, 2016). These findings demonstrate a need for complementary, cost-effective ASD interventions that can be provided to young children between the time they are diagnosed, typically around 3-5 years of age (Ouellette-Kuntz et al., 2009; Piccininni & Penner, 2016; Public Health Agency of Canada, 2018), and the time they begin to receive behavioural interventions, approximately three years later on average (Piccininni & Penner, 2016). The time between diagnosis and access to intervention may be particularly stressful for parents due to the lack of support services available to aid in the development of their child with ASD (Stuart & McGrew, 2009).

Motor Skills and ASD

Based on the current literature, the prevalence of motor deficits among young children with ASD is high (Fournier et al., 2010; Lloyd, MacDonald, & Lord, 2013; Ming, Brimacombe, & Wagner, 2007). In fact, poor motor skills are considered to be a core symptom of ASD by many (Dziuk et al., 2007; Fournier et al., 2010; Liu, 2012). Delays in motor milestone achievement, lack of coordination, deficits in gross and fine movement, and impaired postural control encompass some of the motor components

that children with ASD often struggle with, even before the time of ASD diagnosis (Fournier et al., 2010; Ketcheson et al., 2017; Liu & Breslin, 2013; Ming et al., 2007). Furthermore, the literature indicates that children who experience motor deficits are not typically provided with treatment options to address this area of development (Ming et al., 2007; Rosenbaum, 2005). The lack of interventions targeting the motor domain help to explain why the motor skill proficiency gap between children with ASD and children with typical development increases over time (Lloyd et al., 2013). There is a clear need for ASD interventions targeted at fundamental motor skills during the early years to prevent children with ASD from falling further behind their age-matched peers in this area of development.

Fundamental motor skills are movement patterns (running, jumping, throwing, catching etc.) considered to be building blocks for more advanced movements and sport specific skills (Clark & Metcalfe, 2002; Robinson & Goodway, 2009; Seefeldt, 1980). Fundamental motor skills provide children with some independence to explore their environment and contribute to social, cognitive, and physical development (Clark, 2007; Clark & Metcalfe, 2002; Lubans, Morgan, Cliff, Barnett, & Okely, 2010; Robinson & Goodway, 2009). Basic competency within the realm of fundamental motor skills is important for children to overcome the “proficiency barrier” and experience success in a range of physical activities (Clark, 2007; Clark & Metcalfe, 2002; Robinson & Goodway, 2009; Seefeldt, 1980). There are three main groups of fundamental motor skills: locomotor skills (ex. running and skipping), object-control skills (ex. catching and throwing), and body management/stability skills (ex. twisting and balancing) (Lubans et

al., 2010). In addition to providing the foundation for children to participate in active play, motor skill proficiency is an essential component of an active lifestyle which is associated with countless health benefits (Lubans et al., 2010). It is imperative that motor skill proficiency is not over-looked among children, especially for those with ASD (Dziuk et al., 2007; Fournier et al., 2010; Public Health Agency of Canada, 2018).

Motor development and physical activity levels are closely related to physical wellbeing, mental health, and cognitive achievement in young children (Hill, 2010; Iverson, 2010). As children improve their motor proficiency, they are better able to maneuver and explore their environment via play (Wrotniak, Epstein, Dorn, Jones, & Kondilis, 2006). Thus as children improve their motor proficiency, they experience more opportunities to interact with people and objects which can provoke learning and enhance other aspects of their development (Wrotniak et al., 2006). At the same time, these novel opportunities encourage further exploration via motor activity and a cycle emerges whereby children use their motor ability to explore their environment, and by exploring their environment they learn from their experiences; learning to play and playing to learn.

Delays in motor skill acquisition are thought to contribute to the development of atypical movement patterns among children with ASD (Staples & Reid, 2010). Staples and Reid (2010) compared the fundamental motor skills of children with ASD (9-12 years) to children with typical development using the Test of Gross Motor Development-2 ($N= 28$). Children with ASD scored significantly lower for gross motor proficiency compared to their age-matched peers with typical development (Staples & Reid, 2010).

Furthermore, skill-matched comparisons found the gross motor skills of children with ASD to be comparable with children who have typical development that are half their age (Staples & Reid, 2010). Liu and Breslin (2013) also conducted a study to compare the gross motor skills of children with ASD to those of children with typical development, but instead of using the Test of Gross Motor Development-2, they used the Movement Assessment Battery for Children-2. Thirty children with ASD between the ages of 3-16 were matched to children with typical development (Liu & Breslin, 2013). No movement difficulties or motor delays were detected in any of the children with typical development, however 77% of the children with ASD experienced significant motor delays, and 3% were found to be at risk for motor delays (Liu & Breslin, 2013). These results were supported by research done by Provost, Lopez, and Heimerl (2007) where significant delays in gross motor skills were detected among younger children with ASD (21-41months old) using the Peabody Developmental Motor Scales- 2. Furthermore, Lloyd et al. (2013) found toddlers with ASD scored significantly below the expected values for gross motor skills based on chronological age, and that these delays got worse over time, using the Mullen Scale of Early Learning (Lloyd et al., 2013). Delays in fine and gross motor skills are common among children with ASD, across all ages, and they are consistently reported in the literature (Liu & Breslin, 2013; Lloyd et al., 2013; Provost et al., 2007).

The findings of Staples and Reid (2010), Liu and Breslin (2013), Provost et al. (2007), and Lloyd et al. (2013), suggest that poor motor skills among children with ASD may act as a major barrier to participation in sports or active games with their age-

matched peers who have typical development; for example, during physical education class or recess. The discrepancy in motor skill proficiency between children with ASD and children with typical development may promote segregation and discourage play participation (Liu & Breslin, 2013; Lloyd et al., 2013; Provost et al., 2007; Staples & Reid, 2010). Early motor interventions may lessen the movement proficiency gap between children with ASD and their peers with typical development and promote inclusion and participation in active play settings. Active play is known to benefit other areas of children's development including social skills and cognition (Lubans et al., 2010; Payne & Isaacs, 2012).

The United Nations High Commission for Human Rights recognized the importance of play for child development by mandating play as the right of every child (United Nations, 1989). Play is a vehicle through which children use creativity and develop their physical strength, cognitive abilities, emotional control, imagination, and dexterity (Ginsburg, 2007; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004). As children develop the motor proficiency required to explore their world, play allows them to develop new competencies, become more resilient, and improve their confidence in dealing with challenges as they navigate through life (Erickson, 1985; Ginsburg, 2007; Hurwitz, 2002). These qualities are often lacking in children with ASD as they frequently struggle with social communication and emotional regulation (American Psychiatric Association, 2013; Laurent & Rubin, 2004). Early motor interventions may provide opportunities for these children to develop skills, such as resiliency and

confidence, that will help them deal with daily challenges and influence their quality of life (Erickson, 1985; Ginsburg, 2007; Hurwitz, 2002).

Free play is a particular form of child-driven play that lacks instruction or direction from others (Ginsburg, 2007). This valuable form of play affords children the opportunity to learn how to share, negotiate, problem solve, and work with others (Erickson, 1985; Hurwitz, 2002; McElwain & Volling, 2005; Pellegrini & Smith, 1998). In doing so, they are able to develop decision-making skills and engage fully in what they wish to pursue (Erickson, 1985; Hurwitz, 2002; Pellegrini & Smith, 1998). For example, two children who wish to play with the same yellow ball may discover joy in sharing the ball and playing together, or they may discover that it suits them better to take turns so that they each get a chance to play independently with the ball. Free play provides children with a unique opportunity to use their motor abilities for skill development in many different domains; however, when children lack the ability to move proficiently, they tend to engage in more sedentary behaviour during free play and become more isolated from their peers (Williams et al., 2008). In doing so, they miss out on the developmental opportunities listed above. Ensuring children with ASD develop the motor skills required to engage in active play may have important implications for their overall wellbeing.

In order for children to be able to engage successfully in active play, they must first develop a certain level of motor skill proficiency (Logan, Robinson, Wilson, & Lucas, 2012). Even then, studies show that the degree of motor skill proficiency children develop can have an influence on what types of activities they choose to engage in

(O'Neill et al., 2013), and the physical intensity they choose to perform at (Williams et al., 2008). The current literature is sparse with regards to motor skill levels and activity preferences among children with ASD, however, there has been some investigation into this phenomenon among children with typical development. O'Neill et al. (2013) examined the relationship between motor skill proficiency and the types of activities that children with typical development (3-5 years) chose to engage in during free play at preschool ($N=264$). Ultimately, children chose to participate in the activities that required the skills they were good at (O'Neill et al., 2013). Furthermore, children with superior motor skills have been shown to spend significantly more time engaging in moderate-vigorous physical activity compared to children with poorer motor skill proficiency; and children with poor motor skill proficiency typically spend more time performing sedentary activities (Williams et al., 2008). Although these same principles have yet to be investigated among children with ASD, it is likely that the same patterns would emerge, 1) those who are more proficient movers choose to participate at higher intensities, and 2) children choose to engage in activities that require their more proficient motor skills. For example, if a child is not able to kick a ball successfully, regardless of if they have ASD or not, they likely will not want to participate in a soccer game with their peers during recess. The findings of O'Neill et al. (2013) and Williams et al. (2008) showcase the relationship between motor skill proficiency and play among young children. If children lack the motor skill proficiency required to successfully engage in active play with their peers, as children with ASD often do (Liu & Breslin,

2013; Lloyd et al., 2013; Provost et al., 2007), they are more likely to avoid these types of active play settings and fall further behind.

Young children are more likely to engage in things that they are good at (O'Neill et al., 2013); thus poor motor skills may partially explain why children with ASD have lower levels of physical activity compared to children with typical development (Hinckson, Dickinson, Water, Sands, & Penman, 2013). Avoiding active play due to poor motor skill proficiency can also have significant implications for several other areas of development (Lubans et al., 2010). Not only would these children miss out on opportunities to practice their motor skills via play and increase their movement competence, but they would also miss out on opportunities for socialization and cognitive development as well (Lubans et al., 2010; Payne & Isaacs, 2012; Sibley & Etnier, 2003). This is troublesome since children with ASD are often delayed in these areas of development as well (American Psychiatric Association, 2013). Early motor skill interventions should be provided to young children with ASD who have motor delays to facilitate all areas of development.

A number of researchers have demonstrated the efficacy of motor interventions for improving the fundamental motor skills of children with ASD (Bremer, Balogh, & Lloyd, 2015; Bremer & Lloyd, 2016; Ketcheson et al., 2017; Pan, 2010). Bremer et al. (2015) noted significant gains in the gross motor skills of four year old children with ASD following a 12 week intervention. Similarly, Bremer and Lloyd (2016) found significant improvements in the fundamental motor skills of 3-7 year old children with ASD like characteristics following two 6-week blocks of motor instruction. In addition, Pan (2010)

discovered significant improvements in the water skills of 5-9 year old children with ASD following a 10-week aquatic motor intervention. And, finally, Ketcheson et al. (2017) found significant improvements in the motor skills of 4-6 year-olds with ASD following an 8 week motor skill intervention. Overall, these studies demonstrate the potential for motor skill interventions to positively influence the developmental trajectory of children with ASD in the motor domain.

The primary effects of motor skill interventions seem positive and clear; however, the secondary effects of such interventions are not as well understood. Very few researchers have investigated the secondary effects of motor skill interventions for children with ASD (Ketcheson et al., 2017), and, those who have, focused on the secondary effects of the intervention on the child, not on the family. Behavioural shifts among the children receiving the motor intervention are the most common secondary effect studied (Bremer, Crozier, & Lloyd, 2016). Changes in adaptive behaviours, stereotypic behaviours, attention, and social skills encompass the main behavioural changes that have been investigated to date (Bremer & Cairney, 2018; Bremer et al., 2016; Bremer & Lloyd, 2016; Ketcheson et al., 2017; Pan, 2010). The secondary effects of motor skill interventions on families of children with ASD are not well understood due to the lack of research in the area.

Families of Children with ASD

Parents of children with ASD have consistently reported higher levels of stress and lower levels of family quality of life compared to parents of children with typical development and compared to parents of children with other developmental disorders

(Bonis, 2016; Gardiner & Iarocci, 2015; Hoefman et al., 2014; Jones et al., 2017; Stuart & McGrew, 2009). As the prevalence rates of ASD continue to rise, the needs of parents of children with ASD – for example, the need to develop coping strategies in order to better manage their child’s challenging behaviours – are becoming increasingly important to social services (Christensen et al., 2016; Public Health Agency of Canada, 2018). There is an increasing need for cost-effective early interventions for children with ASD that also contribute to family outcomes – such as lower stress levels and higher family quality of life scores – in addition to improving the children’s level of functioning (Lavelle et al., 2014).

It is important that services and interventions designed for children with ASD are sensitive to the needs of the whole family, as family members typically act as the primary support network for the child; caregivers are constantly navigating the many challenges associated with supporting the individual with ASD (Gardiner & Iarocci, 2015). Parents have reported that the challenges associated with caring for their child with ASD are especially burdensome in the first six months after their child’s diagnosis (Stuart & McGrew, 2009). These findings suggest that early interventions carried out between the time of diagnosis and the commencement of fulltime intensive interventions (such as Applied Behaviour Analysis or Intensive Behavioural Interventions) provide a critical opportunity to address the wellbeing of the parents. During this time, parents may be left in a state of limbo whereby they may not have the skills to manage their child’s challenging behaviours, nor the knowledge to promote best developmental outcomes (Jones et al., 2017; Piccininni & Penner, 2016; Rivard, Terroux,

Parent-Boursier, & Mercier, 2014). Access to alternative interventions for children with ASD, such as early motor skill interventions, may reduce parental stress during wait times while also assisting children to reach their full developmental potential. These outcomes could have important implications for overall family quality of life.

There is a lack of research investigating the impact of early interventions for ASD on the family unit. Thus, it is unknown which types of interventions for children with ASD have the greatest influence on parent's and family's wellbeing. Occupational therapy interventions for children with ASD encompass most of the research which has measured family outcomes, including changes in quality of life and parental stress, following children's participation in early interventions (Binnendyk & Lucyshyn, 2009; Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Fava et al., 2011; Kuhaneck, Madonna, Novak, & Pearson, 2015; Okuno et al., 2011). Kuhaneck et al. (2015) recommend that more researchers conducting interventions for children with ASD should measure the intervention's effects on the family unit and consider using more than parenting stress alone to infer family functioning; quality of life measurements in addition to parental stress measurements are thought to be more representative (Kuhaneck et al., 2015). Earlier access to interventions could improve children's developmental trajectory, reduce parental stress, and influence these families' overall quality of life.

Family Quality of Life

There is mounting evidence which suggests that families of children with ASD experience lower quality of life compared to families of children with typical

development (Hoefman et al., 2014; Jones et al., 2017; Vasilopoulou & Nisbet, 2016). Zuna, Summers, Turnbull, Hu, and Xu (2011) proposed a unified theory of family quality of life for families of children with disabilities. They defined family quality of life as “a dynamic sense of wellbeing of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (Zuna et al., 2011, p. 273). Within this conceptualization, interventions are seen as mediators of family quality of life as they impact the family unit as a whole in addition to its individual members (Zuna et al., 2011). From this view, all family members are affected when a child has a disability, and interventions are seen as important resources that can help to elicit optimal outcomes for all family members. Improvements in the quality of life of individuals with developmental disabilities and their family members is an important goal of many public policies and there is a need for more research on the efficacy of services and interventions for achieving this outcome (Zekovic & Renwick, 2003).

Ideally, children with ASD experience behavioural improvements as a result of participation in interventions (Bremer et al., 2016), which in turn, according to Zuna et al. (2011), could impact the overall quality of life of the family. For example, parents may perceive an improvement in their family quality of life if their child with ASD is able to participate in bike rides with their family members as a result of their participation in a motor skill intervention. Alternatively, parents may perceive a decrease in their stress levels after conversing and sharing insights with other parents whose children are also participating in the intervention. Research is needed to build our understanding on the wide-reaching effects of different types of interventions in order to fully appreciate how

these programs impact the families of children with ASD and aid in the development of best practices.

Although it is valuable for researchers to measure the influence of interventions for children with ASD on the family unit, the secondary effects of such interventions are not commonly investigated (Karst & Van Hecke, 2012; Tan & Simmonds, 2018). Thus, the current literature pertaining to family outcomes following children's participation in interventions/services is sparse. Research conducted by Tan and Simmonds (2018) explored parents' perceptions ($N= 5$) of psychosocial outcomes following a horseback riding intervention for children and adolescents (ages 3-14) with ASD. Tan and Simmonds (2018) employed a semi-structured interviewing technique and used an interpretive phenomenological approach to analyze transcripts. Some of the main themes that emerged from the data included perceived improvements in children's self-concept, emotional wellbeing, self-regulatory behaviour, and social skills, as well as some unexpected benefits to parents and families (Tan & Simmonds, 2018). For example, parents reported feeling more relaxed, empowered, valued, prideful, and satisfied as a result of their child's participation in an equine assisted intervention (Tan & Simmonds, 2018). These findings bring attention to the fact that children's participation in interventions for ASD can influence the wellbeing of the parents. Parents also reported less difficulty managing their child's behavioural challenges and that they were able to generalize the skills that the children learned during the study, to other contexts (Tan & Simmonds, 2018). Transferability of skills is important among this

population as ASD is a pervasive disorder that influences several areas of development across a host of different contexts (American Psychiatric Association, 2013).

Early motor interventions for children with ASD provide opportunities for children to learn soft skills, in addition to motor skills, that may also be transferable to several contexts (MacDonald, Lord, & Ulrich, 2013; Tan & Simmonds, 2018). For example, turn-taking and sharing are valuable skills that are emphasized during early motor interventions, and children may be able to utilize these skills in the home and school settings (MacDonald et al., 2013). Furthermore, parents may be able to incorporate the active games they learn from motor interventions into their family life and experience long-term improvements in their perceived quality of life as a result. Transferability of learning and skills from the lab setting, to the home and school settings, could have significant implications for family quality of life.

Benefits experienced by children as a result of their participation in services and interventions for ASD may extend to family members via “flow on” effects (Tan & Simmonds, 2018). A parent who participated in Tan and Simmonds (2018) study explained that the benefits of the intervention for the child “trickled down to the rest of us”, suggesting that the positive effects experienced by the child carried on to other family members. This is consistent with the family quality of life conceptualization put forth by Zuna et al. (2011) whereby changes in individual functioning have an influence on the family as a whole, and in turn, the shift in the family’s dynamic influences each individual further. Thus, it is important for future research to investigate parent and family outcomes following ASD interventions to improve our understanding of the

effects of different treatment options on family quality of life. Interventions for children with ASD that improve family quality of life may bolster positive outcomes for the children in a bidirectional manner.

The specific factors that have the largest influence on family quality of life among families of children with ASD were investigated by Jones et al. (2017) using a survey. The sample consisted of parents of children with ASD who were on a waitlist for Applied Behaviour Analysis intervention. Jones et al. (2017) determined that the health of all family members, not just the child with ASD, had a significant influence on family functioning and quality of life. In addition, the majority of participants (86%) indicated that leisure and recreational activities were important to their family's quality of life, yet many were not engaging in these activities on a regular basis, and those who were, did not consistently include their child with ASD (Jones et al., 2017). Furthermore, when asked what kind of personal support services they would prefer, 52% of parents of children with ASD suggested programs targeted at their own wellbeing, including exercise-based programs, to help them cope with their child's difficult behaviours (Bitsika & Sharpley, 2004). These findings speak to the value of active recreation from parents' perspectives (Bitsika & Sharpley, 2004; Jones et al., 2017). Physical activity is an important component of many recreational opportunities that allow family members to socialize and participate together (family bike rides, backyard soccer games, charity walks within the community, etc.). Active play-based motor interventions may be a cost-effective way to benefit the health of all family members by increasing physical activity levels; and improve family quality of life by developing the motor skills of the child to a

level where they are able to participate fully in such activities with their family members.

By observing and participating in play with their children, parents are able to view the world from their child's perspective as they engage in activities to fit their own needs (Ginsburg, 2007). Social interaction between parents and children during play helps to build enduring relationships and allow for better communication between them as parents are able to understand their children better (Henry, 1990; Smith, 1995; Tamis-LeMonda et al., 2004; Tsao, 2002). Participation in play is especially important among children with ASD since they typically struggle with communication and may be able to use play to express their views and frustrations and help their parents to understand them better. Better communication between parents and their children could impact overall family quality of life.

A study by Toscano, Carvalho, and Ferreira (2018) examined the effects of a 48-week exercise-based intervention for children (6-12 years) with ASD on parent-perceived quality of life, and children's autistic traits and metabolic profiles. Parents perceived an improvement in their child's quality of life as a result of the exercise-based intervention and identified three factors which had the greatest impact on their family's overall quality of life, including: 1) whether or not their child had a major health concern, 2) whether or not services were satisfying the family's needs, and 3) whether or not their family had opportunities to engage in leisure and recreational activities together (Toscano et al., 2018). These findings add to those of Bremer et al. (2016) as they demonstrate the wide reaching positive effects of exercise, and mirror those of

Jones et al. (2017) as they highlight the importance of recreational opportunities for families of children with ASD. As well, Toscano et al. (2018) noted improvements in children's health (metabolic indicators: HDL, LDL, and total cholesterol levels) and autistic traits (such as verbal and nonverbal communication skills) as a result of the exercise intervention. These findings indicate that exercise-based interventions for children with ASD may influence their behaviour which, in turn, can influence parent's perceptions of their child's wellbeing and overall family quality of life.

Parents have reported that participation in recreational activities is important to them (Jones et al., 2017), thus, not surprisingly, limited opportunity for family members to engage in recreational activities has been shown to have a negative influence on family quality of life. Reports of low quality of life among parents have been associated with a reduced ability to effectively manage the special needs of their child with ASD (Gardiner & Iarocci, 2015; Jones et al., 2017). Thus, in order to promote best outcomes for all, early interventions for children with ASD should address the needs of the family, such as their desire to participate in recreational activities together.

Although recreational activities appear to be important to parents of children with ASD - thus influencing their family quality of life - children and adolescents with ASD are less likely to be active compared to their peers with typical development (Gregor et al., 2018; Pan et al., 2016; Tyler, MacDonald, & Meneer, 2014). Many barriers to physical activity participation have been identified by these parents including limited financial resources, difficulty coordinating family members schedules, their child's behaviour, balancing work and family responsibilities, limited awareness of available

programs, and limited program options (Gregor et al., 2018; Jones et al., 2017; Mactavish & Schleien, 2004). Gregor et al. (2018) interviewed parents of adolescents with ASD in order to examine their perspectives and experiences of physical activity participation involving their child. Parents reported that they prioritized treatment of the core deficits of ASD through Applied Behaviour Analysis interventions, Speech/Language Therapy, and Occupational Therapy, following their child's diagnosis (Gregor et al., 2018). Although many parents acknowledged the importance of physical activity for gross motor skill development and health, they reported that physical activity was less of a priority to them given the child's additional needs and parents limited resources (Gregor et al., 2018). Children's behaviour, cognitive functioning, and language development are important for school success which may explain parents' preferences toward these types of interventions. If early motor interventions were, however, made available and affordable during the time between ASD diagnosis and enrollment in intensive intervention programs, engagement in physical activity during the early years may be more likely and could positively influence the health of the individual and their family members, both in the short term and long term.

Gregor et al. (2018) hypothesized that limited engagement in physical activity during childhood contributed to less active lifestyles during adolescence by impeding motor skill development and successful participation. Thus, in addition to the previously mentioned barriers to physical activity participation among these families (finances, time, schedules, etc.), children with ASD often lack the necessary skills to participate successfully in active recreation which likely deters them from wanting to engage in

these activities as they get older (Bhat, Landa, & Galloway, 2011; Gregor et al., 2018; Pan et al., 2016). This is problematic since children with ASD are at a higher risk for obesity and the associated health consequences compared to children with typical development due to their commonly restricted food preferences (Schreck, Williams, & Smith, 2004), lower levels of physical activity (Hinckson et al., 2013), use of antipsychotic medications (Esbensen, Greenberg, Seltzer, & Aman, 2009), and behavioural problems (Broder-Fingert, Brazauskas, Lindgren, Iannuzzi, & Van Cleave, 2014; Shedlock et al., 2016). It is important for children with ASD to gain experience with physical activity and recreation during their early years in order for them to develop the skills required to maintain an active lifestyle and optimize health and functional outcomes (Bhat et al., 2011; Gregor et al., 2018; Lloyd et al., 2013; Pan et al., 2016).

Educating people on the importance of physical activity is one thing, but getting them active is a whole other thing (van Sluijs, McMinn, & Griffin, 2007). Gregor et al. (2018) suggested that physical therapists may be able to facilitate physical activity participation among families of children with ASD by working with the parents to identify, and provide information on, developmentally appropriate motor interventions and/or programs that they would be eligible for. Furthermore, personally meaningful recreation is considered to be a key component of quality of life (Heyne, Schleien, & Rynders, 1997; Mactavish & Schleien, 2004; Velde, 1997), thus, the overall quality of life of the families may improve if children with ASD are able to successfully engage in recreation with their family members.

These studies demonstrate the effects of child behaviour, health, physical activity, and opportunities for recreational activities, on the quality of life of families of children with ASD (Gregor et al., 2018; Hoefman et al., 2014; Jones et al., 2017; Mactavish & Schleien, 2004; Toscano et al., 2018). As the prevalence rates of ASD continue to rise, the poor health status of these children and their families places great strain on the healthcare system (Public Health Agency of Canada, 2018). The needs of these families should be considered when designing interventions and services for children with ASD, and, it is important that they are made available in a timely fashion following the child's diagnosis as to not exacerbate parental stress while encouraging best outcomes for all (Lavelle et al., 2014; Piccininni & Penner, 2016).

Parental Stress

Parents of children with ASD report higher levels of stress, anxiety, and depression compared to parents of children with typical development and parents of children with other developmental disabilities (Bonis, 2016; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Padden & James, 2017; Zablotsky, Bradshaw, & Stuart, 2013). Parents' social networks including their family, friends, and community members, have been reported as one of the factors that influence parents' stress levels (Altiere & von Kluge, 2009). Parents of children with ASD have expressed that their friendships often become compromised as they spend much of their time managing the many needs of their child and have less time for social activities (Altiere & von Kluge, 2009). As well, parents of children with typical development often express discomfort in response to the child with ASD when they exhibit challenging behaviours (Altiere & von Kluge, 2009).

Group interventions for children with ASD may indirectly facilitate socialization among parents and create opportunities to build their social networks. A study by Bromley, Hare, Davison, and Emerson (2004) found that 69% of mothers of children with ASD wanted opportunities to meet other parents; it is possible that shared waiting rooms may provide a comfortable environment for parents to do so (Kutash & Northrop, 2007). When children are engaging in an intervention, parents of children with the same diagnosis may ask each other questions, share insights, and develop friendships; thus, building their social networks (Kutash & Northrop, 2007). The development of such friendships may positively impact parental stress levels and reduce feelings of isolation (Kutash & Northrop, 2007).

Many studies have identified the challenging behaviours exhibited by children with ASD as a primary contributor to elevated stress levels among parents (Bonis, 2016; Rao & Beidel, 2009; Shawler & Sullivan, 2017). Some of these challenging behaviours include aggression and self-injury (Fodstad, Rojahn, & Matson, 2012), tantrums (Ludlow, Skelly, & Rohleder, 2012), inappropriate statements in public places, tuning out, repetitive movements, poor body control, and unusual responses to sensory stimuli (Bonis, 2016). Rao and Beidel (2009) analyzed stress levels among parents of high functioning children with ASD compared to parents of children with typical development using the Parenting Stress Index. Additionally, they compared parent reported scores of family functioning between the two groups using the Family Environment Scale (Rao & Beidel, 2009). Lastly, the Child Behavioral Checklist was used to measure the severity of challenging behaviours expressed by the 8-14 year-old children (Rao & Beidel, 2009).

Parents of children with ASD reported significantly higher stress levels as a result of the challenging behaviours expressed by their children (Rao & Beidel, 2009). An investigation conducted by Shawler and Sullivan (2017) found similar results using the Parenting Stress Index and Eyberg Child Behaviour Inventory. Parent's stress levels were positively correlated with disruptive behaviours exhibited by their child(ren) with ASD between the ages of 3-11 years-old (Shawler & Sullivan, 2017). Despite the age difference between the children in each of these studies, the results are consistent in reporting the association between greater behavioural challenges in children and higher stress among parents.

Few researchers have studied the association between motor skills and behavioural challenges in children with ASD. A study conducted by Papadopoulos et al. (2012) used the Movement Assessment Battery for Children to measure motor impairment, and the Developmental Behavioural Checklist to measure emotional and behavioural disturbances in 6-13 year-old children with ASD ($N=73$). Researchers found significant positive correlations between impairments in motor proficiency and emotional/behavioural disturbances (Papadopoulos et al., 2012). In a separate study, Bremer and Cairney (2018) used the Movement Assessment Battery for Children to measure motor coordination, and the Vineland Adaptive Behavior Scales (2nd edition) to assess adaptive behaviour among 7-12 year-old children with ASD ($N=26$). This study also found a correlation between motor coordination difficulties and challenging behaviours (Bremer & Cairney, 2018). Overall, these findings suggest that we may be able to use motor interventions as a means to have a positive impact on the behaviour

of children with ASD. The positive, secondary effects of behavioural improvements on parents stress levels may be particularly impactful immediately following the child's diagnosis as families wait to gain access to government-funded services (Piccininni & Penner, 2016).

The effects of children's behavioural problems on parental stress is clear, perhaps less obvious are the effects of parental stress on interventional outcomes among children. Osborne, McHugh, Saunders, and Reed (2008) performed a study that investigated the effects of parenting stress on young children's (2-4 years of age) responses to their first ASD intervention; for example, speech therapy. Several tools were used, including: the Psycho-educational Profile-Revised to assess the strengths and weaknesses of the children, the British Abilities Scale to assess children's cognitive abilities, the Vineland Adaptive Behavior Scale to assess children's adaptive functioning, and the Questionnaire on Resources and Stress to assess parents stress levels (Osborne et al., 2008). Researchers found that high levels of parenting stress counteracted intervention effectiveness for intellectual, educational, and adaptive behaviours in children with ASD (Osborne et al., 2008). In other words, these findings suggest a need for parental stress reduction and management prior to children's participation in interventions targeted at these developmental domains. Again, the period spent waiting, between the child's diagnosis and their eventual admission to intensive behavioural interventions, may be a prime opportunity for interventions to reduce parental stress and facilitate best outcomes for all. Research on early interventions for children with ASD, rarely measure the effects of the intervention on the family unit.

Thus, it is difficult to know which types of interventions for children with ASD translate into the best outcomes for families as a whole (Kuhaneck et al., 2015).

Behavioural improvements are the goal of many interventions for children with ASD as they often struggle with emotional regulation and control (American Psychiatric Association, 2013). A systematic review conducted by Bremer et al. (2016) sought to examine the behavioural outcomes of children with ASD following their participation in exercise interventions. Thirteen studies were included and a range of physical activities were used among them, including; jogging, horseback riding, martial arts, dance, swimming, and yoga (Bremer et al., 2016). The results of this review demonstrated the efficacy of exercise-based interventions for improving behaviour among children with ASD (Bremer et al., 2016). Some notable behavioural outcomes included reduced stereotypic behaviours (Bahrami, Movahedi, Marandi, & Abedi, 2012; Petrus et al., 2008), improved attention and cognition (Nicholson, Kehle, Bray, & Heest, 2011; Rosenthal-Malek & Mitchell, 1997), and improved social-emotional functioning (Bass, Duchowny, & Llabre, 2009; Gabriels et al., 2012; Movahedi, Bahrami, Marandi, & Abedi, 2013). These are important findings considering the correlation between improved behaviour among children with ASD and lowered stress levels reported by parents (Rao & Beidel, 2009), and the relationship between reduced parental stress and better outcomes for parents and children (Bonis, 2016; Osborne et al., 2008). Bremer et al. (2016) recommend that future research involving exercise interventions for children with ASD should focus on the behavioural outcomes of the children in order to better understand the extent of the benefits associated with physical activity among this

population. Furthermore, investigation into the effects of these behavioural improvements on parental stress levels and overall family quality of life will provide valuable insight regarding exercise-based interventions in a wider context.

Motor skill interventions for children with ASD provide opportunities for parents to build their social networks, for children to improve their behaviour (Bremer et al., 2016), and for families to engage in recreation, which have all been shown to reduce parental stress levels. In addition, exercise-based interventions also provide a means for families to increase their physical activity levels, which in and of itself have major implications for health and wellbeing (Jackson, 2013). Reduced stress levels among parents lead to better health outcomes for the parents, and better intervention outcomes for their children (Osborne et al., 2008). Unfortunately, there has been little qualitative investigation into the effects of motor interventions for children with ASD on parental stress. Moreover, the influence of changes in parental stress levels on overall family quality of life has yet to be studied within this population. Future research should address this gap in the literature as these findings could have implications for practice.

Conclusions

The wellbeing of parents of children with ASD are becoming a greater concern for social services as the prevalence of ASD continues to rise (American Psychiatric Association, 2013; Zekovic & Renwick, 2003). Parents of children with ASD consistently report high levels of stress and lower levels of family quality of life compared to parents of children with typical development, and parents of children with other developmental disabilities such as Down Syndrome (Bonis, 2016; Gardiner & Iarocci, 2015; Hoefman et

al., 2014; Jones et al., 2017; Stuart & McGrew, 2009). There is a need for future research to investigate the effects of early interventions for children with ASD on the family unit in order to understand the impact of these interventions in a wider context. Early motor interventions may have an influence on several areas of children's development and effect parents stress levels and family quality of life as a result. However, no research, to our knowledge, has explored parents' perspectives pertaining to the effects of an early motor intervention on their stress levels and family quality of life. Investigation into the experiences of parents whose children have completed an early motor intervention is needed in order to understand the true effects of the intervention on the family unit.

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SECTION 3 MANUSCRIPT 1:

**Why Do Parents Enroll Their Children with ASD in Early Motor Skill Interventions and
How Do Parents Benefit From the Experience?**

Abstract

Purpose: The purpose of this qualitative investigation is to describe: (1) the stress and family quality of life of parents of children with Autism Spectrum Disorder (ASD), (2) parents' motivations for enrolling their child(ren) with ASD in the early motor skill intervention, (3) the parent-level benefits of an early motor skill intervention for children with ASD, and (4) how those benefits influence the family unit.

Methods: Parents of four year-olds with ASD who participated in an early motor skill intervention, were invited to take part in a single interview session (N=8). Semi-structured interviews were audio-recorded, transcribed, and analyzed using NVivo software. Interpretive phenomenology was used to ground this qualitative study in order to gain a deep understanding of parents' lived experiences.

Results: (1) Parents described high stress levels and several factors that influence their family's quality of life (e.g. child's challenging behaviours). (2) They also explained several reasons for enrolling their children in the motor skill intervention that could be grouped into three major themes: *potential child-level benefits* (e.g. social skill development), *potential parent level benefits* (e.g. opportunity to meet other parents), and the fact the intervention was *free and had no waitlist*. (3) Three major themes emerged regarding parents' experiences with the motor intervention for their child.

Theme 1: Parent attendance was essential for parent-level benefits (e.g. observing child success), *Theme 2: Eye-opening experience for parents* (e.g. shed light on children's challenges and capabilities). *Theme 3: Parents viewed the intervention as a positive*

experience. (4) Parents also described several ways in which the parent level benefits of the intervention extended to their family unit.

Conclusions: Overall these findings indicate that the experience of an early motor skill intervention for children with ASD can have a positive influence on parents and families.

Introduction

Families of Children with ASD

Parents of children with Autism Spectrum Disorder (ASD) have consistently reported higher levels of stress and lower levels of family quality of life compared to parents of children with typical development and compared to parents of children with other developmental disorders (Bonis, 2016; Gardiner & Iarocci, 2015; Hoefman et al., 2014; Jones, Bremer, & Lloyd, 2017; Stuart & McGrew, 2009). As the prevalence rates of ASD continue to rise, the needs of the parents – for example, the need to develop strategies in order to better manage their child’s challenging behaviours – are becoming increasingly important to social services (Christensen et al., 2016; Public Health Agency of Canada, 2018). There is a growing need for cost-effective, early interventions that contribute to family outcomes, such as lower stress levels and higher family quality of life scores, in addition to benefiting the children with ASD (Lavelle et al., 2014).

Interventions and services for children with ASD should be designed in a way that is sensitive to the needs of the whole family, as parents and siblings typically act as the primary support network for the child (Gardiner & Iarocci, 2015; Tint & Weiss, 2016). Parents have reported that the challenges associated with caring for their child with ASD are especially burdensome in the first six months after their child’s diagnosis (Stuart & McGrew, 2009). In previous years, children in Ontario (Canada) waited an average of 2.7 years from the time they were diagnosed to the time they gained access to government-funded behavioural interventions (Piccininni & Penner, 2016). These findings suggest that early interventions carried out between the time of diagnosis and

the commencement of fulltime intensive interventions (such as Applied Behaviour Analysis or Intensive Behavioural Interventions) provide a critical opportunity to address the wellbeing of the parents as well as the children with ASD. During this period, parents may be left in a state of limbo where they may not have acquired the skills to effectively manage their child's challenging behaviours, nor the knowledge to promote the best developmental outcomes (Jones et al., 2017; Piccininni & Penner, 2016; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Access to interventions for children with ASD, such as early motor skill interventions, may reduce parental stress during wait times for traditional services while also assisting children to reach their full developmental potential. Lower stress among parents and better developmental outcomes among children could have important implications for overall family quality of life.

The literature investigating the impact of early interventions for ASD on the family unit is currently in its infancy. Thus, it is unknown which types of interventions have the greatest influence on parents' and families. Occupational therapy interventions encompass most of the research which has measured family outcomes, including changes in quality of life and parental stress, following children's participation in early interventions (Binnendyk & Lucyshyn, 2009; Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Fava et al., 2011; Kuhaneck, Madonna, Novak, & Pearson, 2015; Okuno et al., 2011). It has been recommended that more researchers investigate the intervention's effects on the family unit as a whole, and consider using more than parenting stress alone to infer family functioning; perceptions of family quality of life in addition to parental stress may be more representative (Kuhaneck et al., 2015).

Family Quality of Life

Family quality of life is one outcome variable that can be measured to infer overall wellbeing of the family unit (Zuna, Summers, Turnbull, Hu, & Xu, 2011). Zuna et al. (2011) proposed a unified theory of family quality of life for families of children with disabilities. They defined family quality of life as “a dynamic sense of wellbeing of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (Zuna et al., 2011, p. 273). Within this conceptualization, interventions are seen as mediators of family quality of life as they impact the family unit as a whole in addition to its individual members (Zuna et al., 2011). From this view, all family members are affected when a child has a disability, and interventions are seen as important resources that can help to elicit optimal outcomes for all family members. Improvements in the quality of life of individuals with developmental disabilities and their family members is an important goal of many public policies (Zekovic & Renwick, 2003).

Potential for Early Motor Skill Interventions to Influence Families

Fundamental motor skills include movements such as running, jumping, throwing, and catching (Payne & Isaacs, 2012). These skills provide an important foundation from which children can develop more advanced movements and sport specific skills (Clark & Metcalfe, 2002; Robinson & Goodway, 2009; Seefeldt, 1980). In order to successfully engage in active play and sport, a certain level of motor skill proficiency is required (Mandigo, Francis, Lodewyk, & Lopez, 2009), yet children with ASD often have delayed and poor-quality motor skills (Dziuk et al., 2007; Fournier, Hass, Naik, Lodha, &

Cauraugh, 2010; Liu, 2012). In an effort to improve children's movement proficiency and promote their engagement in active play, several researchers have conducted motor skill interventions (Bremer, Balogh, & Lloyd, 2015; Bremer & Lloyd, 2016; Ketcheson, Hauck, & Ulrich, 2017; Pan, 2010). The efficacy of these interventions for achieving their primary purpose- improving children's motor skills- seem positive and clear, however, the effects of early motor skill interventions on the family unit, are not well understood.

Purpose

This study aims to describe parents' perspectives of their stress and family quality of life, the parent-level benefits of an early motor skill intervention for children with ASD, and how those benefits influence the family unit. The secondary aim of this study is to understand parents' motivations for enrolling their child(ren) with ASD in the early motor skill intervention.

Methods

Recruitment/Participants

This study was approved by the Research Ethics Board at the University of Ontario Institute of Technology (UOIT) in Oshawa, Ontario (Appendix 1). Parents of four year-old children with ASD who had participated in a 12-week motor skill intervention at UOIT were invited to participate in an interview session. Six families were randomly selected and contacted via email by the principal investigator on the motor skill intervention study (Appendix 3). All six families confirmed their desire to participate in this study and each parent who expressed interest (either one parent or both parents from each of the six families) was provided with additional information about the study

(Appendix 4) as well as the consent form (Appendix 2). A total of eight parents participated (N=8), including two couples. All participants signed informed consent before the study began.

Motor skill intervention description.

The motor skill intervention included small groups of three to five year-old children with ASD. It ran twice per week for 12 weeks and each session lasted one hour. Staff to child ratios were high- approximately 1:1 or 1:2- and sessions were designed to follow a similar structure: a short warm-up guided by music, a series of motor-based activities (individual and group-based), and 15 minutes of free play to finish. The motor-based activities targeted a specific motor skill (running, throwing, jumping, etc.) each week (two sessions). Visual demonstrations and verbal instructions were provided for each activity. For individual motor-activities, children were first required to listen to the instructions while sitting on their designated square, in order to receive a turn.

Study Design

This study employed a qualitative research approach and was grounded in interpretive phenomenology. Interview sessions were conducted by the primary author using a semi-structured interviewing technique to elicit a rich description of parents' experiences with the early motor skill intervention for their child(ren). Interviews lasted between 40-90 minutes and each session was audio-recorded. Particular attention was paid to parents' motivations for enrolling their children in the motor skill intervention, the direct benefits of the intervention for the parents (e.g. reduced stress), and how those benefits influenced families (e.g. family quality of life). Since interview

participants were parents of children with ASD, the terms “parents” and “participants” will be used interchangeably for the remainder of this work.

Procedures

After consent was obtained, parents were given a voluntary Demographic Information Form (Appendix 5) to complete. The purpose of this form was to provide the researchers with some additional information that would help them to interpret the participants' comments in the context of their family life. Parents who had more than one child participate in the motor intervention were asked to complete one Demographic Information Form for each child.

Once the forms had been completed the audio-recorders were turned on and the interview began. The interview consisted of eight main questions, some of which had multiple follow-up questions as displayed in Table 1.

Table 1

Semi-Structured Interview Guide Questions

Interview Questions
1. Can you tell me a little bit about your child with ASD?
2. Why did you choose to enroll your child in the motor intervention?
3. What did you expect that you or your child would gain from the intervention?
4. Did the outcomes that you/ your child experienced actually match what you expected? Why, or why not?
5. Have you noticed any changes in your child's behaviour as a result of the intervention? <ol style="list-style-type: none">If so, how have these changes in your child's behaviour influenced the wellbeing of your family, including yourself?Are there any additional changes - good or bad – that you can think of?
6. What factors influence your family's quality of life most? <ol style="list-style-type: none">How would you describe your family's quality of life during an average week?If at all, how has your child's participation in the motor intervention influenced your family's quality of life?
7. What factors influence your stress level most? <ol style="list-style-type: none">How would you describe your stress during an average week?If at all, how has your child's participation in the motor intervention influenced your stress?
8. Can you describe any other benefits or challenges that you or your family experienced as a result of your child's participation in the motor intervention?

The semi-structured interviewing technique allowed for the moderator to probe participants based on their responses to the questions in the interview guide (see Table 1). This technique promoted a deeper discussion of the subjects covered within the interview guide. As recommended by Creswell and Poth (2018), the interviewer took detailed hand-written notes during and after each interview to capture nuances that

would not be picked up in an audio-recording and to start the preliminary theme-identification process. After each interview, the word-for-word transcript was created using the audio-recording and the note-taking process continued (Creswell & Poth, 2018).

Within one week of the interview, the member checking process began (Creswell & Poth, 2018). Participants were emailed the transcript from their session and given an opportunity to add, remove, or further clarify any of their statements in the document. Participants were given two weeks to make revisions to their transcript, however they were not required to make any changes if they were satisfied with how their interview went. Each participant was happy with their interview and did not request revisions. Once all of the transcripts had been finalized, the primary author read and listened to them several times in order to become fully immersed in the data and continue with the theme-identification process/coding framework development (Creswell & Poth, 2018).

After completing the note-taking process, the focus was shifted from analyzing transcripts, to analyzing notes in order to identify the emerging themes (Creswell & Poth, 2018). This step involved formulating concise phrases to encapsulate each emerging theme. Each cluster of themes was then given a descriptive label, resulting in a list of themes and subthemes, each with their own detailed description (Creswell & Poth, 2018). The research team collaborated on several occasions to discuss the framework until agreement was reached about the themes within. The coding framework (Appendix 9) was entered electronically into NVivo 11 Pro and all six transcripts were uploaded for analysis.

Each transcript was coded by the primary author in solitude using the NVivo qualitative data analysis software. The coding framework evolved slightly during this step. Next, a third person, who was not intimately involved in the development of the study, was taught how to code within NVivo using the coding framework to establish inter-rater reliability. After coding one transcript with the primary author to ensure the coding process was understood, the individual coded a different transcript in solitude. A coding comparison was run in an effort to identify potential bias in the data coded by the interviewer. Inter-rater reliability was calculated between the primary author and the third party. The results showed that each node was over 95% in agreement. These results suggested that the coding framework was sound and the data had been coded appropriately into each theme.

Results

All of the participants' children who took part in the early motor skill intervention were described by their parents as verbal and able to participate in the motor-based activities. Four families included a single child with ASD, one family included twins with ASD, and one family included triplets with ASD. Of the nine children, seven were boys and two were girls. The Public Health Agency of Canada (2018) reported that the gender ratio of ASD diagnoses is approximately 4-5 boys for every one girl; the gender ratio of our participants' children reflect this. More detailed demographic information can be found in Table 2.

Table 2

Family Demographic Information

	Participant(s)	Child(ren) Sex	Age at ASD Diagnosis (months)	Other Diagnoses	Other Difficulties
Family 1	Mother Father	Male	18	n/a	Anxiety, Anger, Transitions
		Male	18	n/a	Transitions
Family 2	Mother	Female	22	ADHD	n/a
Family 3	Mother	Male	30	n/a	Transitions
Family 4	Mother Father	Male	30	ADD, GAD	Anxiety, Anger, Transitions, Attention
Family 5	Father	Female	36	n/a	Anxiety, Transitions
Family 6	Mother	Male	30	DD	Transitions, Anxiety, Anger
		Male	30	DD, SPD	Transitions
		Male	30	DD	Transitions, Anxiety, Anger

**ADD: Attention Deficit Disorder; ADHD: Attention Deficit Hyperactivity Disorder; DD: Developmental Delay; GAD: Generalized Anxiety Disorder; SPD: Sensory Processing Disorder; n/a is 'not applicable'*

Motivations for Enrolling Child(ren) in an Early Motor Skill Intervention

When parents were asked why they enrolled their child(ren) in the early motor skill intervention they identified a number of reasons that could be clustered into two

major themes; *potential benefits for the child(ren)* and *potential benefits for the parents*.

In other words, parents enrolled their children with hopes that they would both (children and parents) benefit from the experience. In terms of the potential benefits for the children, parents hoped that their child(ren) would improve their motor skills as well as their social skills, be provided with an opportunity to play and have fun, and increase their readiness for school.

“That's another reason I joined so we can actually work on stairs, her balance. She wasn't good at balancing. She wasn't good at walking. She would trip, she was clumsy I found.”

“The idea behind it that if she can develop some of these motor skills it translates into, being able to sort of, be more social. Like it's a common thing for kids to play, if you can't play, it automatically sets you out, so we wanted to make sure, let's give her every opportunity we can and if this is one of those things that we can get her involved in, then let's go ahead and do it.”

“Like, they're still kids, they still have personalities, and so, we kind of walked away from other types of therapy but wanted stuff like this to be more play-based and more... a bit less rigid if you will.”

“Knowing that they will be going to school... we wanted to work on getting them exposed to different activities and different structures and different transitions.”

In terms of the potential parent level benefits, parents hoped that they would be able to meet other parents of children with ASD, have an opportunity to observe other children with ASD, and learn strategies that they could use with their child(ren) at home.

“We thought too that going into a program where there's maybe other parents where we can talk to them, and we can pick their brain because maybe they've dealt with it before, we have questions and we could get the answer.”

“It was also like a huge plus that he would be amongst other children with autism. This was the first time we've met anyone who is on the spectrum as well. None of our friends have children, that I know of, that are on the spectrum.”

“I was expecting really to learn from you guys going forward on what I can pick up to teach them in the future.”

Parents were also drawn to the intervention due to the fact that it was free and involved no waitlist. A summary of the reasons why parents enrolled their children in the early motor skill intervention can be found in Table 3.

“We were just like oh my god it’s free for two hours a week!? Like... it's unheard of. So... and there's no waitlist! Like, you know, I’m not waiting years to get something. So that was, again, probably one of the biggest factors”

“And it was free and it was run by a university...”

“When she was first diagnosed, we were told the key is early intervention. So sitting on waitlists, and not really having a whole lot happen... umm, having this come across our plate was an opportunity for early intervention.”

Table 3

Parents’ Motivations for Enrolling Their 4 Year-Old Children with ASD in an Early Motor Skill Intervention

Reasons for Enrollment
1. Free/No Waitlist
2. Potential Child Level Benefits
- Motor skills
- Social skills
- Play/fun
- School readiness
3. Potential Parent Level Benefits
- Meet other children with ASD
- Meet other parents of children with ASD
- Learn strategies to use at home with child(ren)

All in all, parents reported that the outcomes they and their children experienced either met or exceeded their expectations.

“Matched everything that I was expecting.”

“For me it surpassed what I expected.”

“I would say I have seen progress and actually it maybe exceeded some of my expectations.”

Parents’ Descriptions of Their Stress

When asked to describe their stress during an average week, most parents started out with a short phrase such as “high”, ranked their stress out of 10, or scored their stress as a percentage, before explaining the reasons why.

“I mean, my stress is probably like a, a six, six or a seven.”

“I’m, for me it’d be a seven.”

“I’d say maybe 60% stressed, maybe 50%.”

“Pretty... it can get pretty high.”

“Yeah it’s very high but we get through it. But yeah, it’s stressful, every day is stressful.”

“High stress. There is high stress going on.”

Parents identified several factors that were contributing to their stress levels, including: meltdowns/tantrums, trying to anticipate/prevent tantrums from happening, judgement/comments from strangers during public meltdowns, children walking/running away during outings, having to yell at children, children’s poor listening skills, difficulties with transitions, sleep issues, lack of understanding, and parent’s work life. Parents of multiples with ASD explained that their stress is further heightened when

more than one of their children are engaging in a difficult behaviour. Many parents spoke about their relationship with their spouse and breaks from their child(ren) (children at school, parents at work, socializing with friends, etc.) as being important mitigating factors. Overall, the early motor skill intervention reduced parents stress due to a number of child- and parent-level benefits associated with the experience, according to the participants themselves. The intervention did not increase any of the participants stress levels.

“... influenced it in a positive way, it's gone down.”

“It's gone down with me anyway, with transitions.”

“Lessened it a little bit.”

“It hasn't worsened it in anyway! And maybe even reduced it a bit.”

“It's helped.”

Parents' Descriptions of Their Family Quality of Life

Parents consistently described their family life as being very busy. ASD workshops, work responsibilities, household chores, school meetings, and child(ren)'s appointments/extracurricular programs were all identified as contributing factors to family's busy schedules. Parents mentioned the following factors as being important to their overall family quality of life: sleep, child(ren)'s independence, one-on-one time with their child(ren) (with and without ASD), one-on-one time with their spouse, family time/outings, and opportunities for socialization with other adults. Nearly all parents reported that they were unable to strike a balance with these types of activities due to their busy lifestyles and their children's complex needs. One parent explained “it's

always go, go, go”, while another said “there is not enough time in the day”.

Participants reported that the intervention benefited their family’s quality of life in a number of ways. For one, parents noticed more interaction and cooperative play between siblings. As well, parents reported an increase in the physical activity levels of their family overall, since 1) their child(ren) with ASD became more interested in these types of activities (e.g. tee-ball, soccer, catching/throwing games, follow-the-leader type games, etc.) after their positive experiences with them, and 2) parents began encouraging active play at home more often because the intervention shed light on the importance of these activities for child development. Lastly, and perhaps most notably, nearly all parents reported that they started going out more with their children. Parents reported two main intervention-related reasons for this shift: 1) improvements in their child(ren)’s behaviour (e.g. listening skills), and 2) parents were able to learn strategies to prevent and manage their child’s difficult behaviours more effectively. Overall, the experience of the early motor skill intervention had a positive influence on family’s quality of life.

The Effects of Children’s Participation in an Early Motor Skill Intervention on Parents

Participants reported several parent-level benefits associated with the early motor skill intervention for their children. Researchers identified several themes amongst parents’ responses and grouped them into three major categories and several subcategories. The theme structure is outlined in Table 4.

Table 4

Parent-Level Benefits of the Child-Centered Motor Skill Intervention

Themes
<ol style="list-style-type: none">1. Parent Attendance Allowed for Direct Benefits to Parents<ul style="list-style-type: none">- Observing child(ren) succeed<ul style="list-style-type: none">▪ Hopeful about future/less worried- Meeting other children with ASD<ul style="list-style-type: none">▪ Gained perspective on child(ren)'s development in relation to others- Meeting other parents of children with ASD<ul style="list-style-type: none">▪ Able to socialize/decrease feelings of isolation/loneliness- Learning<ul style="list-style-type: none">▪ Going out more2. Eye-Opening Experience for Parents<ul style="list-style-type: none">- Importance of motor skills, play, and fun for child development<ul style="list-style-type: none">▪ Incorporating more active play in daily life- Child(ren)'s challenges and capabilities<ul style="list-style-type: none">▪ Changed perspective of their child(ren)▪ Shifted family dynamic3. Parents Valued the Intervention and Viewed it as a Positive Experience<ul style="list-style-type: none">- Children also enjoyed the experience

Attending, Observing, and Parent-Level Benefits

Many parent-level benefits stemmed from parents attending and observing the motor intervention sessions for their child(ren). Parents were able to observe their child(ren) succeed, meet other children with ASD and their parents, learn strategies to use with their child(ren) at home, and develop a better understanding of them.

Observing success.

By observing the intervention, parents were able to witness their child(ren), as well as the other children, succeed. Observing success was an important factor that

contributed to positive feelings among parents. Parents frequently described children's successes as "amazing".

"Other things we've seen, they kind of push them behind the door and we don't really know what's going on. But here we can actually see what they're doing, and sort of measure their success, umm, at least on a day-to-day basis."

"And I think for us as parents to see that he is succeeding outside the nest, umm, was a huge thing... I think that took a lot of stress away, a lot of pressure. It was just like okay, relax, chill, it's okay. So I don't have the stress like I did before."

"There was a day where she was playing with the instructor and the mom was like "oh my gosh are you watching that" and even I was seeing that was a huge improvement... so ya just seeing those benefits, not just for our kids, but for other kids was also nice to see and sort of reaffirmed our choice to do the study."

"Plus to see him succeed in things like at first he couldn't catch a ball. He barely even kicked the ball. But to see him, you know, to see him balance on one leg, and things like that. See him like gaining the ability to do it and getting self confidence and being happy about what he, that he's succeeding, and sharing that joy with all the other people that were there. That was amazing."

As parents observed their children succeed several times over the course of the intervention, they began feeling more hopeful about the future and reported a diminished sense of worry.

"He can succeed at things without me... I don't have to worry about him for the rest of my life."

"To have that, you know, to have that confidence in his future... kind of so we don't have to worry too much."

Meeting other children with ASD.

Many of the participants' children were newly diagnosed with ASD and they had yet to meet another child with the disorder. For parents, this makes it difficult to gauge the developmental level of their child(ren) and has been shown to contribute to feelings

of uncertainty about the future (Glascoe & MacLean, 1990). The intervention was the first opportunity for many parents to meet and observe other children on the spectrum. Naturally, it allowed parents to compare their child(ren)'s level of development to others and gain some perspective on their child's abilities.

“Everybody's on their own path. We could, we kind of compare it, or kind of put us into perspective, where our journeys is, our path with [him].”

“And I think for us going to that intervention and seeing those other kids, and seeing the struggles or imagining the struggles that they have to go through, you know, it put it in a little bit of perspective for our situation.”

“It was, it was good for us too, just as much as it was for [him] because this is one of our first, our own exposures to the world of autism and being on the spectrum and there was other children here that were different than [him]. So some were higher functioning, some lower functioning. At the time [he] was still younger. So there were some children that, that we saw were more advanced than him, or were able to follow through on the routine better than [he] was, or there was children that couldn't. So that kind of gave us an idea of where we needed to work with [him] too...”

Meeting other parents of children with ASD.

Not only was the early motor skill intervention many parents' first opportunity to meet other children with ASD, it was also their first exposure to other parents of children on the spectrum. The parents in this study perceived these interactions as a benefit of the intervention for multiple reasons:

“You got to see other parents and sort of how they interact with their children and it sort of gave us some tools and some things to think about.”

“So it's pretty cool to see that you're in the same situation. And you're not really left out. Because my husband's always saying “Oh, it's just us it's just us” and when my husband came, he's like, “no, it's not just us, I actually see it now”.”

“I liked interacting with the parents... talking to the parents definitely, getting to know some of them and their children.”

“In the process, you know, like meeting other parents, for sure there have been benefits to it. [She] has built some friendships with some of the other kids and we've built some relationships with some of the other parents where we do see them outside sometimes. So we did, those are definitely some benefits that we did not expect.”

Parent learning.

Parents reported that they were able to learn strategies that they could use at home with their children as a result of being present during the intervention. Parents felt that their own learning had a positive effect on their family unit.

“Especially like the whole concept of sharing like one of the key phrases here is they'll say a child's name and then “turn” like “Ashley's tuurrrrrnnnn” or like “Johnny's tuuuurrrnnnn”. So when we do that with her and her brother, we'll say “Ashley's tuurrrrrnnnn... okay, now it's Johnny's tuuuurrrnnnn” so she gets, she gets it like “okay I have to wait my turn” instead of thinking like “oh this is getting taken away from me.”

“I learned some things from [the instructor], you know, that, just ignore him and it will stop, it will go away, he will turn around and come back. Ya, just, just the normal, you know patience.”

“I would have never thought to think and say those things in order to get them to do that. She [instructor] was so particular with what she said it was literally step by step by step, and they got it.”

Parents also reported that they were able to learn about their child(ren) and gain a better understanding of them by observing the intervention.

“Ya, and I think it was more just interesting for us to see, have a better understanding of how to deal with him in certain situations.”

“I think we got a better understanding, or I got a better understanding of [him]... so it definitely gave me a different perspective on, at least understanding his behaviour. And then figuring out how to kind of keep him engaged with stuff.”

And lastly, participants were able to learn about their own capabilities, as parents, throughout the experience.

“I was afraid of initially like oh my god the thought of having to go to like in the evening once a week, or twice a week... it's like, it might look like a big thing, it might look like it's going to be a lot of struggle, but once it gets going, it's a good thing. So it's a little bit like... don't not do it because it might be a struggle. Just go for it. You can do it. You're going to be fine.”

“Umm I think coming to this program has also taught me the ability of what I can do with my children alone... which is a big step for us where I don't need as much help.”

“I think for me it comes down to umm, like some of it is the relief of some of my anxiety of being able to take her out and sort of like I've learned how to manage certain meltdowns or how to like prevent some meltdowns.”

Due to all of the things that parents learned during the intervention, many participants expressed that they are now able to go out as a family more often. Learning how to better predict/prevent/manage their child(ren)'s challenging behaviours provides a sense of comfort for parents when taking their children out with them.

“I tend to take them places a bit more. And, you know, like I said, the stress level is not there, umm sort of getting out of the car, that they're going to have a meltdown.”

“It has helped... we're not as apprehensive to take them to new environments.”

“After the program was done she wanted to get out more with her sister and she'd say “I want to go out, I want to go out”. But before that everything was like “I want to go home, I want to go home” as soon as you took her out, that's all she ever said. So now it's more staying out and being involved and being more social.”

Eye Opening Intervention

A second major theme that emerged from the data were parents' descriptions of the experience as “eye opening” or “a wake-up call”. Some used these terms because

they felt they had developed tunnel vision in terms of what they were focusing on with their children at home, prior to the intervention.

“There is nothing anyone tells you about the physical, you know, even as a parent at home we constantly do speech sessions, you do behavior things, like you repeat things. And, you know, you drill them that way. Throwing a ball at home then isn’t important anymore. So that goes a little bit into the background... you don't think about “hmm your son can’t catch the ball, maybe you should work on that”... no, you’re focusing on all the other aspects.”

“It's like a wake-up call... I felt like once you have the autism diagnosis, you get drilled in a way with the information that you get from doctors, from internet forums, from everywhere, you know, that behavior, and speech, and social things, that those are the three factors that you need to look for. So you keep focusing on them. And, you know, it's like, you get tunnel vision in a way... for me, it was a little bit like hang on, stop. Again, there is more to this little boy.”

For many parents, the intervention shed light on the importance of motor skills, play, and fun for children’s development and also highlighted children’s challenges and capabilities. Ultimately this eye-opening experience changed parents’ perspectives of their children which resulted in a shift in the family dynamic of many.

Importance of motor skills, play, and fun for children’s development.

By witnessing the joy and success, along with the other benefits, that their children experienced during the motor intervention, parents developed a new appreciation of the motor domain as an important part of child development. Many parents began making an effort to incorporate more motor-based activities into their children’s daily lives. Several participants bought sports equipment, started taking their child(ren) to parks more often, and some even enrolled their child(ren) in a soccer program as a result of their experience.

“Seeing how they interacted with the play therapy here, umm I think that it also kind of opened our eyes to a few different things, for me, now we take them to a few different parks around the area, we go to the waterfront and we throw rocks...”

“My husband built a treehouse in the backyard! It was for the kids to go out there and play and climb up the rock wall, and we have tee-ball set up out there, so now we're thinking of things to actually have them go like, activities for them to do.”

“We bought him that basketball net, we put him in soccer, we got him the T-ball stuff, we take him outside to the park and like kick the ball.”

Consequently, several parents also reported that their family’s physical activity levels increased.

“It's just maybe made us a little bit more active, having to tend to him when he wants to play.”

“We’ve become more active to a degree.”

“It’s a bit more family time. And it's good too because he's not staring in front of an iPad or a phone, right? We're playing a game, we're all together like interacting.”

Children’s challenges and strengths.

Another eye-opening aspect of the intervention for parents involved their child(ren)’s challenges and capabilities. In some cases, parents weren’t aware of certain circumstances (e.g. transitions) that would trigger challenging behaviours from their children. Parents viewed this enlightenment as a positive factor.

“We did discover that they have difficulties with certain transitions. So the good thing is that we discovered it... otherwise I don't think we would have discovered it until school... which then would have made school even tougher.”

“The program has kind of like shed some light on some of the challenges right? To make us understand some of the challenges. I mean all of the influence has been positive.”

More often than not however, instead of being surprised by challenging behaviours, parents were surprised by the abilities that their child(ren) demonstrated during the intervention.

“So it even opened our eyes when we would come here like “oh look wow look at him throw the basketball”, “oh look at him stopping and listening and jumping and hopping”, “oh we’re so proud of him”, “oh look what he can do”.”

“He demonstrated ability and skill that we would have not known and we probably wouldn’t have put him in soccer, or wouldn’t have assumed that he could interact in a group with other kids that are on spectrum and not on the spectrum.”

“It's also given me the ability to recognize that she is capable of doing a lot more than I thought she was. Which is great because I, you know, now like looking back, it's just like, wow, I can't believe, I, it's not that she couldn't do it, I just didn't think she could do it.”

“And also, you know, just overall happiness because I was pleasantly surprised and genuinely surprised when I saw her doing certain things.”

As parents discovered that their children were capable of much more than they previously thought, their perspectives of their children and how they treated them changed. Parents started holding their children to higher standards at home and allowing them more opportunity to be independent.

“He is more treated like a typical child now.”

“He is no longer so sheltered. We don't excuse him that much anymore so if he does wrong, he does wrong, and he gets the consequences for it... and now he's sitting on the naughty bench just like she [sibling] is.”

“Now it's like no no he did it in the classroom, he can do it again. So I know what he's capable of. I know you can teach him, that he can do this stuff, so now we're at a different level.”

“I have to remind myself to just give her that little bit of opportunity to do it herself because I'm also not doing her any favors by constantly doing it for her over and over again. And you know it's just like simple tasks of just getting ready like it's going to take her probably 10 minutes to get ready, but I've got to let her do it, and that's the expectation of where I'm at now with her is like, okay, like let's get ready for school 10 minutes earlier so then you can do this yourself.”

Several participants experienced a shift in their family's dynamic as a result of their updated views of their child(ren)'s abilities. Parents explained how this new confidence in their child(ren)'s abilities had an influence on their family unit as a whole.

“Seeing that he can do things... It gave me the feeling that he's going to be okay... that belief, that trust, being able to let go and send him out into the world kind of thing... I think that has had an effect on all of us [family members].”

“Ya, because we could step back, we could watch, we could observe him, we could see him interact with others and you know he's proven to us that he is okay. He is good. You know too, to have that confidence has shifted the dynamic in the house a little bit because before everything was about him.”

“He was always the problem child kind of thing. So, my older one, had to a lot of times step back, because he would throw a tantrum so she would have to give in, and give in, and that has changed. That has changed a lot.”

“I think this intervention as well has helped us a little bit like grow together in a way. To see like okay we don't have to shelter him so much. He can be just a normal part of our family... and gaining that confidence has changed a lot in our family.”

Parents Valued the Intervention and Viewed it as a Positive Experience

The third and final major theme that emerged from the data involved parents' positive opinions about the intervention. Several parents stated that they would do it again and that they wished the intervention would continue. Two parents went as far as saying that they feel motor skill interventions should be provided to all children with ASD in conjunction with traditional behavioural therapy.

“It’s an amazing program, I would do it again.”

“Studies like that [early motor skill intervention] would be amazing if they could go on and on and on and on and on.”

“This should be something all kids on the spectrum should do. It’s such a good, it’s another way of getting to them, to help them, instead of, or in conjunction with traditional therapy. I think it was really good.”

“In my personal opinion, I think this should be a mandate, I think this should be part of therapy in the mainstream... this is, to me, very effective for children on the spectrum at all levels because it gets their blood flowing, it gets them moving, it gets them interacting. Any little interaction from a child that’s on the spectrum, is to me, amazing. Because they don't want to interact, they don't know how to interact, they're afraid to interact. So having a child who, who's autistic and usually wants to sit by themselves, or is in their own world, now they're interacting, that's one foot in the right direction, to get them to a place where they're going to be able to exist in this world long term. So I think it's really good.”

Not only did parents value the intervention, but they felt their children also greatly enjoyed the experience. The fact that children enjoyed the program made it easier for parents to commit to the intervention twice/week for 12 weeks.

“Coming here and kind of seeing the environment and the fact that the kids took to it so quick. I think even if we had to pay if it was like a nominal fee, we would probably still do it just because we saw that they enjoyed the environment.”

“Plus again, that factor that as a parent of an autistic child, you focus on other things. You don't focus on running in circles. You don't focus on balancing. You just don't do that. And then to go and see what you guys did... and how those kids loved it. Every single one of them. It's just like, okay you're on to something! So it's, it was, it was amazing.”

“Just the excitement that they had coming here. This was actually one of the easier times for us to say “hey we're going somewhere, put on your shoes, let's go to the door, let's get in the car”, you know, there was no “oh well one person doesn't want to go”, because everybody wanted to go.”

“I think a positive is just her being able to enjoy coming somewhere and not, and not want to dispute coming here.”

Discussion

The purpose of this study is to describe parents' perspectives of (1) their stress and family quality of life, (2) the parent-level benefits associated with an early motor skill intervention for their 4 year-old(s) with ASD, and (3) how those benefits influenced the family unit overall. This study also aimed to improve our understanding as to why parents choose to enroll their children with ASD in early motor skill interventions.

Parents Descriptions of Their Stress and Family Quality of Life

Most parents reported high levels of stress and identified several factors that contributed to their stress levels; some factors were related to their children with ASD, and some were not. Each of the stressors identified by the parents have previously been reported in the literature. For example, parents identified their children's meltdowns/tantrums as being a major source of stress for them, especially during public outings, and parents of multiples explained how their stress becomes further amplified when more than one of their children is experiencing a tantrum at the same time. Ludlow, Skelly, and Rohleder (2012) found that parents of 4-14 year-old children with ASD also identified this behaviour as stressful and difficult to manage, especially in public, and in part due to the unpredictability of the behaviour. In addition to tantrums and meltdowns, parents in the current study reported that their children's poor listening skills, difficulties with transitions, restricted food preferences, and sleep issues also contribute to their high stress levels; again, these findings are supported by the results of several other researchers (Bonis, 2016; Curtin, Jojic, & Bandini, 2014; Giallo, Wood, Jellett, & Porter, 2013; Phetrasuwan & Shandor Miles, 2009; Stoner, Angell,

House, & Bock, 2007). When parents are unable to attain adequate sleep because their child is awake and needs them during the night, it can negatively affect both parties; chronic fatigue can reduce parents ability to cope with their child's challenging behaviours, and also exacerbate the child's behavioural issues (Giallo et al., 2013; Ludlow et al., 2012). Future research may consider investigating the effects of an early motor skill intervention on sleep issues within this population.

Parents identified several factors that influence their family's quality of life, including: opportunities to spend time together as a family, opportunities for parents to spend one-on-one time with each of their children (with and without ASD), and opportunities to interact with other families. These factors support the current literature focused on families of children with ASD as many parents have reported feelings of isolation and struggling to strike a balance between keeping up with their daily responsibilities (e.g. work, household chores, appointments for their children/themselves) and making sure to spend quality time with each of their family members separately and together (Galpin et al., 2017; Hoogsteen & Woodgate, 2013; Woodgate, Ateah, & Secco, 2008). Parents in the current study reported that the motor intervention allowed their children to develop the skills required to participate in active play, and also shed light on different types of activities that parents could engage their children in during family time (soccer games in the basement, tee-ball in the backyard, family trips to different parks in the community, etc.). As a result, parents reported an improvement in their family quality of life. These findings further support the significance of participation in recreational activities as a component of family quality of

life (Jones et al., 2017). Communities should consider developing inclusive motor-based programs that can be carried out in recreation centers to provide more active play opportunities for families with and without children with ASD.

Positive marital relationships, breaks from their daily routine of caring for their children with ASD, and sleep quality were also described by parents as important components of their family quality of life. Again, these factors have previously been identified in the literature (Giallo et al., 2013; Harper, Dyches, Harper, Roper, & South, 2013; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Richdale & Schreck, 2009). Parents reported that their family quality of life was positively influenced through a number of different avenues as a result of their experience with the motor skill intervention for their child(ren). The specific avenues are discussed in more detail throughout the “Parent-Level Benefits” section of this discussion.

Parent Level Benefits

Observing children’s successes and abilities.

Parents of children with ASD likely witness their children struggle with activities on a daily basis due to the pervasive nature of the disorder (Weiss, Cappadocia, MacMullin, Vecili, & Lunsy, 2012); as one participant put it, *“it’s never easy”*. By virtue of observing the motor skill intervention, however, parents were able to witness their children succeed on a regular basis. For example, learning how to over-hand throw, wait their turn, listen to instructions, as well as play games and interact with the other children. These seemingly small achievements had a large impact on parents. After describing one of their child’s accomplishments during the intervention, many parents

mentioned how it made them feel. Parent's often wrapped up their stories with phrases such as *"that made me happy"*, *"it was amazing to see"*, and *"we were so proud"*.

Feelings of pride are consistent with what other parents reported after they watched their children with ASD participate in an equine assisted intervention (Tan & Simmonds, 2018). Sandler and Mistretta (1998) explained that the stage beyond parent's acceptance of the child's diagnosis, involves the development of an appreciation for the positive aspects of life with their child, such as feelings of pride when the child learns a new skill or succeeds at a task. Early motor skill interventions may therefore promote the process of adjusting to life as a parent of a child with a disability by providing parents with opportunities to witness success and foster feelings of pride.

Similar to how parents were delighted to witness their child(ren)'s successes, they were also pleasantly surprised by the abilities their child(ren) demonstrated. Prior to the intervention many parents hadn't seen their child participate in a group setting, and based on the difficult behaviours they had witnessed within the home setting/during public outings (e.g. grocery store), parents went into the intervention with their child not knowing what to expect. However, many children demonstrated, for the first time, their interest in motor-based activities, the ability to wait their turn, listen to instructions, and establish relationships with other children. Although the children had difficult moments at times during the intervention, what stood out to parents was their capabilities as opposed to their challenges. It was as though children's challenges were being highlighted during their daily lives prior to the intervention, but during the intervention, it was their strengths that became highlighted. Climie and Mastoras (2015)

emphasized the benefits of a strengths-based perspective (i.e. positive psychology) in which clinicians and caregivers pay equal attention to children's strengths and successes as they do to their challenges. When children's strengths and success are highlighted via intervention, it can result in more balanced support from caregivers, enhance family wellbeing, and increase resilience (Climie & Mastoras, 2015); important components of families' quality of life (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011; Lee et al., 2012). In the current study, parents often described their realizations that their children were capable of much more than they previously thought, and how this realization changed their homelife. One parent explained that "*he is no longer so sheltered*" while many others stated that they now have higher expectations for their children at home and refrain from using the ASD diagnosis as an excuse for poor behaviour. These findings further support the notion that the experience of an early motor skill intervention may help parents to better understand their child's abilities, elevate their expectations, and lead to a shift in their parenting behaviours to better suit their child. These changes may positively affect the developmental trajectory of the child with ASD.

There is no clearly defined prognosis that can be provided to parents of children with ASD at the time of their diagnosis due to the large variation in symptom type and intensity along the spectrum (Rivet & Matson, 2011); this uncertainty about what the future holds can be very stressful for parents (Ergüner-Tekinalp & Akkök, 2004; Weiss, 2002). Parents in the current study reported feeling more hopeful about the future and less stressed and worried after observing their children succeed and demonstrate their

abilities during the intervention. This is an important finding because higher hope is associated with several positive health and psychosocial outcomes, including: resiliency, adaptive coping, life satisfaction, and lower levels of depression and anxiety (Faso, Neal-Beevers, & Carlson, 2013; Ogston, Mackintosh, & Myers, 2011; Snyder, 2000). These outcomes are, in turn, associated with a better family quality of life (Bandura et al., 2011; Jones et al., 2017; Lee et al., 2012). On the other hand, excessive worry can serve as an obstacle for parents when responding to the needs of their children (with and without disabilities), their marriage, and themselves (Ogston et al., 2011). Therefore, increasing hope and decreasing worry among parents could have significant implications for the wellbeing and quality of life of families of children with ASD. Future research should investigate the efficacy of different types of early interventions for accomplishing these outcomes.

Meeting other parents and their children with ASD.

Parents of children with ASD have reported that their friendships often become compromised due to the fact that they have less time for social activities, and because their friends who have children with typical development often express discomfort when the child with ASD exhibits challenging behaviours (Altiere & von Kluge, 2009). Thus, perhaps it is not surprising that parents within this population have previously expressed feelings of isolation (Woodgate et al., 2008). Research, however, has also demonstrated the powerful buffering-effects of meeting other parents who have children with the same disability (Kerr & McIntosh, 2000). Participants in this study also reported the benefits of meeting the other parents at the motor skill intervention.

Socializing with one another, developing friendships, and witnessing how others interact with their children on the spectrum were identified as enjoyable and impactful experiences. As a result, parents reported a reduction in their feelings of isolation after receiving social support from the other parents during the intervention; as one parent stated *“I knew exactly what they were going through, and how hard it is”* while another said *“it was good... to know that you’re not alone”*. One participant even described how this parent-level benefit extended to his whole family as they have since engaged in social activities with some of the families they met at the intervention. A lack of social support has been identified as a strong and consistent predictor of caregiver burden among parents of children with ASD, and most families report especially high levels of burden following their child’s diagnosis (Galpin et al., 2017; Stuart & McGrew, 2009). These findings suggest that early motor skill interventions may be a feasible method for reducing caregiver burden between the time of the child’s diagnosis and their access to intensive and fulltime government-funded services by strengthening parents’ social networks and reducing feelings of isolation.

The opportunity for parents to meet other children with ASD was also viewed as a beneficial component of the intervention. Many described engaging in a process of comparison while watching the motor skill intervention in order to gain perspective on their own child(ren)’s abilities; a phenomenon previously described by Festinger as the Social Comparison Theory (Festinger, 1954). One parent explained how some children were *“more advanced”* than her son while others were not, and how seeing this put her journey with her son into perspective. Opportunities for comparison have previously

been identified as an important process in order for parents to accurately appraise their child's development (Glascoe & MacLean, 1990). And, accurate appraisals of children's development are necessary for parents to be able to identify their child's strengths and weaknesses and subsequently target the areas of development that require attention (Glascoe & MacLean, 1990). Comments made by parents in the current study suggest that they may not have fully understood their children's abilities prior to the intervention. As one parent explained "*it highlighted their strengths but also their weaknesses and what you need to work on with them at home*". The literature, as it is now, has not investigated parents' ability to accurately assess the developmental level of their children with ASD. Since these families often experience isolation from the greater community (Woodgate et al., 2008), and opportunities for comparison are necessary for accurate appraisals (Glascoe & MacLean, 1990), it is possible that these parents are at a disadvantage for gauging their children's domain specific strengths and weaknesses. This phenomenon warrants further study as children could greatly benefit if their parents are able to accurately appraise their child's development from an early age.

Parent learning.

Children with ASD do not have distinctive physical features that would otherwise notify the public of their diagnosis, therefore strangers have been known to make negative comments about the child's behaviour as well as their caregivers parenting skills, partly because they do not fully understand the family's position (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Parents in the current study described

similar instances of strangers “*throwing in their two cents*” by saying things like “*someone is spoiled*” in reference to the child with ASD after the parents give the child what they want (e.g. chocolate) to stop a meltdown in a public place. Parents described these encounters as stressful, thus, learning strategies to prevent or manage tantrums in public places may help parents to avoid negative encounters with strangers and contribute to their comfort level during outings with their child(ren) (Divan et al., 2012). Parents in this study reported that they were able to learn effective strategies to cope with their child’s challenging behaviours by observing the trained instructors and other parents during the intervention even though behaviour management was not the primary focus of the intervention. Moving forward, clinicians and researchers should consider the important learning effects that early interventions can have for parents, and make every effort to include them in the experience when possible.

Parents reported that they developed a better understanding of their child(ren) with ASD, their own capabilities, and strategies that they could use with their child(ren) at home, which benefited them in a number of ways. One parent said:

“This program has also taught me the ability of what I can do with my children alone, and It’s also taught them stuff that has allowed me to go out with them alone, which is a big step for us where I don’t need as much help. I can go to the grocery store now. You know, I can go, I will do these things with them by myself. So getting out. Being more active.”

Another parent talked about the “*relief of some anxiety*” in terms of “*being able to take her [child with ASD] out*” because he “*learned how to manage/prevent certain meltdowns*” by observing the motor skill intervention. The experience of the early motor skill intervention seems to have promoted learning amongst the children as well as the

parents, and as a result, allowed parents to feel “*more comfortable going out and doing more things*” and “*not as apprehensive to take them to new environments*”. This was a clear and positive secondary effect of the motor skill intervention that turned out to be quite important for parents. Parents of children with ASD often experience social isolation due to the intensity of their child(ren)’s needs and the avoidance strategies that are sometimes used to cope with the stigma and unwelcomed comments of others (e.g. choosing to avoid public outings) (Divan et al., 2012; Galpin et al., 2017). Thus, based on parent reports, the experience of a motor skill intervention soon after ASD diagnosis may help to encourage socialization and reduce isolation for families.

Although it is likely that parents can learn about their child with ASD by observing them participate in different types of early interventions, it is possible that motor skill interventions, in particular, result in greater opportunities for parents to gain insight about their children. Fundamental motor skill interventions teach children the movement skills that are required to participate in active play (Payne & Isaacs, 2012); play is a universal behaviour carried out for the purpose of enjoyment that also allows children to make sense of their world (Jobling, Virji-Babul, & Nicholas, 2006; Van Hoorn, 2007). These activities provide children with an opportunity to engage fully in what they wish to pursue while expressing themselves in an energetic and spontaneous manner, giving parents an opportunity to gain a deeper understanding of their child’s authentic self (Broughton, 2017; Jobling et al., 2006; Pellegrini & Smith, 1998). The findings of the current study support the notion that parent-level learning was elicited through observation of children’s participation in play-based motor activities during the

intervention. Future research may consider measuring the parent-level learning effects of different types of early interventions for children with ASD, to develop our understanding of observational learning processes and how they can be promoted most effectively across all types of interventions.

Eye-Opening Intervention

One of the reasons parents explained their experience with the intervention as “eye-opening” was because prior to the intervention many didn’t view the motor domain as an important aspect of their child’s development. This finding highlights a gap in the information being provided to parents in terms of the motor delays that are often experienced by children with ASD and the importance of motor skill development (Lloyd, MacDonald, & Lord, 2013; Rosenbaum, 2005). Parents may be able to assist in the development of their child’s motor skills earlier, and contribute to better outcomes, if they are made aware that the development of these skills are critical in order for children to be able to fully participate in active play and experience the many physical and psychosocial benefits of doing so (Lloyd et al., 2013; Lubans, Morgan, Cliff, Barnett, & Okely, 2010; Payne & Isaacs, 2012). Luckily for the parents in this study, the early motor skill intervention did shed light on the importance of motor skills for child development. As parents began to value the importance of motor skills, they reported buying sports equipment for their children to play with at home (t-ball, soccer ball, basketball, etc.), enrolling their children in sports programs (soccer and swimming), and engaging them in more types of active play (treehouse/climbing wall in backyard, exploring new parks, skipping rocks at the waterfront, etc.); as a result, many parents

stated that their family's physical activity level increased as well. Not surprisingly, more frequent engagement in family oriented recreation, is associated with greater quality of life scores amongst families who have children with ASD (Jones et al., 2017).

The new types of physical activities that children began engaging in, with and without their family members, are typically viewed as common childhood activities. The question of why these families were not engaging in and encouraging these types of activities on a regular basis before the intervention, is perhaps not as straight forward. Jones et al. (2017) hypothesized that this phenomenon may, in part, be explained by the challenges associated with finding and accessing inclusive programming, a lack of understanding of the benefits of physical activity for children, and financial constraints. Several parents in the current study confirmed that they had not fully appreciated the importance of the motor domain prior to the intervention and several also alluded to the financial burden associated with ASD interventions. Parents also identified several other barriers to their family's regular engagement in active play at home and in group settings. For one, many parents explained that they feared how their child would behave amongst a group of other children (e.g. fear that their child would accidentally hurt another child or have a meltdown that garnered negative attention from other parents). They also explained that their focus at home had been on developing their child's social skills and improving their behaviour (i.e. motor skills became less important). Lastly, they described how their children lacked motor skills proficiency prior to the intervention (i.e. they did not have the skills to participate successfully); this is consistent with the growing literature (Bremer et al., 2015; Lloyd et al., 2013; Pan,

2010). Future research should investigate the specific reasons why families of young children with ASD often refrain from regular engagement in typical, active childhood games. Researchers may also consider measuring the physical activity levels of all family members before and after an early motor skill intervention to further explore this relationship.

Physical activities are a common component of recreation for families of young children, and research has shown that parents of children with ASD view recreation as an important component of their family quality of life (Jones et al., 2017). Activities such as swimming and riding bikes provide families with opportunities to experience joy and get to know one another on a deeper level (Jones et al., 2017). Active recreation is also associated with physical, psychological, and emotional wellbeing in the general population as well as behavioural improvements among children with ASD (Bremer, Crozier, & Lloyd, 2016; Janssen & LeBlanc, 2010; Warburton, Nicol, & Bredin, 2006). Thus, it is not surprising that regular engagement in family-oriented recreational activities is associated with an increased family quality of life, however, Jones et al. (2017) found that most families of children with ASD are not engaging in these types of activities on a regular basis, and those who are, do not typically include their child with ASD. Although the reason for this was unclear, Jones et al. (2017) hypothesized that this may be due to a lack of understanding among parents regarding the benefits associated with engaging children with ASD in physical activities. The findings of the current study suggest that the experience of an early motor skill intervention may improve family

quality life by encouraging parents of children with ASD to engage their family members in active recreation more often.

Parents Valued the Intervention and Viewed it as a Positive Experience

Overall, parents valued the motor skill intervention due to the combination of parent-level and child-level benefits that they experienced. Several parents explained how their child(ren) *“loved it”* and how this made it easy for them to commit to the intervention twice/week for 12 weeks. The intervention mode likely played an important role in children’s positive experiences since the activities were designed to be fun. Ensuring that children have a positive experience with an early intervention as they wait to gain access to government-funded services, may be an important consideration for clinicians when designing treatment plans as it appears to greatly influence parents and families, in addition to the children themselves, during this especially sensitive time (Stuart & McGrew, 2009).

Parents’ Motivations for Enrolling Their Children

Parents revealed multiple reasons for why they chose to enroll their child(ren) with ASD in the early motor skill intervention, as illustrated in Table 3. The fact that parents were motivated to enroll their child in a motor intervention with hopes that it would benefit themselves in addition to their child, speaks to the many challenges associated with raising a child with a developmental disability (Barker et al., 2011). These findings support those of other researchers who have identified a need for services and interventions for children with ASD, that also benefit the parents (Karst et al., 2015). The current literature pertaining to the parent-level benefits of early motor

skill interventions is sparse, thus prior to enrollment it is likely that many parents may not realize the potential for this experience to benefit them in addition to their child(ren). This is the first study to our knowledge within the ASD literature that has investigated parents' motivations for enrolling their children in an early motor skill intervention. More research is needed to fully understand the types of parent-level benefits that parents of children with ASD are seeking.

The factors that motivated parents to enroll their children in the early motor skill intervention should be used to inform the design and delivery of motor-based programs and interventions in the future. For example, one reason why participants in this study were motivated to enroll their children in the motor intervention was so that they could meet other parents of children with ASD. Inviting parents to watch the intervention from a designated area within the intervention room, as opposed to having them drop their child(ren) off, provides an opportunity for them to meet other parents. It also gives them an opportunity to meet other children with ASD and learn strategies to use with their children at home which were the other two things that parents in this study were hoping to accomplish. In circumstances where this is not possible (small space, distraction to children, etc.), shared waiting rooms have also been found to encourage interaction among parents (Cohn, 2001; Kutash & Northrop, 2007). For example, parents of children with sensory integrative dysfunction gave and received support for one another during their time spent within an occupational therapy waiting room, thus creating a sense of community (Cohn, 2001). However, unless parents are able to watch the intervention through a window or on a screen, they may miss out on a host of other

parent-reported benefits associated with observing the motor skill intervention, such as learning strategies to use with their children at home.

Taking parent-involvement a step further, there is evidence to suggest that parent participation in certain types of interventions and therapies for children with ASD are associated with greater learning outcomes for parents and children (Bratton, Ray, Edwards, & Landreth, 2009; Leblanc & Ritchie, 2001; Zachor & Itzhak, 2010; Zwaigenbaum et al., 2015). Using this method, parents are taught strategies to use with their children in a hands-on manner which may then be transferred to the home setting with greater ease and result in more long-term positive change (Bratton et al., 2009). Parents in the current study identified learning as a motivating factor for enrolling their children, thus, designing motor interventions in a way that includes parents in the motor activities- where the parent becomes the instructor at certain points during the session- may further promote parent learning and better outcomes. A parent in the current study actually suggested *“a parent and child one [motor intervention], where together [both parents] you tell your child “you do this, you do that”. Where it’s a learning curve for the parents as well”*. Researchers conducting motor skill interventions in the future may consider parental involvement as a motivating factor for parents to enroll their children and promote learning through experience (e.g. practice using instructor-taught, evidence-based strategies to keep the child on-task).

The three parent-level benefits that were identified as motivating factors for enrollment (see Table 3) could be used to inform recruitment strategies for motor-based programs and interventions in the future. Researchers may be able to increase

interest and enrollment in motor-based programs by informing parents of the opportunity for them to learn through observation, and meet other parents of children with ASD as well as the children themselves. This information may be communicated to parents in a number of ways, including: posters and pamphlets about motor-based programs for children with ASD, recruitment emails, screens in pediatric clinics, and physical therapists (Gregor et al., 2018). As pointed out by Hebert (2014), there are a number of different types of interventions for children with ASD and parents are faced with the difficult task of choosing which evidence-based treatments would be best for them. Participants in the current study made reference to this decision-making process; after explaining the progress his child had made, one participant said “...it sort-of affirms the decisions we made early on in terms of the types of treatments that we would take...”, and later added “we kind of walked away from other types of therapy but wanted stuff like this to be more play-based”. Informing parents of the potential parent-level benefits, in addition to the potential child-level benefits, associated with different types of early interventions, may allow them to make more fully informed decisions regarding which interventions are best suited to theirs and their child’s needs, and result in better outcomes for all.

Strengths and Limitations

Although this study had several strengths, such as the inclusions of mothers as well as fathers (Braunstein, Peniston, Perelman, & Cassano, 2013), it also had some limitations. For one, parents appeared to have a difficult time verbally “describing” their family quality of life. Although it is common practice within qualitative research to ask

open-ended questions so as to not limit participants potential responses (Creswell & Poth, 2018), when investigating multifaceted concepts such as family quality of life, more pointed questions may be necessary. As well, two families in this study had multiples with ASD who completed the early motor skill intervention. Therefore, it is possible that the findings may have differed if each family only had a single child with ASD. Despite these limitations, the findings of this study make a strong contribution to the current literature regarding parents' motivations for enrolling their children in motor skill interventions and the parent level benefits of doing so.

Future Research

This study identified several areas of research requiring further investigation. First, the literature indicates that sleep issues are quite prevalent amongst children with ASD (Giallo et al., 2013; Ludlow et al., 2012). The findings of this study further support that reality and suggest children's sleep issues are contributing to high stress levels among parents and lower quality of life among families. The efficacy of early motor skill interventions for improving sleep difficulties should be investigated. As well, parents in this study reported increased feelings of hope, decreased worry about the future, and substantial learning, as a result of the experience; future researchers should investigate the efficacy of different types of early interventions for achieving these outcomes. Additionally, the findings of this study and research by Jones et al. (2017) indicate that families of children with ASD are not regularly engaging in physically active play during the child's early years, however it is unclear why. And lastly, the findings of this study

should be used to help inform the design and delivery of motor skill interventions in the future so as to maximize benefits for all family members.

Conclusions

Parents in the current study reported several reasons for enrolling their children with ASD in an early motor skill intervention, including potential benefits for the children (motor skills, social skills, play/fun, school readiness), potential benefits for themselves (meet other children with ASD as well as their parents, and learn strategies to use with their children at home), and the fact that it was free and had no waitlist. Parents also described various factors that influence their stress levels and family quality of life on a day-to-day basis, which were consistent with the current literature (meltdowns/tantrums, trying to anticipate/prevent meltdowns/tantrums, negative comments from strangers in public places, poor listening skills, difficult transitions, sleep issues, lack of understanding, and parents work life/household responsibilities). They also reported improvements in their stress and family quality of life through a number of different parent level benefits associated with the early motor skill intervention for their children with ASD. The main benefits of the intervention for parents included: observing their children succeed, meeting other children with ASD and their parents, learning strategies to use with their children at home/gaining a better understanding of their children (e.g. their strengths/challenges, capabilities, and behavioural triggers), and the light that was shed on the importance of motor skills, play, and fun, for child development (i.e. parents are now engaging their children in more active play at home and in the community). Overall, parents reported that they and their children had a very

positive experience with the early motor skill intervention and wished that there were more opportunities like this within the community. The findings of this study highlighted parents' motivations for enrolling their children with ASD in an early motor skill intervention, the parent-level benefits of doing so, and how those benefits extended to the family unit.

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SECTION 4 MANUSCRIPT 2:

**Parents' Perspectives of the Child-Level Benefits of an Early Motor Skill Intervention
for Children with ASD and Their Effects on the Family Unit**

Abstract

Purpose: The purpose of this qualitative study is to investigate the child-level benefits of an early motor skill intervention for young children with Autism Spectrum Disorder (ASD) as perceived by their parents, and describe how these child-level benefits influenced the family unit.

Methods: Parents of four year-old children with ASD who had participated in a 12-week motor skill intervention, were invited to participate in a one-time-only semi-structured interview (N=8). The interview guide included questions about the intervention's effects on the children and how those effects influenced parents and families. All interviews were recorded, transcribed, and analyzed using NVivo 11. This study was grounded in interpretive phenomenology to elicit rich descriptions of participants' lived experiences and allow for the natural emergence of themes from the data.

Results: Five main themes emerged in terms of the child-level benefits of the motor skill intervention, including improvements with: (1) *motor skills*, (2) *social skills*, (3) *listening skills*, (4) *turn-taking skills*, and (5) *transition skills*. Parents also described a number of ways in which the child-level benefits of the intervention reduced parents' stress levels and improved their family's quality of life.

Conclusions: Overall these findings suggest that early motor skill interventions for children with ASD have several child-level benefits that can subsequently extend to parents and families in many different ways; ultimately reducing parental stress and improving family quality of life.

Introduction

ASD and Early Intervention

Autism Spectrum Disorder (ASD) is a lifelong, pervasive developmental disorder characterized by difficulties with social interaction and communication, as well as restricted/repetitive behaviours, interests, or activities, beginning in the first few years of life (American Psychiatric Association, 2013). Research has shown that earlier access to intervention is associated with better outcomes for children with ASD (Corsello, 2005; Piccininni & Penner, 2016; Rogers & Vismara, 2008). For example, the Ontario Autism Program funds early Intensive Behavioural Intervention (often called IBI therapy) which uses the principles of applied behavioural analysis at varying levels of intensity, to target multiple areas of children's development, including speech and language, social, motor, and adaptive skills via repetition, rewards, and goal adjustment (Harris & Weiss, 1998; Piccininni & Penner, 2016). These programs are effective, and are considered the gold-standard for ASD treatment (Butter, Wynn, & Mulick, 2003); however, government-funded interventions have been associated with long wait times and private services are costly (Jones, Bremer, & Lloyd, 2017; Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006). In previous years, children in Ontario have waited an average of 2.7 years before gaining access to government-funded behavioural interventions (Piccininni & Penner, 2016). There is a need for cost-effective, early interventions that can be provided to young children in a timely manner in order to promote best outcomes for all family members.

Motor Skills

Children with ASD often experience delayed and poor-quality motor skills; in fact, poor motor skills are considered to be a cardinal feature of ASD by many (Dziuk et al., 2007; Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Liu, 2012). Fundamental motor skills are movement patterns (running, jumping, throwing, catching, etc.) that act as the building blocks for more advanced movements and sport specific skills (Clark & Metcalfe, 2002; Robinson & Goodway, 2009; Seefeldt, 1980). Therefore, a certain level of motor skill proficiency is needed for children to be able to successfully engage in active play and sport (Mandigo, Francis, Lodewyk, & Lopez, 2009). Regular engagement in activities such as these are associated with better physical and mental health as well as opportunities for socialization (Lubans, Morgan, Cliff, Barnett, & Okely, 2010; Pellegrini & Smith, 1998). However, without the motor competence to engage in active play with their peers, children with ASD may miss out on important opportunities for learning and development and consequently fall further behind their peers with typical development as they get older (Bremer & Cairney, 2018; Lloyd, MacDonald, & Lord, 2013).

The United Nations High Commission for Human Rights recognized the importance of play for child development by mandating play as the right of every child (United Nations, 1989). Play is a vehicle through which children use creativity, develop their physical strength, cognitive abilities, decision making skills, emotional control, imagination, and dexterity (Erickson, 1985; Ginsburg, 2007; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004). Active play also affords children the opportunity to learn how

to share, negotiate, problem solve, and work with others (Erickson, 1985; Hurwitz, 2002; McElwain & Volling, 2005; Pellegrini & Smith, 1998). As children develop the motor skills required to explore their world, play allows them to develop new competencies, in other developmental domains, that improve their resiliency and confidence for dealing with challenges as they navigate through life (Erickson, 1985; Ginsburg, 2007; Hurwitz, 2002). These qualities are often the exact areas that pose the greatest challenges for children with ASD as they frequently struggle with social communication and emotional regulation (Laurent & Rubin, 2004). Early motor skill interventions may be an effective and feasible intervention option for children with ASD between the time they are diagnosed and the time they gain access to traditional, government-funded, behavioural interventions that target multiple areas of their development.

Primary Outcomes of Motor Skill Interventions

Many researchers have demonstrated the efficacy of motor interventions for improving the motor skill proficiency of children with ASD (Bremer, Balogh, & Lloyd, 2015; Bremer & Lloyd, 2016; Ketcheson, Hauck, & Ulrich, 2017b; Pan, 2010). Bremer et al. (2015) noted significant gains in the gross motor skills of four year-old children with ASD following a 12 week intervention. Similarly, Bremer and Lloyd (2016) found significant improvements in the fundamental motor skills of 3-7 year old children with ASD like characteristics following two 6-week blocks of motor instruction. In addition, Pan (2010) discovered significant improvements in the water skills of 5-9 year old children with ASD following a 10-week aquatic motor intervention. And, finally, Ketcheson, Hauck, and Ulrich (2017a) found significant improvements in the motor skills

of 4-6 year-old's with ASD following an 8 week motor skill intervention. Overall, the evidence indicates that early motor skill interventions have the potential to increase children's motor skill proficiency. Moving forward, the effects of improved motor skills on other areas of children's lives should be investigated.

Secondary Effects of Motor Skill Interventions

The primary effects of motor skill interventions are clear (Bremer et al., 2015; Bremer & Lloyd, 2016; Ketcheson et al., 2017b); however, the secondary effects of such interventions are not as well understood (Karst & Van Hecke, 2012; Tan & Simmonds, 2018). Very few researchers have investigated the secondary effects of motor skill interventions within this population, and all but one study employed a quantitative method of inquiry. Behavioural shifts among children are the most common secondary effect studied using quantitative methods (Bremer, Crozier, & Lloyd, 2016). Changes in adaptive behaviours, stereotypic behaviours, attention, and social skills encompass the main behavioural changes that have been investigated to date (Bremer & Cairney, 2018; Bremer et al., 2016; Bremer & Lloyd, 2016; Ketcheson et al., 2017a; Pan, 2010).

To our knowledge, Tan and Simmonds (2018) have conducted the only qualitative investigation into the secondary effects of a motor-based intervention for children with ASD. Following a horseback riding intervention for children and adolescents, parents were interviewed about their perceptions of the secondary effects. Parents perceived improvements in children's self-concept, emotional wellbeing, self-regulatory behaviour, and social skills, as well as some unexpected benefits to parents and families. For example, parents reported feeling more relaxed, empowered, valued,

prideful, and satisfied as a result of their child's participation in an equine assisted intervention (Tan & Simmonds, 2018). These findings bring attention to the fact that the secondary effects of motor-based interventions can extend beyond the child receiving the intervention, to their family members. Unfortunately, research regarding the effects of child-level benefits on families is sparse.

Families of Children with ASD

Parents of children with ASD have consistently reported higher levels of stress and lower levels of family quality of life compared to parents of children with typical development and compared to parents of children with other developmental disorders (Bonis, 2016; Gardiner & Iarocci, 2015; Hoefman et al., 2014; Jones et al., 2017; Stuart & McGrew, 2009). High parental stress levels can negatively influence the progress of children with disabilities (Karst & Van Hecke, 2012; Lessenberry & Rehfeldt, 2004; Osborne, McHugh, Saunders, & Reed, 2008), while at the same time, low family quality of life scores indicate that the needs of the family are not being fully met (Hu, Summers, Turnbull, & Zuna, 2011). Family members typically act as the main support network for the child as they navigate the unique challenges associated with ASD services (Gardiner & Iarocci, 2015). Therefore, services and interventions should be designed in a way that is sensitive to the needs of the whole family in order to maximize benefits for all. More research is needed to better understand the ways in which programs for children with ASD influence the family unit so that interventions and services can be designed accordingly.

Positive changes in parents' perceptions of their family quality of life and stress following a child-centered ASD intervention would indicate that the benefits of the intervention had extended beyond the children themselves. There are many potential avenues through which an early motor skill intervention may benefit the child, and from there, extend to benefit parents and siblings. For example, if the experience of an early motor skill intervention resulted in improved social skills among children, parents may then feel less stressed about their child's upcoming transition into the school system and their ability to make friends. Parents themselves are best suited to explain the child-level benefits of the intervention and how these benefits extended to themselves and their families.

Purpose

The purpose of this study is to investigate the child-level benefits of a motor skill intervention for four year-old children with ASD as perceived by their parents, and describe how these child-level benefits influenced the family unit.

Methods

Recruitment/Participants

This study was approved by the Research Ethics Board at the University of Ontario Institute of Technology (UOIT) in Oshawa, Ontario (see Appendix 1). Parents of four year-olds with ASD who participated in a fundamental motor skill intervention at UOIT were invited to talk about their experience in a one-time-only interview. Parents who had specified that they would like to be notified about new research opportunities on the motor intervention consent form, were eligible for this study. Six families were

selected at random and contacted via email about the opportunity. Either one or both parents from all six families confirmed that they would like to participate in this study. Each parent was provided with the consent form (Appendix 2) and given an opportunity to ask questions about the study via email or telephone.

Between the six families, a total of eight parents participated (N=8), including two couples. Each interview took place at 202 Simcoe St. N. in Oshawa, Ontario. This location was chosen to maximize comfort for parents as it was where the fundamental motor skill intervention for their children took place. All participants signed informed consent before the interview began.

Motor skill intervention description.

The fundamental motor skill intervention that the parents' children participated in took place twice per week for 12 weeks and each session lasted one hour; three to five children with ASD participated in each session. Staff to participant ratios were high-approximately 1:1 or 1:2. Sessions included a short warm-up routine to a pre-recorded song, a series of activities focused on motor skill development (individual and group-based), and 15 minutes of free play at the end. Each week (two sessions) included motor-based activities that were focused on a particular motor skill (e.g. running). Verbal and visual demonstrations of each activity were provided and children were required to listen and follow instructions in order to receive a turn.

Study Design

This qualitative study was grounded in interpretive phenomenology to promote accurate interpretation and understanding of participants' experiences through

descriptive verbal accounts from the parents themselves (Creswell & Poth, 2018). A semi-structured interviewing technique was used to elicit rich verbal accounts from parents about their experience with the motor skill intervention for their child(ren). Each interview was audio-recorded and lasted between 40 and 90 minutes. Particular attention was paid to parents' perceptions of the child-level benefits associated with the intervention, and how those benefits influenced parents and their families. More specifically, the researchers sought to understand the relationship between child-level benefits and changes in parental stress and family quality of life from parents' perspectives. For the remainder of this work the terms "participants" and "parents" will be used interchangeably to describe those who were interviewed.

Procedures

Once informed consent had been obtained, parents were provided with the Demographic Information Form (Appendix 5). This additional information about the family was collected to aid researchers with interpreting participants verbal statements. Families of multiples were asked to complete one form for each of their children who participated in the motor skill intervention. The interview began once the Demographic Forms were completed.

Each interview included the same core questions (see Table 5). The interview questions were designed to elicit an in-depth description of parents' lived experiences with the motor intervention for their child, and also highlight any relationships between child-level benefits and the family-level outcomes.

Table 5

Semi-Structured Interview Guide Questions

Interview Questions
9. Can you tell me a little bit about your child with ASD?
10. Why did you choose to enroll your child in the motor intervention?
11. What did you expect that you or your child would gain from the intervention?
12. Did the outcomes that you/ your child experienced actually match what you expected? Why, or why not?
13. Have you noticed any changes in your child's behaviour as a result of the intervention? <ol style="list-style-type: none">If so, how have these changes in your child's behaviour influenced the wellbeing of your family, including yourself?Are there any additional changes - good or bad – that you can think of?
14. What factors influence your family's quality of life most? <ol style="list-style-type: none">How would you describe your family's quality of life during an average week?If at all, how has your child's participation in the motor intervention influenced your family's quality of life?
15. What factors influence your stress level most? <ol style="list-style-type: none">How would you describe your stress during an average week?If at all, how has your child's participation in the motor intervention influenced your stress?
16. Can you describe any other benefits or challenges that you or your family experienced as a result of your child's participation in the motor intervention?

The semi-structured format of the interviews permitted the interviewer to probe participants further according to their responses to the main interview questions in Table 5. This allowed for an in-depth conversation pertaining to each of the topics covered in the interview guide. During and after each interview session, the moderator took detailed hand-written notes to document the subtleties that would not otherwise

be picked up by the audio-recorder (Creswell & Poth, 2018). These notes also served to kickstart the preliminary theme-identification process. Once the interview was finished, the audio-recording was used for the transcription process while the note-taking process continued (Creswell & Poth, 2018).

Within seven days of the interview session, participants were sent their transcript via email in order to begin the member checking process (Mero-Jaffe, 2011). Participants were given an opportunity to request the removal or addition of any content to/from the transcript within 14 days of receiving the document. Edits were not required from participants if they were happy with how their interview went. All parents were satisfied with how their interview went, thus no revisions were requested. Next, the moderator immersed herself in the data by re-reading the transcripts and listening to the audio-recordings several times. From here, theme-identification and coding framework development continued (Creswell & Poth, 2018).

Once the note-taking process was complete, the attention was shifted from analyzing transcripts and audio-recordings, to analyzing the detailed notes pertaining to each interview; this allowed for the emergence of more themes (Creswell & Poth, 2018). Concise phrases were then generated to encapsulate each of the themes that were identified; in essence, each theme was given a title. From here, themes were clustered and given a higher-level descriptive label (an “umbrella term”). Ultimately, this process resulted in a descriptive list of themes and subthemes that can be found in Appendix 9. The coding framework was discussed by the research team on several occasions until

agreement was achieved. Transcripts were then uploaded to NVivo 11 Pro and the coding process began.

First, the moderator coded each transcript independently using the qualitative data analysis software. During this step, the coding framework was updated slightly (Appendix 9). Next, a researcher who was not otherwise involved in the study was taught how to code the data using NVivo to establish inter-rater reliability. To ensure the coding process was understood, the third party coded one transcript alongside the primary author. Once training was complete, the individual coded a different interview transcript independently. A coding comparison was conducted within NVivo to highlight any potential bias in the data that had previously been coded by the primary author. Inter-rater reliability scores were calculated between the third party and the primary author. The results revealed that the data coded by each independent reviewer was over 95% in agreement. These results bolstered the credibility of data originally coded by the primary author.

Results

Parents described their children who participated in the fundamental motor skill intervention as verbal and capable of engaging in motor-based activities. Four out of the six families had a single child participate in the motor skill intervention, one family had twins who participated, and one family had triplets who participated. In total, these families represented nine children with ASD; two girls and seven boys. The gender ratio of these children matched the 1 (girl):4-5 (boy) ratio previously estimated by the Public

Health Agency of Canada (2018). See Table 6 for more detailed demographic information pertaining to each family.

Table 6

Family Demographic Information

	Participant(s)	Child(ren) Sex	Age at ASD Diagnosis (months)	Other Diagnoses	Other Difficulties
Family 1	Mother Father	Male	18	n/a	Anxiety, Anger, Transitions
		Male	18	n/a	Transitions
Family 2	Mother	Female	22	ADHD	n/a
Family 3	Mother	Male	30	n/a	Transitions
Family 4	Mother Father	Male	30	ADD, GAD	Anxiety, Anger, Transitions, Attention
Family 5	Father	Female	36	n/a	Anxiety, Transitions
Family 6	Mother	Male	30	DD	Transitions, Anxiety, Anger
		Male	30	DD, SPD	Transitions
		Male	30	DD	Transitions, Anxiety, Anger

**ADD: Attention Deficit Disorder; ADHD: Attention Deficit Hyperactivity Disorder; DD: Developmental Delay; GAD: Generalized Anxiety Disorder; SPD: Sensory Processing Disorder; n/a is 'not applicable'*

Parent Reported Progress Among Children

When describing what their child(ren) gained from the intervention, parents consistently reported many of the same learning and skill related outcomes. Improved motor skills, social skills, listening skills, turn-taking, and transitions were the most commonly reported benefits to the children. Parents also reported that the children were able to transfer their learning to several different environments including home, school, and extracurricular activities.

Motor skills.

All parents reported improvements in their children's motor skills; the primary aim of the intervention. These included skills such as walking, kicking, running, balancing, catching, throwing, ascending and descending stairs, jumping, one-foot hopping, and skipping. As the children learned new motor skills, and gained confidence with their physical abilities, they began using their skills outside of the intervention and including others in their play-based motor activities. Many parents reported that this positively influenced how they interact with one another at home by giving them more activities to “*fall back on*” rather than using technology (TV, iPad, cell phone) as their main form of entertainment.

“We take them to a park near our house and usually there was hesitance with child A or kind of shakiness with him with climbing certain things but now he’s a pro.”

“Stairs, she can do stairs now and she doesn’t have no fear of going up or going down, walking on her feet, holding the railing, going down independently without a railing. I think stairs for me was the biggest thing ever.”

“She likes catching the ball now. When we took her to Great Wolf Lodge that’s all she wanted to do. She wanted to play with the ball in the water.”

“Like they really mimic... oh they were doing it where they were running around the house, you know the song that you play with the galloping and hopping... so they do that. So one is I guess the leader at the time, so I was watching child B was the leader at they time and they were running, running, running, and then he says “okay, now we waallkkkk” and they walked around and then he says “now we gallop” and they all gallop.”

“He was not a very big ballplayer before. Especially the ball- that was a big change. He was never... he never really took to playing with balls before... but I think you know like seeing the fun in it and seeing what you can do with a ball... and that he can do it... I think it brought a little bit of... I wouldn't say passion but.... he now asks me to play ball with him and he never did that before.”

Social skills.

Improvements in children’s social skills were perceived by several participants.

The children were able to interact and develop social relationships with each other and the instructors during the study. Eventually, many became excited to go and see their friends at the intervention which was a completely new behaviour for some that parents valued. Parents frequently described this process of becoming more social as “*coming out of their shell*”. Furthermore, many parents felt that improvements in their child’s social skills had a positive influence on sibling relationships.

“He is more social! He’s not shy. He wants to run and play. If he sees a group of kids, he's in there. He's interactive, it's great, it's amazing!”

“As the intervention was going on and they were in the program they learned to develop these relationships, they learned to like these people, right? So their social skills with other people... I feel like this was the kickstarter.”

“He started getting excited to see some of the kids, “where’s Rachel”, “where’s Henry”, right? And then he’s like “I'm going to go see them” so then it's like, “oh, great!”. Because a lot of times with social interaction he won’t go near a kid or go talk to a kid, so we'd be like “ohh, how is he going to make friends, is he going to have friends or be one of those kids that's by himself?”. But for me, I was kind of happy because I'm like, “oh wait, he's excited to see these people, maybe he will have friends”, and it’s just, he’s better around kids.”

“It helped him, get out of his little, his little shell and now realized the things that he can do and things that are fun, umm, because he really enjoyed it.”

“Ya, so it definitely brought in this whole group play into our dynamic, which wasn't really happening up until, until we started doing this... before it would be more like parallel playing. They would play the same thing, but not necessarily with each other. Not necessarily having sort of, like, a dialogue happening. That imagination, that, you know... here, I'm going to explain something to you. Like, they didn't do that with each other before.”

Listening skills.

When asked what they expected their child(ren) would gain from participating in the intervention, nobody mentioned listening skills. However, when discussing the secondary effects of the intervention, nearly all parents noted improvements in their child(ren)'s listening skills both during and after the intervention. This was an unexpected, and much appreciated, benefit from parents' perspectives. In fact, several parents reported that improvements in their child(ren)'s listening skills actually lowered their own stress levels. One parent even described this secondary effect as “*the biggest takeaway*”.

“Umm, it also taught him that he had somebody else that he had to follow, whether it was school or here, wherever, he has to follow directions and listen and wait for cues.”

“I think with this therapy now seeing him in soccer, he's actually following instructions and I think it's also kind of balanced with school as well where you know prior to this he was a bit more reluctant.”

“So helped to lower stress a little bit because the boys are able to listen.”

“Helped to minimize, I guess, some stress because they have learned to listen to instructions, so it also helped us.”

“I think it's between listening to instructions, and following instructions, I think is

the biggest take away.”

Turn-taking.

Turn-taking was another important skill children learned as a result of the intervention. Again, parents reported that this was an unexpected benefit of the intervention that their children were able to transfer to different environments. The transfer of these skills seemed to be most noticeable to parents who have more than one child (with or without ASD) as they were able to witness their child use his/her improved turn-taking skills during sibling interactions at home. In some cases, learning how to take turns shifted the family dynamic (e.g. able to play board games as a family).

“The other thing I liked too was the turn-taking. [She] is actually getting better at turn-taking I think due to this program. Ya, it, it takes a lot of work to turn take.”

“They actually play together now, not straight games but they do take their turns in terms of playing the track and with their toys.”

“Them learning how to wait and be patient and turn-take, It's incredible... it's awesome to see... they actually still remember and they take it home with them because definitely she has.”

“And you would hear a lot of the same conversations that happened here, would happen at home. Almost like they became the instructor, so they were the teachers, they were telling their brothers what they had to do and how the game went. And they would take turns doing that.”

“They also learned that whole waiting and turn taking, right? So when you play games at home “okay mommy’s turn”. There's a few board games that we pulled out. So that waiting for “okay, now you're going to do your thing, and then it’s his, and then it’s his, and then it’s mine”.”

Transitions.

Although improvements with transitions were discussed less frequently than listening skills and turn-taking, parents who did perceive improvements with this skill

emphasized the weight of its impact on their daily life. As children became better at transitioning between activities/environments, parents were able to take them places more easily. Improvements with transitions also helped children adjust to school according to some parents.

“The transitions I feel are a lot better.”

“Definitely transitioning to different environments more easier.”

“Mind you, the transitions are still there, but, like going to the doctors would like, they would have attacks and they would not want to go to the doctors, right? So the fact that we were able to walk in, go in the elevator, open the door, go walk into the office, and you know what I mean? Like, that's a big deal. They use to just scream the entire time. So, and I kind of feel that's because we did so many transitions here.”

“I find that his transitions have improved a lot and even in the short time because like I said school used to be a challenge. Now he's the first one walking out of the car, foods, same sort of thing. Now he's actually trying foods... but it's not just school, even just, I take them to the doctor and I was expecting a full meltdown or whatever. And it wasn't, I was in shock.”

“They still have difficulties in the transitions, but when we first got here it was real bad, and towards the end it got a little better. But I also think if we didn't do that, the transition into school would have been worse. So we benefited from that.”

Discussion

Parent Reported Progress Among Children

Participants perceived several benefits of the early motor skill intervention for their children. The five major areas of improvement (themes) that were identified by parents, include: motor skills, social skills, listening skills, turn-taking skills, and transition skills. Parents also described several different ways in which these child-level benefits extended to the family unit.

Motor skills.

Within the motor domain, parents identified several skills that their children became more proficient with, ranging from locomotor skills (e.g running) to object control skills (e.g throwing) to body management skills (e.g balancing). This finding supports the growing literature concerning the efficacy of motor skill interventions for improving the motor skills of young children with ASD (Bremer et al., 2015; Bremer & Lloyd, 2016; Ketcheson et al., 2017a; Pan, 2010). Fundamental motor skills are often required for children to participate in games and activities during physical education class, recess, and sport (Bremer & Lloyd, 2016), therefore, motor skills are important for children to develop in order for them to successfully engage in active games with their peers at school, at home, and in the community. In addition to the psychosocial and health related benefits of active play for children, parents have identified recreation- which often involves motor skills/physical activities- as an important component of their family's quality of life (Jones et al., 2017).

Not only did parents notice a change in the type of play their children were engaging in (more active) but many also noticed a sharp increase in sibling interaction during play at home. Parents explained that rather than siblings engaging in parallel play (playing the same thing side by side) they began to play together and incorporate dialogue into their games. Previous research has also found that active, group play provides children with an opportunity to strengthen their ability to work with others and improve their decision making skills and problem solving skills, along with several other benefits (Erickson, 1985; Ginsburg, 2007; Hurwitz, 2002; McElwain & Volling,

2005; Pellegrini & Smith, 1998; Tamis-LeMonda et al., 2004). Parents noticed that as their children with ASD engaged in play with their siblings more often, they began “*standing up for themselves*” more frequently by voicing their preferences. This may be explained, to some extent, by the learning processes associated with play where children learn to negotiate with their peers to get what they want or come to a compromise (Ginsburg, 2007). Relationships between children with ASD and their siblings can become strained when challenging behaviours bring about frequent conflict (Rivers & Stoneman, 2003). Parents of children with ASD have previously reported that strained sibling relationships contribute to their own stress levels (Rivers & Stoneman, 2003). Improving children’s social communication skills through the experience of an early motor skill intervention could meaningfully reduce parents stress levels. Furthermore, the development of these skills prior to school enrollment may promote the inclusion of children with ASD as they may be better able to interact with the other children and peacefully resolve certain issues (Craig-Unkefer & Kaiser, 2002).

One potential reason why children were not engaging in active play with their siblings before the intervention could be because many lacked the skill and experience required to facilitate such activities with their siblings (Harada, Siperstein, Parker, & Lenox, 2011; Oppenheim-Leaf, Leaf, & Call, 2012). Although this idea warrants further investigation, parents’ reports support the notion that their child(ren) with ASD were exposed to certain active games and sports equipment for the first time during the motor skill intervention. One parent explained that her son had not demonstrated interest in playing with a ball before the intervention and she felt as though he didn’t

understand the potential for it to be fun. This parent went on to explain how she felt as though she had developed “*tunnel vision*” because she was so focused on the other aspects of her son’s development (behaviour, speech, and social skills) that motor skills “*fell into the background*”. She described how throwing a ball at home became less important because of all the other things that they needed to work on. Previous research with parents of adolescents with ASD also found that parents had prioritized behavioural/communication interventions for their children, partly due to their lack of knowledge about the importance of motor skills for child development (Gregor et al., 2018). One parent in the study by Gregor et al. (2018, p. 59) said “*The message of physical activity being important for ASD kids is not there*”. The results of the current study support the findings of Gregor et al. (2018), suggesting that there is a need for clinicians to educate parents on the importance of motor skill development during the formative years in order to promote participation in physical activities across the lifespan. Clinicians should clearly communicate the potential for early motor skill interventions to positively influence other aspects of children’s development (e.g. social skills and behaviour) by teaching them the skills required to engage in active play with their peers and family members; an important component of family quality of life (Jones et al., 2017).

Social skills.

Difficulties with social skills are a core characteristic of ASD, and many types of therapies/interventions aim to improve them (American Psychiatric Association, 2013; Ke, Whalon, & Yun, 2018). The results of this study suggest that active play may provide

a medium through which children can improve their social skills by using their motor abilities to interact with their peers in a fun and motivating environment. Improvements in social skills as a result of motor skill intervention have been demonstrated in previous research (Bremer et al., 2015; Bremer & Lloyd, 2016; Pan, 2010). For example, Bremer et al. (2015) found improvements in motor skills and social skills as well as a reduction in challenging behaviours following a motor skill intervention for four year-olds with ASD. Furthermore, MacDonald, Lord, and Ulrich (2013) found that children who have more proficient motor skills tend to have stronger social and communication skills as well. Parents in the current study explained that their child(ren) were able to develop friendships with other children during the intervention and how they now worry less about their child(ren) starting school and socializing with other children. The findings of this study further support the notion that early motor skill interventions can positively influence the social domain of children with ASD, and, that social improvements among children can positively influence parents.

Listening skills and turn taking skills.

Listening skills are essential in many areas of daily life including social, occupational, and educational settings (Bourdeaud'hui, Aesaert, Van Keer, & van Braak, 2018). The literature suggests that primary school students are required, on average, to spend 50-75% of their classroom time listening to teachers, fellow classmates, and media sources (Imhof, 2008). Listening skills are the primary means through which information is transferred from teachers to students (Bourdeaud'hui et al., 2018). Thus, it is no surprise that listening skills are closely related to learning outcomes and

academic success as they provide children with: (1) an opportunity to follow along with classroom lessons that have a line of reasoning, (2) an opportunity to understand instructions and new concepts, and (3) an opportunity to compare and contrast new information with previous knowledge (Imhof, 2008; Owca, Pawlak, & Pronobis, 2003). In the current study, parents consistently reported improvements in children's listening skills as a result of the early motor skill intervention. This is an important finding that may suggest motor skill interventions for young children with ASD can increase school readiness (Brigman, Lane, Switzer, Lane, & Lawrence, 1999). Furthermore, strong listening skills are essential for relational and social skills within the context of primary school (classmate interactions at recess, during in-class group discussions, etc.) (Bourdeaud'hui et al., 2018). Research suggests that children's ability to make friends relies, to some degree, on their ability to listen to others (Bourdeaud'hui et al., 2018). Therefore, promoting listening skill development prior to Kindergarten could have a significant effect on the educational experience of children with ASD as well as their quality of life in general. Further investigation into the effectiveness of motor skill interventions for improving the listening skills of children with ASD is warranted.

Preschool programs for children with typical development are designed to increase school readiness by promoting the development of skills (e.g. cognitive, listening, social) that are required for school success (Barnett, 1995; Logue, 2007). The results of this study show that the experience of an early motor skill intervention improved children's ability to listen to their parents even though their parents were not directly involved in the intervention. It is possible that improvements in listening skills-

resulting from an early motor skill intervention- may also contribute to school readiness among children with ASD (Brigman et al., 1999), however, more research is needed. Furthermore, developing listening skills to a level where children with ASD are able to get the most out of their government-funded behavioural interventions, could significantly influence their developmental trajectory. Early motor skill interventions may be particularly effective for promoting the development of listening skills for a few reasons. First, most of the motor-based activities involved in the current study seemed to be inherently fun for the children (e.g. obstacle courses incorporating two-foot hopping, one-foot hopping, and crawling). Thus, children may have been motivated to listen to the instructions for each activity as they could see all of the colorful toys set up; in order to be able to go and play with them, they needed to listen first. As well, the instructions for each motor activity involved a short verbal description in conjunction with a physical demonstration. Visual displays of skill sequences have been shown to be quite effective for children with ASD (Quill, 1997). Therefore, pairing the two instructional methods within a positive and motivating environment, may create optimal conditions to promote the development of listening skills for children with ASD.

The literature is clear in describing the benefits of strong listening skills among young children in school settings (Bourdeaud'hui et al., 2018; Imhof, 2008), however parents also reported that their child(ren)'s improved listening skills and turn-taking skills had a significant impact on their overall family life. One parent described his interpretation of the shift in his daughter's thought process from *"oh this is getting taken away from me"* to *"okay I have to wait my turn"*, stating *"she gets it now"*.

According to many participants, their child(ren) were better able to follow rules and instructions at home which resulted in less conflict between the child(ren) and their parents. At the same time, children began sharing toys with their siblings more easily (turn-taking) and participating in games with their family members that required turn-taking (e.g. board games). Early motor skill interventions may provide children with the skills required (motor skills, listening skills, turn-taking skills, etc.) to participate in a host of leisure and recreational activities with their family members. The weight given to these new experiences by participants may be explained, in part, by the findings of Jones et al. (2017) where parents of children on waitlists for ASD services reported that they considered leisure and recreation opportunities with their family members to have a significant influence on their family quality of life. To our knowledge, the current study is the first to identify improvements in listening skills and turn-taking skills, and their influence on the family dynamic, as a result of an early motor skill intervention for children with ASD. More research is needed to explore the secondary effects of motor skill interventions on children with ASD, including changes in listening skills, turn-taking skills, and transitions.

Transitions.

Early interventions that improve children's ability to transition between activities/environments would likely benefit many families as difficulties with transitions have been reported as a significant stressor for parents (Silva & Schalock, 2012). Planning is an important practice for many parents in order to promote successful transitions and avoid causing confusion and anxiety for their child(ren) with ASD

(Stoner, Angell, House, & Bock, 2007). However, parents in the current study reported that planning and trying to anticipate every possible scenario each time they leave the house, is extremely stressful. One participant said *“you have to pack for a holiday just to go do the groceries right... and that is so so stressful!”*, while another parent said *“You're always thinking ahead. What do we have to prepare for, is a meltdown going to happen here?”*. In a study by Stoner et al. (2007) parents of young children with ASD reported that preparing for transitions begins with an understanding of the child. In the current study, several parents reported that they gained a better understanding of their child(ren) by observing each intervention session and that their child(ren)'s transitions improved. The findings of Stoner et al. (2007) suggest that parents improved understanding of their child(ren) may have allowed them to better prepare for transitions with their child which then could have contributed to the smoother transitions that they experienced. As children endure long wait times for government-funded ASD services, clinicians should recommend effective strategies that parents can use in order to gain a better understanding of their child(ren). This could benefit the children (e.g. less transition-provoking anxiety) as well as their parents (e.g. avoid stress associated with difficult transitions).

Child-Level Benefits- Extended

Overall, the findings of this study suggest that the child-level benefits of an early motor skill intervention can extend to the child's family members as well. Tan and Simmonds (2018) coined the term *“flow-on effects”* to describe the mechanism through which parents and siblings can be positively influenced by the progress made by

child(ren) with ASD during an intervention. A parent who participated in Tan and Simmonds (2018, p. 764) study explained that the benefits of the intervention for the child *“trickled down to the rest of us”*. Similarly, a parent in the current study explained how the child-level benefits of the intervention *“had an effect on all of us [family members]”*. This is consistent with the family quality of life conceptualization put forth by Zuna, Summers, Turnbull, Hu, and Xu (2011) whereby changes in each individual's functioning have an influence on the family as a whole, and in turn, the shift in the family's dynamic positively influences each individual further.

Future Research

Most research involving motor interventions for children with ASD have focused on the primary effects of the intervention (changes in motor skill proficiency), and those that have considered the secondary effects (e.g. changes in social skills) usually employed quantitative methods such as surveys or questionnaires (Bremer & Cairney, 2018; Bremer & Lloyd, 2016; Ketcheson et al., 2017a; Pan, 2010). It is possible that children with ASD participating in motor skill interventions in the past have also experienced improvements in listening skills, turn-taking skills, and transitions which subsequently shifted their family's dynamic, but perhaps the findings of the interventions' secondary effects were limited by the study's mode of inquiry (Bremer et al., 2016; Pan, 2010). Qualitative methodology allows for participants to provide a rich description of their lived experiences without restricting their possible responses the way that quantitative methods sometimes do (Creswell & Poth, 2018). There is a need for further investigation into parents' perceptions of the secondary effects of all types of

early interventions/therapies for children with ASD- using qualitative methodology- to improve our understanding of the wide-reaching effects of intervention/therapy designs.

On one hand, it is possible that any type of early intervention for children with ASD will result in secondary benefits to some extent. However, on the other hand, it is also possible that early motor skill interventions are particularly effective when it comes to eliciting secondary benefits for children with ASD since play and learning are dimensions that stimulate each other (Pramling Samuelsson & Johansson, 2006). In other words, because many motor-based activities are inherently fun, this may motivate children to participate more fully and therefore benefit in more ways (Pramling Samuelsson & Johansson, 2006). Moreover, the fact that motor skill interventions often involve small groups of children (Bremer et al., 2015), and naturally incorporate physical activity- which is associated with a host of benefits in and of itself (Hill, 2010; Iverson, 2010)- may further contribute to the utility of this particular modality for eliciting secondary outcomes. Understanding the secondary effects of different types of interventions/therapies will allow clinicians to make more fully informed treatment recommendations to families of newly diagnosed children in terms of which types of interventions/therapies would be best suited to their child's and family's needs; thus, more research is warranted.

Strengths and Limitations

This study had several strengths- for example, fathers, who are typically underrepresented in ASD family research (Braunstein, Peniston, Perelman, & Cassano,

2013), made up 38% of our sample- however, like all research, this study was not without limitations. First, the fact that parents provided their perspectives on an event that had already happened increased the risk for retrospective recall bias (Schmier & Halpern, 2014); more research is needed to substantiate the findings of this work. Additionally, although the doctor-declared “severity” of ASD diagnoses were not recorded, the participants children were similar in terms of their level of functioning (mild-moderate ASD), thus the results of this study may have differed if the children had lower levels of functioning. Future research should investigate the effects of early motor skill interventions on children with “severe” ASD vs “mild-moderate” ASD, as well as families of a single child with ASD vs families of multiple children with ASD. Despite the limitations, this qualitative investigation provides a significant and meaningful contribution to the literature which supports the efficacy of early motor skill interventions for benefiting children with ASD as well as their family members.

Conclusions

The present study highlights parents’ perceptions of the secondary effects of an early motor skill intervention for children with ASD. Parents described five main child-level benefits of the intervention, including improvements with: motor skills, social skills, listening skills, turn-taking skills, and transitions. As well, parents described how the child-level benefits extended to the family unit (e.g. reduced parental stress/ improved family quality of life). This phenomenon was previously observed and defined by Tan and Simmonds (2018) as “flow-on effects”, where the child-level benefits of a motor skill intervention subsequently “flow-on” to other family members. All parents in

the current study perceived the early motor skill intervention as a positive experience for themselves in addition to their children. These findings suggest that inclusive, motor-based programs within the community could benefit children with ASD, as well as their families, in a cost-effective and accessible way. More research is needed to improve our understanding of the secondary effects of different types of early interventions for the children with ASD, and their family members. This will allow us to direct families to ASD services that are best suited to the child's and family's needs- especially during long wait times for government-funded behavioural interventions.

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SECTION 5: THESIS CONCLUSIONS

Overview

ASD is a lifelong, pervasive neurodevelopmental disorder characterized by challenges with communication and social interaction, as well as restrictive and repetitive patterns of behaviour, activities, and interests (American Psychiatric Association, 2013). In addition to the core characteristics of the disorder, children with ASD often experience delayed and poor-quality motor skills (Lloyd, MacDonald, & Lord, 2013); in fact, motor deficits are considered to be a cardinal feature of the disorder by many (Dziuk et al., 2007; Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Liu, 2012). The motor domain is an important area of child development that enables children to engage in active play with their peers (Mandigo, Francis, Lodewyk, & Lopez, 2009), yet the motor deficits of children with ASD are virtually ignored in the clinical literature (Rosenbaum, 2005). Regular engagement in active group play has been shown to facilitate other areas of children's development including social skills and cognition (Lubans, Morgan, Cliff, Barnett, & Okely, 2010; Payne & Isaacs, 2012). However, without the motor skills required to participate, it is likely that children with ASD will avoid these types of active play settings, miss out on important opportunities for development, and fall further behind their peers with typical development as they get older (Lubans et al., 2010; Payne & Isaacs, 2012; Sibley & Etnier, 2003). Therefore, interventions designed to improve the motor skill proficiency of young children with ASD, could have a significant, and positive influence on their developmental trajectory.

In previous years, children in Ontario (Canada) have waited an average of 2.7 years from the time they were diagnosed to the time they began receiving government-

funded behavioural intervention (Piccininni & Penner, 2016), and parents have reported that the burden associated with caring for a child with ASD is most pronounced during this sensitive time (Stuart & McGrew, 2009). Parents of children with ASD consistently report higher levels of stress and lower levels of family quality of life compared to parents of children with typical development and compared to parents of children with other development disorders (Bonis, 2016; Gardiner & Iarocci, 2015; Hoefman et al., 2014; Jones, Bremer, & Lloyd, 2017; Stuart & McGrew, 2009). This is concerning since high parental stress is associated with poorer health among adults and reduced intervention effectiveness among children (Osborne, McHugh, Saunders, & Reed, 2008; Thoits, 2010). In addition, reports of low quality of life among parents have been associated with less ability to effectively manage the special needs of children with ASD (Gardiner & Iarocci, 2015; Jones et al., 2017). There is a need for effective and affordable ASD interventions that can be provided to children during long wait times for government-funded services, that will benefit the children as well as their family members. The results of this study suggest that early motor skill interventions for young children with ASD may be one strategy that could be used to achieve these outcomes.

According to the family quality of life conceptualization put forth by Zuna, Summers, Turnbull, Hu, and Xu (2011), along with the Family Systems Theory (Cridland, Jones, Magee, & Caputi, 2014), there are a number of ways in which the experience of an early motor skill intervention for a child with ASD could influence the family unit. Figure 1 was adapted from Zuna et al. (2011) and depicts three potential mechanisms through which the experience of an early motor skill intervention may influence families

of children with ASD- assuming parents and siblings attend the intervention with the child who is participating. Each solid dark circle symbolizes a gear where a change in one family member reciprocally influences the others and shifts the family dynamic overall.

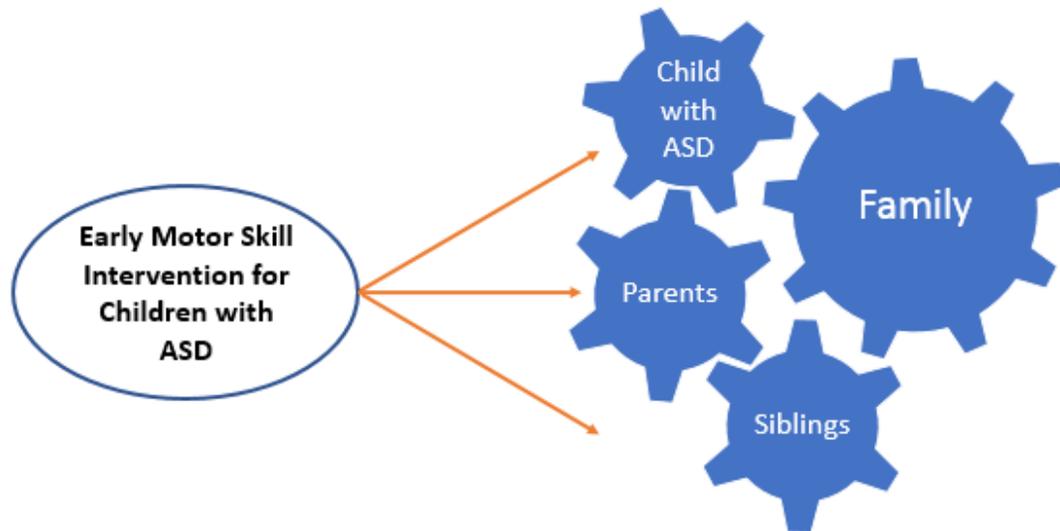


Figure 1. Three mechanisms through which the family unit may be affected by the experience of an early motor skill intervention for a child with ASD. Adapted from *Enhancing the Quality of Life of People with Intellectual Disabilities* (p. 264), by N. Zuna et al., 2011, New York, NY: Springer Nature. Copyright 2010 by Springer Science and Business Media.

The primary purpose of this study was to describe parents' perspectives of the child and parent-level benefits associated with an early motor skill intervention for four year-old(s) with ASD, and how those benefits influenced the family unit. The secondary purpose of this study was to describe parents' perspectives of their stress and family quality of life, as well as their motivations for enrolling their child(ren) with ASD in the early motor skill intervention. Manuscript one addressed the first aim (describing parents' perspectives of the child-level benefits and their influence on the family unit) and manuscript two addresses the others (describing parents' perspectives of the

parent-level benefits and their influence on the family unit; describing parents stress, family quality of life, and motivations for enrolling their children).

Parents described five key child-level benefits associated with the early motor skill intervention, including improvements with: motor skills, social skills, listening skills, turn-taking skills, and transition skills. These benefits extended to parents and families in a number of ways. For one, improved motor skill proficiency among children promoted more active play among families as the child became interested and able to engage in the activities; as a result, parents reported an increase in their family's physical activity levels and overall quality of life. This finding supports previous research where parents of children with ASD reported that opportunities for engagement in leisure and recreation as a family, are an important component of their overall family quality of life (Jones et al., 2017).

Parents in the current study also reported that improvements in their children's social skills improved sibling relationships and reduced their own stress levels as they worried less about their children's ability to interact with others and make friends in the future. Previous literature has demonstrated that part of the reason why parents of children with ASD experience high stress levels is due to their uncertainty about the child's future and what to expect (Galpin et al., 2017). The findings of the current study suggest that the act of observing child-level improvements (e.g. social skills) may greatly reduce parent's stress levels and result in benefits to the whole family. Play-based motor interventions may be particularly effective when it comes to eliciting observable child-level improvements as the emphasis is shifted from trying to "fix" or eliminate

difficult behaviours, to using play and fun to facilitate learning. In essence, motor skill interventions encourage children to “just be kids” and have fun, while also providing parents with a front row seat to the experience.

Improvements with children’s listening skills and turn-taking skills were reported to have the biggest influence on parents and families. Better listening skills reduced conflict in the home as children were better able to listen and follow rules/instructions. Refined listening skills also allowed parents to feel more comfortable when going out with their children; thus, parents reported an increase in the frequency of their family outings which reduced their feelings of isolation and positively influenced their family’s quality of life. This finding further supports the current literature as social isolation has previously been linked to lower levels of family quality of life within this population (Vasilopoulou & Nisbet, 2016). In terms of turn-taking skills, improvements were especially beneficial for families with multiple children as they are now able to engage in games, as a family, that require patience between turns (e.g. board games). Lastly, parents of children who improved their ability to transition between activities/environments, experienced a reduction in their stress as they were able to navigate their lives with greater ease (e.g. doctors’ appointments). Overall, parents’ reports of the numerous child-level benefits associated with a motor skill intervention, demonstrate the potential for this non-traditional interventional method to achieve similar outcomes to traditional, intensive behavioural interventions (social skills, motor skills, adaptive behaviours, etc.) (Hayward, Eikeseth, Gale, & Morgan, 2009). This study also highlighted several different ways in which the child-level benefits extended to

parents and families. This is consistent with the Family Systems Theory which says that a change in one family member (e.g. improved listening skills of a child with ASD) will carry over to the family unit (e.g. reduced conflict between the child and their family members/more frequent family outings).

In addition to the child-level benefits associated with the early motor skill intervention, parents also described several ways in which they themselves benefited from the experience. The main parent-level benefits included: observing their child(ren) succeed, meeting other children with ASD and their parents, learning strategies to use with their children at home/gaining a better understanding of them (e.g. strengths/challenges, capabilities, and behavioural triggers), and a newfound appreciation for the importance of motor skills, play, and fun, for child development (i.e. parents are now facilitating more active play at home and in the community). Observing success and seeing what their children are capable of made parents happy, changed their perspective of their children, and shifted the family dynamic in a positive way (holding children to higher standards at home, letting children be more independent, etc.). The fact that “observing success” was so influential for parents in this study, suggests that children with ASD may not be provided with many opportunities to showcase their abilities, via positive experiences, prior to gaining access to intensive behavioural interventions. In other words, because the “observing success” finding was almost surprising to the parents, it indicates that the daily struggles or challenges with the behaviour, social, and communication skills of their children dominate their daily experiences. Observing their child succeed was expressed in such a positive light it

indicates that at this early age these opportunities are infrequent. Instead, parents are being instructed (by clinicians, website forums, etc.) to focus on improving the very behaviours that the children struggle with the most; possibly resulting in conflict and resistance which, for parents, seems to overshadow the children's positive attributes and abilities. Based on the findings of this study, it is possible that parents may be able to use structured, active play within the home setting to create an environment that is conducive to success and behavioural improvements (e.g. listening/following instructions), while also minimizing resistance and conflict between parents and children. This may naturally enable parents to view their children in a more positive light while still facilitating child development in the home setting, and promote a fundamental shift in parents' perspectives about what it means to be a parent of a child with ASD.

Meeting other children with ASD, and their parents, provided participants with perspective regarding their own journey with their child(ren) and decreased feelings of isolation. Again, this finding supports the current literature which highlights a negative association between social isolation and family quality of life (Vasilopoulou & Nisbet, 2016). Some families in this study had developed friendships and spent time together outside of the intervention; creating opportunities for children and parents to socialize. Learning strategies that they could use with their children, allowed parents to feel more comfortable going out as a family and contributed to more frequent family outings; ultimately decreasing parents' feelings of isolation and positively influencing their family's quality of life (Vasilopoulou & Nisbet, 2016). And lastly, parents reported

seeking out more opportunities for active play at home and in the community as they developed a greater appreciation for the motor domain as an important part of child development. Consistent with the Family Systems Theory, these findings highlight several different avenues through which the parent-level benefits associated with an early motor skill intervention for children with ASD, can extend to the family unit.

Parents' descriptions of their high stress levels were consistent with the literature (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Hoffman et al., 2008; Ludlow, Skelly, & Rohleder, 2012; McStay, Trembath, & Dissanayake, 2014). Meltdowns/tantrums, trying to anticipate/prevent meltdowns/tantrums, negative comments from strangers in public places, poor listening skills, difficult transitions, sleep issues, lack of understanding, and parents work-life/household responsibilities, were all identified as factors that contribute to high stress levels. As well, parents described several factors that affected their family's quality of life including: opportunities to spend time together as a family, opportunities for parents to spend one-on-one time with each of their children (with and without ASD), and opportunities to interact with other families. Again, these factors support the current literature focused on families of children with ASD as many parents have reported feelings of isolation and difficulties striking a balance between keeping up with their daily responsibilities (e.g. work, household chores, appointments for their children/themselves) and making sure to spend quality time with each of their family members separately and together (Hoogsteen & Woodgate, 2013; Woodgate, Ateah, & Secco, 2008). The findings of the current study strengthen the literature and bring attention to the need for ASD

interventions that improve parent and family level outcomes such as parental stress and family quality of life. Early motor skill interventions can provide a positive learning experience for children and their parents by focusing on play and fun (rather than “fixing” difficult behaviours), encouraging parent observation/participation, and including small groups of children with ASD (rather than one-on-one intensive therapy or large groups).

Lastly, parents described several reasons for enrolling their children with ASD in the early motor skill intervention. Potential benefits for the children (motor skills, social skills, play/fun, school readiness), potential benefits for themselves (meet other children with ASD as well as their parents, and learn strategies to use with their children at home), and the fact that the motor skill intervention was free and had no waitlist, were all identified as factors that motivated parents to enroll their children. These factors highlight some shortcomings of current government-funded services following a child’s ASD diagnosis. This is the first study, to our knowledge, that has explored parents’ motivations for enrolling their children in an early motor skill intervention. Parents responses indicate that their families are in need of affordable intervention opportunities that can be provided during long wait times for government-funded services. Motor-based interventions for children with ASD could be integrated into communities across Canada to feasibly and effectively fill the need for affordable, evidence-based early intervention options during long wait times for government-funded services.

Overall, the results of this study indicate that the experience of an early motor skill intervention can benefit children with ASD as well as their parents, and that these benefits can extend to the family unit. In the current literature, there is a paucity of research describing the effects of child-centered ASD interventions on parents and families. Some occupational therapy studies have investigated the intervention's effects on children's family members, however most have only considered changes in parental stress as an outcome measure and quantitative methods were the predominant means of inquiry (Gika et al., 2012; Reed et al., 2009; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). Additionally, most, if not all, interventions that have considered family outcomes are not child-centered, meaning the intervention actually targeted the parents and/or families and measured family outcomes afterwards (Gika et al., 2012; Okuno et al., 2011; Reed et al., 2009). Therefore, further qualitative investigation into the effects of child-centered early interventions on all family members is warranted.

Recommendations

This study has highlighted several important avenues of research that should be investigated in the future. The small sample size of this study restricted our ability to detect differences between the perspectives of mothers versus fathers. Future research should investigate and compare the perspectives of each parent separately, as mothers and fathers may be affected differently by the experience of an early motor skill intervention. Moreover, the effects of the intervention may differ for children with mild versus moderate versus severe ASD; all of the children discussed in the current study would be considered as having mild to moderate challenges associated with their ASD

diagnosis based on parents' descriptions. As well, researchers investigating changes in parental stress and family quality of life as a result of an intervention, should consider including a control group and a pre/post data collection strategy for the experimental group. A control group would allow for the distinction between changes due to the intervention versus changes due to child maturation, etc. Pre-intervention interviews may generate a better understanding of each participants baseline stress level and family quality of life, and allow for better detection of change post-intervention. A mixed methods approach, combining the use of interviews and questionnaires to measure stress and family quality of life pre and post-intervention may also generate a more complete understanding of parents' realities.

Based on the findings of this study, the influence of motor interventions on sleep quality is an important avenue of future research. Sleep disturbances among the children were described as having a significant influence on family's quality of life in this study. Thus, interventions that can be provided during wait times for sleep clinics, to benefit children's sleep quality, could greatly influence children's and parent's wellbeing. Higher levels of physical activity have been associated with improvements in sleep (Kredlow, Capozzoli, Hearon, Calkins, & Otto, 2015), and parents in the current study reported an increase in their family's physical activity levels as they began to engage in active play together, more often. Therefore, motor-based interventions may have a positive effect on children's sleep patterns. Quantitative investigation of each family member's physical activity levels (including the child with ASD) pre and post-intervention would bolster the credibility of these findings. Lastly, participants in this

study reported that they were able to learn useful strategies to use with their children by observing the intervention. Future research should investigate the parent learning outcomes resulting from different types of interventions for children with ASD. Designing interventions to allow for parent observation will likely promote learning for parents that could benefit families of children with ASD.

Conclusions

This is the first study to our knowledge that has qualitatively investigated the effects of an early motor skill intervention for children with ASD, on the children, their parents, and their families overall. Therefore, this research has filled a gap in the current literature, adding to our understanding of 1) the wide-reaching effects of early motor skill interventions within this population, and 2) parents' motivations for enrolling their children in this type of intervention. Inclusive motor-based programs can be carried out in communities with relative ease as they involve minimal financial burden: a play room, some toys, and an instructor. These types of community programs would provide parents with an affordable intervention option during long wait times for government-funded ASD services. The findings of this study suggest that community-based programs such as these could significantly benefit families of children with ASD. Researchers and clinicians should continue to investigate the benefits of motor interventions and communicate these findings with parents.

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SECTION 6: APPENDICES

Appendix 1: Letter of Approval from the University of Ontario Institute of Technology Research Ethics Board

Date: October 31, 2018
To: Meghann Lloyd
From: Ruth Milman, REB Chair
File # & Title: 15012 - Parents' Perspectives on the Secondary Effects of an Early Motor Skill Intervention for 3-5 Year-Old Children with Autism Spectrum Disorder
Status: **APPROVED (conditions from October 28, 2018 letter have been addressed)**
Current Expiry: **October 01, 2019**

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (all forms are accessible from the [IRIS research portal](#)):

- **Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (**15012**) on future correspondence. We wish you success with your study.

Dr. Ruth Milman
REB Chair
ruth.milman@uoit.ca

Janice Moseley
Research Ethics Officer
researchethics@uoit.ca

Appendix 2: Informed Consent Form

Informed Consent Form

Parents' Perspectives on the Secondary Effects of an Early Motor Skill Intervention for 3-5 Year-Old Children with Autism Spectrum Disorder

Investigators:

Leanne Elliott Masters Student
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Background and Rationale:

You are invited to participate in a voluntary interview session. The purpose of this project is to explore parents' perspectives on the effects of the 12-week motor skill intervention that your child(ren) participated in. In particular, we are interested in your opinion about the effects that the intervention had on your, and your family's life.

Why is this work important?

Parents of children with ASD consistently report higher levels of stress and lower levels of family quality of life compared to parents of children with typical development. There is a need for early interventions to promote best outcomes for all family members. This project will help us to understand the wide-reaching effects of early motor skill interventions from parents' perspectives.

Study procedures:

Parents who participate in this study will be asked to attend a single one-on-one interview session with Leanne Elliott at 202 Simcoe St. N. in Oshawa (the building where the motor skill intervention took place). The interview will last 60-90 minutes and will be audio recorded. The recording will help the researcher remember everything that was said during the session. Following the interview, the researcher will transcribe the audio recording into a typed document. The transcript from your interview session will be sent to you via email within two weeks and you will be given two weeks from this point to add to, eliminate, or revise any of your comments. You do not need to make any changes to your transcript if you don't want to.

If you wish to bring your child(ren) with you, we will have trained research assistants available to supervise free play in the Motor Behaviour and Physical Activity lab (the room where the motor skill intervention took place) during your interview session.

Study Plan

<p>Interview Session</p> <ul style="list-style-type: none">- 202 Simcoe St. N. Oshawa, ON- 60-90 minute total duration, includes:<ul style="list-style-type: none">o Consenting Processo Demographic Information Form (each question is optional)o Brief Family Distress Scale (one single question- circle one answer)o Interview (audio recorded)
<p>Transcription: sent via email</p> <ul style="list-style-type: none">- The transcript from the interview session will be sent to you via email no longer than two weeks after your interview date- You will be given two weeks to add to, remove, or revise any of your comments- You do not need to provide any input if you do not want to
<p>Findings: sent via email</p> <ul style="list-style-type: none">- A short summary of the findings will be sent to you via email once the study is complete

More details about each part of the study are included below:

- Location: 202 Simcoe St. N. Oshawa, ON
 - o Interview location: small office on the second floor
 - o Child care location: Motor Behaviour and Physical Activity lab on the second floor (the room where the motor skill intervention took place)
- Audio Recording: The purpose of recording the interview is twofold:
 - 1) To assist the researcher in remembering all that was said during the interview session. This will allow for a comprehensive analysis and interpretation of the data.
 - 2) The researcher can transcribe the recording word-for-word and send it to the participant via email. Participants will be given the opportunity to add or remove any comments.
- Demographic Information Form: The purpose of this form is to provide the researcher with some background information about each participant. This will help the researcher interpret comments from the interview conversation. Each question on the form is optional.
- Child Care: Supervised free play will take place in the Physical Activity and Motor Behaviour lab. Trained undergraduate Kinesiology students from UOIT will provide the supervision.

Risks and Benefits:

Your participation in this study does not pose any risk that differs from what you would normally encounter in daily life. Due to the fact that the discussion will be centered around your child and

your family, there is potential for emotional sensitivity. However, your name will not be used in any documents related to this study, you will be given a fake name in any/all publications resulting from this study so that your comments will remain anonymous. Your transcribed interview will be emailed to you using a UOIT institutional email, however information sent via the internet can not be guaranteed to be secure.

The findings of this study may positively influence intervention/ therapy design and delivery for children with ASD and their family members in the future.

Confidentiality:

The data collected in this study is used for current and potentially future research and will be secured safely. All information that you provide will be anonymized (you will be given a fake name). Overall results may be published for scientific purposes, but participant's identity will remain confidential. Limits of this confidentiality include situations of suspected child abuse, concerns of harm to self or others, or any request for information by court order.

Right to Withdraw:

You are free to withdraw from this study at any time without penalty; before, during, or after the interview session, up until the time of study publication. If you choose to withdraw, any data that has been collected will be destroyed and will not be used in any analyses, publications or further research. If you wish to withdraw from the study you can do so by contacting one of the investigators by telephone or email (see contact information above).

Questions about the study:

If you have any questions about this study, please contact Leanne Elliott via email (see contact information above). This study has been approved on October 31st 2018 by the University of Ontario Institute of Technology Research Ethics Board (REB #15012), which is a committee of the university whose goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent/guardian or child's judgment about what decisions and choices are best for you. If you have any questions about your child's rights as a research participant you may contact the University of Ontario Institute of Technology Research Ethics Board at 2000 Simcoe St. N., Oshawa, On, L1H 7K4, 905-721-8668, ext. 3693 or compliance@uoit.ca

Informed Consent to Participate: *Parents' Perspectives on the Secondary Effects of an Early Motor Skill Intervention for 3-5 Year-Old Children with Autism Spectrum Disorder*

I, _____:
(Your Name)

- Give consent** for my participation in the above study.
- Give consent** for my interview session to be audio recorded as part of the study.
- Give consent** for my child to be supervised in the Motor Behaviour and Physical Activity Lab during my interview session.
- Give consent** to be contacted about future research studies that my child or I may be eligible for.

I have read and understood the attached information sheet or had the attached information sheet verbally explained to me and have received a copy of this consent form. I have been fully informed of the details of the study and have had the opportunity to discuss my concerns. I understand that I am free to withdraw my child at any time or not answer questions. I understand that by consenting, I do not waive any legal rights or recourse.

Email: _____

Participant Name

Contact Phone Number

Participant Signature

Date

Witness Signature

Date

Appendix 3: Motor Intervention PI Recruitment Email

Hello [potential participant name],

I noticed that you indicated on your consent form that you would like to be contacted about future research opportunities. I thought I would let you know that one of my master's students is conducting a study that you qualify for.

Her name is Leanne, and she is interviewing parents of kids who have participated in the motor intervention at 202 Simcoe St. N. in Oshawa. The purpose of the study is to improve our understanding on the wide-reaching effects of the intervention. For example- whether you noticed any changes in your child's behaviour as a result of the intervention and whether or not those changes have impacted your family overall.

If you decide to participate you would be required to attend a single interview session at 202 Simcoe St. N in Oshawa (same location where the motor intervention took place). It will last between 60 and 90 minutes and you are welcome to bring your child(ren) with you- we will have trained students available to supervise free play in the lab while your interview takes place down the hall.

Please let me know if you are interested in taking part in this voluntary study. If so, I will forward your email address to Leanne and she can send you some more detailed information about the study.

Thank you for your time,

Dr. Meghann Lloyd

Appendix 4: Study Information Recruitment Email

Hello **[potential participant name]**,

Dr. Meghann Lloyd has informed me of your interest in our study and provided me with your email address. Thank you for your interest! Below you will find a short overview of the study, and attached you will find the consent form. This form is included to provide you with additional information about the study, you are not required to print or fill out the consent form at this time.

Study Summary

- The purpose of this study is to explore parents' perspectives on the effects of the 12-week motor skill intervention that your child(ren) participated in. In particular, we are interested in your opinion about the effects that the intervention had on yours and your family's life.
- Your participation would require you to come to 202 Simcoe St. N. in Oshawa (where the motor intervention took place) for a one-on-one interview session
 - Free parking is available on site
- The interview session will last between 60-90 minutes
- You can request child care (free service) during your interview session
 - We will have trained students from the kinesiology program at UOIT available to supervise your children in the room where the motor intervention took place
 - The toys in the lab will be set up for free play just as they were at the end of each intervention session
- The interview session will be structured in the following manner:
 - If you have your child(ren) with you, we will "drop them off" in the Motor Behaviour and Physical Activity lab (the room where the motor intervention took place) and proceed to the interview room down the hall
 - First, I will go over the consent form with you and answer any questions you may have
 - Next, you will be given the Demographic Survey (each question is optional) and Brief Family Distress scale to fill out
 - Finally, the audio recorders will be turned on and the interview will begin
- Within two weeks of your interview session, you will be sent the interview transcript (typed out version of our conversation) via email, and given the opportunity to add or remove any comments to/from the transcript
 - You are not required to make any changes to the transcript if you do not want to
- Once the study is complete (by April 2019), you will be sent a summary of the study findings via email

- Study significance: The findings from this study will help us to understand the secondary effects of early motor skill interventions for children with ASD. They may also help us to design interventions and service in the future, in a way that will promote best outcomes for all family members.

*** I have provided some interview date/time options below in case you would like to schedule an interview at this point:

[Will provide five date/time options for parents to choose from here]

If none of these date/time options work for you, please provide me with two dates/times that would work for you and I will do my best to accommodate you.

*** To request child care (free service) during your interview session, please indicate how many of your children you will be bringing, their ages, and any other important information we should know.

Thank you again for your interest in our study! Please let me know if you have any questions.

I look forward to hearing back,

Leanne

Appendix 5: Demographic Information Form

Demographic Information Form

This form includes questions about your family that will provide the researcher with some general background information. This information will help the researcher to interpret your comments from the interview session. Please feel free to ask questions if you would like further clarification. All questions are optional.

1. Participant name: _____
2. Child's name who participated in motor intervention: _____
3. Birth date of child who participated in the motor intervention: _____
(dd/mm/yyyy)
4. At what age did your child receive their diagnosis? _____
5. Has your child also been *diagnosed* with any of the following?

<input type="checkbox"/> Attention Deficit Disorder	<input type="checkbox"/> Obsessive Compulsive Disorder
<input type="checkbox"/> Attention Deficit Hyperactivity Disorder	<input type="checkbox"/> Operational Defiant Disorder
<input type="checkbox"/> Developmental Delay	<input type="checkbox"/> Seizures
<input type="checkbox"/> Epilepsy	<input type="checkbox"/> Sensory Integration Disorder
<input type="checkbox"/> Generalized Anxiety Disorder	<input type="checkbox"/> Visual Problems
<input type="checkbox"/> Intellectual Disability	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Learning Disability	_____
6. Does your child have difficulties with any of the following at this time?

<input type="checkbox"/> Anxiety	<input type="checkbox"/> Transitions
<input type="checkbox"/> Depression	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Self-injury	_____
<input type="checkbox"/> Anger	_____

7. Is your child currently receiving any other form of intervention/ therapy (i.e. PT, OT, speech-language, ABA-based services, etc.)? If yes, please specify type and duration.

8. Please self-declare your child's ethnicity using the options below:
(consistent with Statistics Canada, 2011)

- Aboriginal
- Chinese
- Korean
- Southeast Asia
- Arab/West Asian
- Filipino
- Latin American
- White
- Black
- Japanese
- South Asian
- Undeclared
- Bi-racial
- Other:_____

9. Please indicate your child's birth order and the number of siblings they have:
Birth order: _____ # of siblings: _____

10. Ages of Children:

1st born: _____

2nd born: _____

3rd born: _____

4th born: _____

5th born: _____

6th born: _____

11. Do any of your other children have ASD? If yes, please indicate their age(s): _____

12. Please indicate the highest level of education completed by each parent:

Mother: _____

Father: _____

Appendix 6: Interview Guide

Interview Guide

Introduction

Thank you very much for coming to participate in our study today.

The purpose of this research study is to help us understand the effects of the intervention on you and your family.

In completing this study, we hope to improve our understanding of the indirect effects of early motor skill interventions. Indirect effects are any effects other than changes in your child's motor skills. These include the effects experienced by you and/or your family members, as a result of the intervention. A few examples of indirect effects include:

- changes in your child's behaviour
- changes in how you spend time together as a family
- changes in your stress levels

Ultimately, the results of this study may help to:

- 1) Inform the design of interventions and services in the future- in a way that will promote best outcomes for all family members
- 2) Provide direction for future research focusing on families of children with ASD

Consent Form Overview

- Today's session will last roughly 60-90 minutes and will be audio recorded
- There are two purposes for the audio recording:
 - 1) To help me remember everything that was said during our conversation
 - 2) So that I can type out our conversation word-for-word, send it to you via email, and give you an opportunity to add to, remove, or revise any of your comments
 - you are not required to provide any input if you don't want to
- If you do not wish to be audio recorded you can withdraw from the study at this time and we will not proceed with the interview
- Doing so will not affect the care your child receives in any way and you will still be eligible to be contacted for other research opportunities in the future
- In fact, you are free to withdraw from this study at any time before, during, or after our session today, without penalty
- If you choose to withdraw, any data that has been collected will be destroyed and will not be used in any analyses
- If you do not withdraw, you will be given a fake name in any/all publications resulting from this study so that your comments will remain anonymous and your confidentiality stays protected

- Do you have any questions about the study?
- Lastly, my contact information is on the front of the consent form in case you have any questions or comments after our session today
 - Collect/ review consent form (ensure boxes are checked, and form is signed)*
 - Provide participant with blank consent form to take home (for their own records)*

Demographic Information Form Overview

- The purpose of this demographic information form is to provide us with some background information about your family
- This will help us to interpret your comments in the context of your family life
- Each question on the form is optional, meaning you are still eligible to participate in the study if you do not answer certain questions
 - Collect demographic information form*

Brief Family Distress Scale Overview

- The purpose of this scale is to assess your family's current state in terms of crisis
- Please circle whichever statement best describes your family at this time
 - Collect Brief Family Distress Scale*

Do you have any questions before we begin?

- Turn on audio recorders*

Interview Questions

1. Can you tell me a little bit about “name”?
 - i. Probe: Strengths? Challenges?
2. Tell me a bit about why you chose to enroll your child in the motor intervention.
3. What did you expect that you or your child would gain from the intervention?
 - i. Probes: Motor skills, being around other kids/ social skills
4. Did the outcomes that you/ your child experienced actually match what you expected? Why, or why not?
5. Have you noticed any changes in your child’s behaviour as a result of the intervention?
 - i. Probe: Motor skills, soft skills (turn taking, cooperating/ interacting with others, communication, listening, following instructions), adaptive behaviours/ everyday skills (toilet training, self-care), activity levels
 - If so, how have these changes in your child’s behaviour influenced the wellbeing of your family, including yourself?
 - i. Probe: Emotional wellbeing, parenting ease, stress, ability to participate in activities together, mutual enjoyment
 - Are there any additional changes - good or bad – that you can think of?
6. My next two questions are focused on family quality of life, which is essentially a measure of the “goodness” of your family life. There are many factors that influence family quality of life, such as:
 - The health status of you and your family members
 - The energy levels of you and your family members
 - Opportunities to accomplish things individually
 - Opportunities to do things together as a family, such as play and laugh
 - The ability to experience the outdoors individually and together
 - Feelings of connectedness and love for one another
 - Opportunities to interact with other families and the community
 - a. What factors do you think influence your family’s quality of life most?
 - b. How would you describe your family’s quality of life during an average week?
 - c. If at all, how has your child’s participation in the motor intervention influenced your family’s quality of life?
 - i. Probes: Communication, interactions, feelings of connectedness, how you spend time together, engagement in community,

recreation time, energy levels, friendships resulting from intervention

7. a. What factors influence your stress level most?
 - b. How would you describe your stress during an average week?
 - c. If at all, how has your child's participation in the motor intervention influenced your stress?
8. Can you describe any other benefits or challenges that you or your family experienced as a result of your child's participation in the motor intervention?
 - i. Probes: Talking to other parents, having a break, seeing your child succeed, getting out of the house, relationship with instructor(s), transportation burden, schedule burden

Conclusion

That concludes all of the questions I had for you, thank you for sharing your thoughts with me. Is there anything else you would like to add before we wrap up?

- If the participant has said they are in crisis at any point in the interview, or scored 6+ on the Brief Family Distress Scale, provide crisis resources*

Thank you again for your participation. Just to remind you, my contact information is on the front of the consent form. Feel free to contact me if you have any questions or concerns moving forward. Otherwise, I will send you the transcript from today's session within a week. You can remove comments, add to it, or leave it as is.

- Turn off audio recorders*

Appendix 7: Email Sent to Participants Following Participation

Hello [participant name],

Thank you again for your participation in our study! I have attached the transcript from our discussion on **[insert date of interview here]** to this email. If you wish to make any changes to the transcript, please send me your updates by **[insert date two weeks from the date this email will be sent]**.

- You do not need to make any changes to the transcript if you do not want to
- If you would like to remove any of your comments from the transcript, please copy and paste the specific comments within your response to this email
- If you would like to add any comments, please include them within your response to this email

I look forward to your response whether you decide to make changes or not,

Leanne

Appendix 8: Crisis Resources for Participants in Crisis

Crisis Resources

If your child is registered in the Ontario Autism Program (OAP), you can contact Grandview Children’s Centre and identify your need for a Family Support Worker (FSW)

Grandview Children’s Centre General Telephone: 905-728-1673
Grandview Children’s Centre Toll Free Telephone: 1-800-304-6180

- If you already have a Family Support Worker you can contact them
- In the event that you have a “Safety Plan” and you are experiencing an immediate crisis (risk of harm to self or others), initiate the Safety Plan, transport to hospital emergency department, or call 911

If your child is not registered in the Ontario Autism Program (OAP), you can contact:

Resources for Exceptional Children and Youth: Durham Region

Telephone: (905)-427-8862 ext 504
Toll Free Telephone: 1-(800)-968-0066 ext 504

- Leave a voicemail and they will call you back
- In the event that you are experiencing an immediate crisis (risk of harm to self or others), transport to hospital emergency department, or call 911

Appendix 9: NVivo Coding Framework

Name	Description
General Themes	Themes not specific to the intervention.
Anticipating	Trying to anticipate/prevent their child's challenging behaviours/tantrums is stressful for parents; especially in public settings.
Packing	Having to pack a multitude of things in order to be prepared for the "what ifs" is stressful.
Scared to go places	Parents are nervous/scared to go out with their child because they don't know how their child will behave.
Busy	Parents report being very busy (e.g. work, commuting, appointments for their child, etc.).
Cost/Wait	Private services are costly and wait times for government-funded interventions are long.
Difficult behaviours	Behaviours that parents perceive as stressful.
Adjusting	Child has a difficult time adjusting when things don't go as planned (e.g. there is an unexpected change in the schedule).
Copying siblings challenging behaviour	Child copies their siblings challenging behaviours.
Eating	Child is a picky eater.
Listening	Child has poor listening skills.
Sleep	Child has challenges with sleep.
Transitions	Child has difficulty transitioning from one activity to another.

Name	Description
Understanding/communication	Child has difficulty understanding/communicating what is wrong or what they want/need.
Independence	Important to many parents that their child gains independence and is able to do things on their own.
Lucky	Parents report feeling lucky/fortunate for their situation.
Parent Coping	Parent reported strategies for reducing stress.
Breaks	Breaks are important (e.g. respite, childcare, family help) for parent's stress management. Many parents report that they do not get enough breaks.
Giving in	Sometimes it is easier to "avoid the drama" and give in to what the child wants. Sometimes parents don't have time to deal with the child's outburst so they give the child what they want instead of using more time-consuming parenting strategies. Sometimes described as "catering to the child".
Relationship	Reports of close-knit family/strong marriage as being important mediators of parent stress.
Positive Outlook	Parents report having a positive outlook on life and how this helps them to get through difficult times.
Intervention Themes	Themes specific to the intervention.

Name	Description
Why did you enrol	Reasons why parents chose to enrol their child in the intervention.
Comparison	It would be an opportunity for parents to see other children with ASD.
Motor	Parents felt the child needed help to improve their motor skills.
No cost or waitlist	The fact that the intervention was free/ didn't have a waitlist was attractive to parents.
Parents	It would be an opportunity for parents to meet other parents who have a child with ASD. Parents thought the intervention for their child would benefit themselves in one way or another.
Play and fun	Parents felt this would be an opportunity for their child to play and have fun.
Social	Parents felt the motor intervention would provide an opportunity for their child to develop their social skills (e.g. being around other kids).
Expectations	Parents expectations about the motor intervention.
Met, Exceeded	Parents expectations were met or exceeded.
None but hoping	Parents didn't have concrete expectations going into the intervention but they were hoping they/their child would benefit in certain ways.

Name	Description
Specific	Parents gave concrete examples of what they expected they/their child would gain from the intervention.
Kids	Themes among children related to the intervention.
Enjoyment	Their child enjoyed the motor intervention.
Independence	Parents felt that the intervention increased the child's independence and, in some cases, allowed the parents to let the child be independent. "He is okay with people other than me" "I was over protective before" "she can do things by herself"
Listening/Following Instructions	Parents felt the intervention improved their child's ability to listen/follow instructions.
Motor Skills	Parents felt the intervention improved their child's motor skills and/or increased their physical activity levels.
Patience	Parents feel the child is more patient as a result of the intervention.
Shell	Parents feel that the intervention brought the child "out of their shell".
Sibling Relationships	Parents noted a change in the child's relationship with their sibling(s) as a result of the intervention (e.g. more interactive play, more active play, turn-taking, etc.).
Social	Parents feel their child's social skills improved as a result of the intervention.

Name	Description
Transfer Skills	Children transferred the skills they learned in the intervention to other aspects of their life (e.g. school, home, etc.).
Transitions	Parents noted an improvement in their child's transitions due to the intervention (i.e. their ability to transition between activities/tasks in their daily life).
Turn-taking	Child learned how to take-turns in the intervention.
Parents	Themes among parents related to the intervention.
Again	Parents thought the intervention was great and they want it again for their child. Some parents now think motor skill interventions should be provided as a regular part of therapy for children with ASD.
Break	Intervention provided a break for some parents; able to sit back and hand over the responsibility of their child.
Decreased Stress	Parents reported that the intervention reduced their stress for a variety of reasons.
Easy	It was easy for parents to commit to the program because their child enjoyed it.
Eye Opener	Many parents said the intervention was an "eye opener" or a "wake up call" for the importance of motor skills/play. One described it as another piece of the puzzle.
Motor Skills at Home	Things parents now do or do more of to work on their child's motor skills (e.g. parks,

Name	Description
	skipping rocks, treehouse, soccer team, bought sports equipment, play catch, etc.)
Going Out	Parents are more comfortable taking their child out as a result of the intervention. Some feel their child is better able to regulate their emotions/behaviour and others feel they themselves are better able to manage their child's behaviours due to what they learned in intervention.
Isolation	Parents felt alone before the intervention; it was beneficial to see other parents in the same situation.
Observing	Many parents liked being able to watch their child participate.
Comparison	Parents were able to compare their child to others with the same diagnosis and gain perspective regarding where their child falls on the autism spectrum.
Learned	Parents learned strategies during the intervention that they could use at home (e.g. how to break down a skill to teach their child, how to get their child's attention, phrases they could use to promote turn-taking).
Success	Parents liked watching their child succeed during the intervention.
Other Parents	Parents were able to talk to the other parents during the intervention and ask questions/share insights. Parents weren't worried about their child acting out during the intervention because the other parents "get it".

Name	Description
Surprised with Abilities	Parents were surprised by their child's abilities in the intervention.
Changed View	Seeing what their child is capable of during the intervention changed how parents view/treat their child (e.g. child now sitting in time-out as a consequence for bad behaviour, parent wakes up child 10 minutes earlier so she can dress herself).
Future	Parents are more hopeful/excited about the future after witnessing their child participate in the intervention. Reduced stress about future "he is going to be okay".
Shifted Family Dynamic	The new light that was shed on the child's abilities have shifted the dynamic at home. "It helped us grow together" "it's not all just about him anymore".
Other	Things that don't fit elsewhere.