

Parenting a Child with Asperger's Syndrome

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Abstrak

This study provides an interpretive description of parents' experiences of raising a child with Asperger's syndrome (AS). Thirteen parents (eight mothers; five fathers) from eight families participated. Data were comprised of repeated semi-structured interviews with parents. The core concept of a "balancing act" was identified, and included two key themes: losing our footing and regaining our balance. Parents lost their footing when they experienced escalating challenges and lack of parenting success. They persevered over many years to find an answer to their children's problems. The diagnosis of AS was a turning point that initiated the process of "regaining our balance," enabling parents to better understand both their children and the condition. In this part of the process parents gradually experienced parenting success and rebuilt their confidence. The results of this study suggest that parenting a child with AS is a complex and evolving process in which parents struggle to find the right balance for themselves, their child with AS, and their family as a whole. Parenting encompassed joys and sorrows and an important part of finding balance included the ability to acknowledge both the positive qualities of their children and the challenges of managing the condition. Lack of professional recognition of AS, as well as blame and stigma, negatively affected these participants' ability to parent and points to the critical need for further education of teaching and health professionals.

Kata Kunci: Asperger's syndrome Mothers' and fathers' experience Parenting Qualitative Interpretive description

Introduction

Asperger's syndrome (AS), a high functioning form of autism, is growing in prevalence, having risen tenfold over the past decade (Van Bergeijk and Shtayermman 2005). While definitive data regarding the incidence of AS are scarce (American Psychiatric Association [APA] 1994), within Canada it is estimated

JOECES

Journal of Early Childhood Education Studies

Volume 1, Nomor 1 (2021)

that one in 165 children has an autism spectrum disorder (ASD) (Fombonne et al. 2006). Prevalence estimates of ASD in the United States and Britain are even higher (Centers for Disease Control and Prevention 2007), with a significantly higher incidence among males when compared to females (Centers for Disease Control and Prevention 2012). Likely explanations for the rise in prevalence include greater awareness of ASD symptoms, and the inclusion of broader criteria for the diagnosis of ASDs (Muhle et al. 2004), although a conclusive explanation for such a large increase in the number of diagnoses remains unknown.

Despite the rising prevalence rate, researchers know little about parents' experiences of raising a child with AS. Previous research focused largely on the causes and sequelae of social deficits associated with AS (Blacher et al. 2003).

Children with AS are diagnosed on average at 11 years of age. This is much later than children with other forms of autism who are typically diagnosed at 5.5 years of age (Howlin and Asgharian 1999). Early identification and intervention are critical to promoting successful outcomes for children with ASDs; a late diagnosis of AS increases the vulnerability of these children to poorer health outcomes (e.g., development of co-morbid conditions) and adversely impacts families caring for them (Butter et al. 2003). Delayed diagnosis of AS means parents have difficulty acquiring the essential knowledge, skills, and services to effectively manage the condition (Chell 2006; Gray 2002; Howlin and Asgharian 1999; Lasser and Corley 2008; Portway and Johnson 2003).

Chell's (2006) qualitative study of young people with AS and their parents identified the importance of the diagnosis. It confirmed parents' observations of their child's difference, and validated their experiences. Further, the diagnosis was "like a ticket" (p. 1353), enabling parents to gain access to helpful services and supports. Similarly, Lasser and Corley (2008) found the diagnosis "validated [parents'] concerns, provided them with a word for what they had observed, and directed them to a constellation of resources specifically able to address their needs" (p.

342). While parents in both studies identified the positive aspects of receiving their child's diagnosis, the parents in Chell's study also described its painful impact and their subsequent resistance to the diagnosis because of its negative implications for their child. While these studies highlight parental experiences, they are largely exploratory in nature and tend to privilege mothers' perspectives of raising male children with AS. As a result, there is little insight into parenting from the perspectives of both mothers and fathers of male and female children with AS.

Recent studies have shown that parents of children with AS experience considerable stress (Epstein et al. 2008; Mori et al. 2009). This stress has been linked to their child's problematic behaviours (Mori et al. 2009) and associated features of AS, including sensory sensitivities (e.g., heightened perception of touch, smell, taste) and executive functioning deficits (e.g., problems with goal-directed behaviour, planning, working memory, multi-tasking, and flexibility) (Epstein et al. 2008). Mothers and fathers of children with AS were found to experience comparable levels of stress, although a significant relationship between parenting stress and child characteristics was found only for mothers (Epstein et al. 2008). The reason for this gender difference remains unclear; however, researchers theorize that fathers of children with AS may experience parenting stress differently than mothers (Epstein et al. 2008; Jones et al. 2013). Stigma has also been described as a significant source of stress for parents of children with AS (Calzada et al. 2012; Chell 2006; Gray 2002). Parents of children with AS experienced feelings of rejection or shame, were criticized for their child-raising abilities, and mothers experienced avoidance, overtly hostile staring, and rude comments when in public with their child (Gray 2002).

There is evidence to suggest that parents of children with AS are at high risk of experiencing mental health challenges such as depression and anxiety requiring psychotherapy and medication (Little 2002; Stoddart 2005). According to Dillenburger et al. (2010), parents of children with an ASD, including AS, are nearly three times more vulnerable than the general population

to psychological ill health. Further research is needed to explore fathers' as well as mothers' experiences raising a child with AS, to better understand the uniquely stressful challenges they experience. These parents represent a particularly vulnerable population whose experience is influenced by unique aspects of AS, including delayed diagnosis. More children are being diagnosed with AS than ever before; as a result, the need to access support services tailored to these families' particular needs will increase. Above all, the gaps in the literature support the importance of gaining a better understanding of parenting from the perspectives of both mothers and fathers of both male and female children with AS.

The purpose of this study was to describe and explain the nature of parenting a child with AS from the perspectives of both mothers and fathers. Analysis resulted in the identification of a core construct. For these participants, parenting a child with AS was a dynamic and complex 'balancing act.' The balancing act was comprised of two themes: 'losing our footing' and 'regaining our balance.'

Losing Our Footing

Many parents first noticed their children's differences in the infant and preschool years. During these early years, parents remained in balance because they believed they had a 'unique' but 'normal' child and were comfortable with handling the identified differences. The most common difference was the child's difficulty fitting in with others. Many parents described their children's quiet nature and preference to play alone.

Mother: He wasn't rambunctious. He was always very quiet and very much to himself. He could wander around outside in the yard with one little stick [and] play...for hours on end and not be distracted. He didn't...like to play with toys that I figured were common with boys. (Family 1)

Two families described how their children were expelled from daycare because of difficulties fitting in with others.

Mother: When he was three we were asked to not send him back to daycare because he was too quiet and always withdrew, and didn't want to participate with the other kids. Like when the kids were all playing playdoh, he wanted to read a book, and then once those kids moved onto another activity he'd be happy to play playdoh, but he never wanted to do anything in a group. (Family 3) Father: We knew that he was probably a little more aggressive than some of the other kids out there, that's why he got expelled from daycare. There was another kid who was playing with his toy, and [Child with AS] wanted the toy...and asked very nicely "Can I see the toy?" and the little boy wouldn't let him share it. So he picked the boy up and dropped him on his head and took the toy and walked away. (Family 6)

Parents noticed their children engaged in unusual, often repetitive behaviours such as finger flicking, drawing pictures, and lining up toys. They also observed their children's intellectual differences from same age peers, identifying advanced memory skills, exceptional ability to concentrate on tasks for long periods of time, strong pursuit of interests that exceeded their age level, and extensive vocabulary.

Mother: He was watching a documentary about ani-mals, a two hour documentary. About 6 months later he comes up with some obscure information about some obscure snake that I had never heard of and I said "How do you know that?" and he said "It was on that show I watched." (Family 1)

Initially, parents dismissed their children's differences because they could be reasonably explained and managed. However, as the differences grew, they became problem-atic and parents were seriously challenged in their ability to parent, experiencing lack of parenting success (i.e., they were unable to help their children "be normal").

Many parents became frustrated with their children's insistence on rituals and routines; demands for consistency and sameness. They could not understand the reason for their children's inflexibility, and they struggled to manage the "meltdowns" that ensued if there was the slightest change. Some parents became uncertain about their ability to parent, and when

they questioned helping professionals about what they should do, answers were not forthcoming.

Mother: [Child with AS] had very strict schedules like when he ate cereal I had to use a blue bowl with a purple spoon and I had to pass it to him with my right hand. I could not pass it to him with my left hand without him having a meltdown. And the doctors couldn't explain to me why. I'm like "But why?" and they're like "Well, he's just decided that that's the way it needs to be and he's just being stubborn so we encourage you to pass it to him with your left hand and get him to understand that it is still okay to eat the cereal...." He wouldn't eat breakfast for 3 weeks, and then I'd be calling my doctor again going "Is this okay?" because it's affecting his health now, and they're like "Oh, well we can't really tell you" [laughs], and it was frustrating. (Family 3)

In addition, sensory sensitivities were noted by many parents who described their children's acute perception of, and discomfort within, the sensory environment. Parents struggled to understand why their children became upset with sensory stimuli such as touch, taste, light, and noise.

One mother explained it this way: So we started to see all this sensory stuff happening and then at the same time it was like his clothes weren't right and he couldn't eat that kind of food because it was too squishy, and he couldn't eat that food because it was too crunchy, and we're like "What is going on?" As parents we had no idea, right. (Family 3)

Many parents tried to figure things out on their own but were unsuccessful in changing their children's behaviours. Parents became increasingly puzzled when the sensory sensitivities increased and became problematic at school. One mother described how her son adamantly refused to attend school because of the unpredictable sensory environment. Everything from the rustling of paper in the classroom to the sound of chalk against the chalkboard was upsetting. Another mother described how her son had to touch the carpet in the classroom before sitting down, gauging whether he could tolerate its texture. A few parents described how their children were an 'easy target' for peers who could readily perceive and provoke their triggers.

Parents began to eagerly search for the answers they needed to understand, explain, and manage their children's behaviours. Not knowing the reason for their children's problems, parents looked to themselves for answers, which often resulted in feelings of self-blame, guilt, and helplessness.

Father: Your first instinct is to blame yourself for something that you're doing that's making the situation the way it was. I don't know if I ever looked at it as trying to fix [Child with AS], because the last thing you want to think when you're in a situation like that is there's something wrong with your child.... It's almost like you've lost your child, and probably no different than if they had died. The strife and the feelings of guilt and the feelings of helplessness that you have, like what kind of a parent am I? I can't do anything to help my child. (Family 7)

A few parents blamed each other, questioning each other's discipline style and communication skills. When the children misbehaved and had meltdowns in public, an audience of others (strangers, extended family, professionals) also blamed parents for allowing the misbehaviours, and not properly disciplining their children. Thus, the typical answer to the persistent question of "Why is this happening?" was inadequate parenting. Many parents explained how extended family judged and blamed them for not implementing sufficient discipline, which exacerbated parents' feelings of self-blame and guilt. As a result, parents chose to limit their encounters with these family members, and a few mentioned that a rift occurred in their relationships with extended family.

When parents sought answers from school and health professionals, voicing the concerns they had about their children, many were not taken seriously. Instead, they were blamed for imagining or exaggerating problems and not parenting "well enough." A few parents were encouraged to read parenting books or enrol in parent training to learn how to effectively discipline their children. However, parents found these were unhelpful and ineffective recommendations. For the most part, these parents believed they were strict enough. When the professional spotlight shifted away from the child and towards parenting, some parents became defensive.

Mother: That's the very first reaction is that this is a parenting skills issue or an environment issue at home, so it's yours to deal with, or you need to get this child under control. We said, "Look, we can understand that if we were low income or uneducated or we weren't good parents or there was a divorce in process, or some stressors at home, but there isn't any stressors." (Family 6)

Only one family experienced a relatively direct path towards a diagnosis of AS for their child. Instead, most parents did not receive the help they desired or needed. When problems were recognized at school, parents were not initially informed. School professionals who, like the parents, had trouble managing the children's difficult behaviours resorted to punitive measures, which proved unsuccessful. As a result, the problems at school continued to worsen and parents remained uninformed and unable to help. During this time when parents struggled with unhelpful answers from school professionals, they actively pursued assistance from health care professionals. However, parents received inadequate explanations, inaccurate and incomplete diagnoses, and unhelpful treatment recommendations. Many physicians did not have enough information to diagnose AS, and often did not have the expertise to recognize its subtle cues. Five families received inaccurate diagnoses (i.e., Anxiety Disorder, Pervasive Developmental Disorder-Not Otherwise Specified [PDD-NOS], Sensory Disintegration Disorder, Attention Deficit Disorder, Manic-Depressive Disorder) for their children, and ineffective medications were prescribed. As one father, who rejected an initial diagnosis of PDD-NOS as inadequate, explained:

Early on it was the anxiety disorder...and I was going yeah, that is pretty much bang on 'cause she did have anxiety problems. And then when they came up with the 'PDD-QRMNOS' [referring to PDD-NOS diagnosis] I'm like "these guys don't have a clue." So they wrote out a bunch of initials and said "here's what your kid has." I'm going they don't have a clue, why are we even listening to them? I was...frustrated with the system then. If you don't have a clue just say we don't have a clue...don't be making up stuff "not otherwise specified." (Family 5)

Parents remained at a loss about what to do to help their children. Mother: I think as a culture we kind of expect certain people and professions to have the answers that we need when something doesn't work. And I think doctors can get the short end of the stick. 'Cause we think if something's not working or if something's broken, that they know what it is and they're gonna ask me the right questions to get the right answers, and, when the doctors don't have those answers, it's incredibly frustrating. (Family 3)

Unsure of how to help their children, parents met roadblock after roadblock and floundered. For two mothers and one father, the stress of parenting through the unknown culminated in depression. 'Losing their footing' proved devastating for parents and the ongoing lack of success in finding reasonable explanations for their children's problems and effective ways of parenting led to feelings of defeat. However, despite the difficulty, parents persevered with a desperate hope and devoted determination that they would eventually find the answers they needed. Giving up was not an option:

Mother: What choice do you have, you can't give up, right. Consider the options, it's like, what, leave? [laughs].... Rather than give up you just have to keep trying if you want a better quality of life...you just have to keep trying, it's all you can do. (Family 5)

Regaining Our Balance

All eight families reached the diagnosis of AS through dogged perseverance and it proved to be a pivotal point in their lives. The AS diagnosis helped parents by: (1) enabling understanding of their child, which supported acceptance; affirming parents' experiences as real, which helped to counteract and diminish blame; and (3) opening the door to services and supports, which helped their children and themselves manage the AS. Many parents anticipated the diagnosis of AS, because of familiarity with the condition gained through their readings, academic work, and discussions with others, and had a 'hunch' that it was the reason for their children's differences. Thus, they expected and looked forward to the confirmation of this diagnosis.

Parents characterized learning of the diagnosis as a “light at the end of the tunnel.” It pointed them in the appropriate direction to best help their children. Many parents emphasized that once a diagnosis is made, it is critical to get educated about the AS. As one mother succinctly stated: “I do what I have to do, I read, try to understand, and the more I understand the better it gets.” The diagnosis was also the key that unlocked the door to a wide range of services and supports previously unavailable to them and several saw it as “good news.” This contrasts with the assumption of some professionals that the diagnosis would make parents sad and tearful.

Mother: When we went to get the results she said to me “I have some bad news for you, he has Asperger’s syndrome,” and I said “It’s not bad news because he has it, whether you tell us or not, but now we know what we’re dealing with.” (Family 2)

This experience of mismatched expectations further solidified some parents’ belief that health care professionals did not understand or appreciate how hard they worked to get the diagnosis, and how difficult life had been without a way of making sense of their children’s behaviours.

The process of ‘regaining our balance’ occurred as parents acknowledged, gained understanding of, and moved towards accepting the AS, and the full extent of its influence in the family. With the diagnosis and enhanced knowledge of AS, parents were able to better understand their children, which eased some of the challenges of parenting. The diagnosis was freeing because it enabled parents to distinguish behaviours that could be changed from those that could not. Parents developed varying degrees of tolerance for their children’s problematic behaviours rather than feeling compelled to change them.

Father: All of a sudden it seemed like you could tell what was really true in her and what wasn’t, like sometimes you could tell that she was doing something to just manipulate me, and then I wouldn’t tolerate that, but you could tell when you were being manipulated and when it was really her condition that was showing. (Family 7)

Parents also gained greater acceptance of their own ability to parent and let go of blame in some measure.

Mother: The diagnosis helps because you stop blaming other people, you accept that this is the way he was born, and that is okay. And it's nobody's fault anymore. And no parent is perfect, and we've done the very best that we can, and it's okay. That's huge. (Family 6)

The diagnosis also brought challenges. Parents described co-occurring negative responses, including: regret that their child was not diagnosed earlier, anxiety and sadness about the future for their child, and anger at the unfairness of the parenting burden associated with raising a child with a difference. Thus, parents' responses to receiving their child's diagnosis encompassed relief, celebration, as well as a complex array of challenging emotions.

As parents became experts on their child and the AS, they developed and strengthened strategies to help create balance for their child, themselves, and their family as a whole. One strategy that supported a balanced perspective was cultivating appreciation for the children's unique strengths, talents, and abilities.

Mother: Appreciate your child because they're wonderful.... Some people would call [AS] a disability, other people call it a gift. They say some of the smartest people in society for hundreds of years likely had Asperger's. (Family 5)

Mother: I'd say celebrate it.... We do, to...help combat...stigma. It's a part of who they are. Don't... be shameful about it because...the only way you get rid of [stigma] is to open up about it and for other people to see that this wacky, fun, smart little bugger has Asperger's Syndrome.... Then they go "Oh, well that's not so strange then, is it?" (Family 4)

Eventually, they began to feel more comfortable and confident in their ability to parent along with a sense of regaining their footing. Some parents were surprised by the help now available to them, particularly after experiencing so many years of managing alone. Others felt overwhelmed and struggled to orient themselves to the services and supports available.

Parents learned about AS and began to separate their children from the AS. They gained expertise on “reading” their children and distinguishing whether the behaviours they were seeing were AS-related or child-related. One mother explained it this way: “We often say to each other, is this an ‘Aspie’ thing or is it him being a defiant 11 year old boy?” Parents also learned their children’s capabilities and were better able choose the most effective approach to managing problematic behaviours. Some parents got glimpses into their children’s world.

Mother: It’s almost like a second sight into his world.... I’m with him so much that I start to see things like he does...and what he’s thinking without even asking a lot of the times. (Family 2)

The two subthemes of ‘regaining our balance’ are: balancing expectations, and balancing parental roles and responsibilities.

Balancing expectations

Parents began to adjust their expectations of their children when they recognized that some behaviours were a reflection of the AS, and were not under their children’s control. Mother: A lot of his idiosyncrasies, once we found out he had Asperger’s, immediately we let it go....That’s the way he is, leave it be....Like he’d be flicking his fingers....Didn’t matter. (Family 1)

Mothers often had to remind family members of the need to adjust expectations according to the needs and abilities of the child with AS. They explained their children’s behavioural cues and triggers as a way to avoid escalating problematic behaviours and manage parenting and family life with greater ease.

Father: My wife’s reminders to me [helped]...that he has Asperger’s and...that what might seem like inappropriate behaviour or wrong behaviour is actually expected for him. (Family 4)

As parents confronted the reality of their children having AS, and adjusted their expectations for their children, they grieved the loss of idealized goals and expectations for a ‘normal’ child.

Mother: Our goals changed from [Child with AS] having friendships to developing one true friend.... That he understands

what that means to be a friend. So those expectations change but in that changing there's a part of you that has to let that expectation go, and that's not always an easy place to go as a parent. When you're pregnant...you have hopes and dreams and desires for your kids...then the realization that not all of those things are gonna be possible is hard. (Family 3)

Parents attempted to influence others' expectations and blame by revealing the AS diagnosis. As one mother noted, when teachers understood her child's AS and how it factored into the teaching and learning experience, they "tend to be a little bit more gracious, and they tend to change the way they teach or the way they approach something." However, many parents reported that, even with information about AS, teachers continued to hold unrealistic expectations. One mother explained:

I had one teacher tell me "He's twelve years old, he should be able to do this now," and I said "Hence the title 'special needs.'" [Child with AS] was supposed to write in his journal every day, and [teacher] was to make some comment in there, and she wasn't writing in [it]. I said "Why isn't this being done?" and she said "He doesn't bring me his journal," and I said "Could you not ask him for it?" and she said "By the time you're twelve I figure they should be able to do this"....I went home in tears that day....How many years I've been explaining this and then to have somebody say that to me. (Family 2)

Parents also encouraged extended family members to adjust expectations.

Mother: I remember writing my Dad a long email...explaining this is what it is and then saying to him, "You need to read up on this because he's your grandchild." And my Dad's a really nice guy but he was...acting like well, he should just be able to shape up, pull up by the bootstraps, straighten your tie and chin out, and pull through kind of thing. Nice that he has this Asperger's thing, whatever that is, but get some medication, let's go. Now I think he really understands a lot more, and I know that he did his own research when I asked him to. (Family 4) Balancing expectations both within and outside the family continued over

time; however, parents held on to the hope their children would one day be able to function independently.

Balancing parental roles and responsibilities

Parents emphasized the importance of working together as a team and capitalized on each other's strengths and abilities. Mothers typically did the 'frontline' work.

Mother: I've become the specialist just trying to figure it out on my own, and then talking to [Husband], and working as a team to implement it. [Husband]'s the implementer and the guy whose been home and really supportive, and I'm the one reading and saying let's try this and let's try this and let's not give up and when he crashes I keep going, so we've got some balance between us. (Family 6)

Fathers most often supported mothers by: (1) assertively advocating for their children in meetings with professionals; (2) discussing decisions regarding services and supports; and (3) noticing when mothers needed a break to care for themselves. Although parents were able to manage the roles and responsibilities of the household, they experienced challenges in the areas of career, social functioning, maintaining fairness across their children, and finances.

AS significantly challenged some parents' career paths. For example, children in modified school programs spent more days at home, which meant a parent needed to be present. Some families decided that one parent should move out of the workforce in order to support the child with AS.

Mother: We try to trade off but [Husband] is home for probably more than three quarters of the time. That has severely impacted his career path and they've made that clear in his job....So we're trying to get a better balance but it's been a problem....One of us is always home no matter what. If we choose to go out...we will not leave [youngest child] alone with [Child with AS]. (Family 6)

Parents found themselves torn between meeting the needs of their children with AS and meeting the needs of their typically developing children. Although parents worked hard to allocate their

time, attention, and money equally to all of their children, they were not always successful.

Mother: Fair for us will never be [that typically developing child] will get equal time. She won't. That's just a reality. It's a reality that we've had to accept as parents, which is hard because you want that, I want to be able to give her as much time as I give [Child with AS] every day but I can't, I don't have that many hours in my day. (Family 3)

Parents also recognized that their typically developing children made sacrifices for their siblings with AS. As one mother said, "Is it fair? Absolutely not but it's her reality too." One of the supports that few families had access to was respite. Respite is usually reserved for families experiencing severe forms of autism where the child has major physical health needs, below average intelligence, and/or requires daily medical care, meaning children with AS are excluded. One mother explained her family's need for respite in this way:

So much of it comes back to the one core thing...a few days of respite, where we could've...had that one on one that you need with your [typical] chil-dren....Just so that they could breathe, so...they know what it feels like to be normal. I think that would've been huge. (Family 6)

Overall, "regaining our balance" was a process in which parents were pointed in the right direction by their chil-dren's diagnosis of AS, and developed strategies for managing the complex and varying tensions of parenting. Expectations were continuously adjusted and parenting roles negotiated. Parents experienced success in parenting and gradually regained their confidence, which enabled them to offer advice to others as a way of helping them find their balance.

Discussion

The literature on parenting a child with AS contains themes ranging from difficulty attaining a diagnosis, significant levels of stress, encounters with stigma, and increased susceptibility to mental health problems. However, few studies have addressed the

complete experience of raising a child with AS, including the challenging and positive aspects from both mothers' and fathers' perspectives. Rather, the limited literature on parenting a child with AS is largely descriptive rather than explanatory (Chell 2006; Little and Clark 2006; O'Halloran et al. 2013), and focuses on specific aspects of the parenting experience, such as the wonders and worries (Little and Clark 2006) or experiences of diagnosis, treatment, and service provision (Chell 2006). The purpose of this study was to describe and explain the experiences of parents raising a child with AS. The core construct of parenting as a 'balancing act' was identified. The two themes of the balancing act are: losing our footing and regaining our balance. The work of balancing life with AS was challenging, and involved learning to read the child in order to develop a repertoire of effective management strategies.

This study revealed the serious difficulties associated with parenting a child with AS and the resilience demonstrated by the parents (see also Bayat 2007). Parents showed both remarkable perseverance and resilience in the face of longstanding adversity, striving to find the answers they needed to help themselves, their children with AS, and their families regain their balance. Stressors included parents' difficulty making time for the marital relationship and typically developing children, financial costs of pursuing help, career sacrifices, experiences of parental blame, social isolation from extended family, friends, and the community, and the daily demands of often unsuccessfully managing the AS. Given that one effective strategy involved a parental team approach, questions remain about the risks for sole parents who may lack the supportive resource of another adult to help them cope with and manage parenting a child with AS.

Along with the challenges, parents described the positive experiences associated with raising a child with AS. They remarked on their own personal growth and development, including increased acceptance and tolerance. This mirrors previous research on the positive impact of raising a child with an intellectual disability (Stainton and Besser 1998), including AS (Little and Clark

2006). The ability to find both the joys and the sorrows in the parenting experience can be a constructive, meaning-making process integral to the parental work of adapting to and coping with raising a child with AS (Little and Clark 2006; Pakenham et al. 2004). The findings of this study challenge the perspective that parents who notice the positive aspects of their experience are overly optimistic, denying the true nature of the condition (Scorgie and Sobsey 2000). Rather, successfully parenting a child with a developmental disability is often 'paradoxical' in nature (Larson 1998) characterized by parents' ability to acknowledge both the positive qualities of their children and the challenges of managing the condition (Kearney and Griffin 2001).

Although the parents in this study were well educated and demonstrated strong advocacy skills for themselves and their children, all but one family struggled over a prolonged period to obtain the diagnosis of AS. Parents first noticed their children's differences in the preschool years and did not receive a confirmed diagnosis of AS until their children were, on average, 10.75 years old ($SD \pm 2.87$). This is consistent with previous research revealing parents of children with AS wait on average 5.5 years for a diagnosis that is received when the children are 11 years old (Howlin and Asgharian 1999). Although the autism literature does not specify what constitutes a 'delayed' diagnosis, there are consistent reports of a 'significant' lapse in time between the age of first parental concern and the age of first autism spectrum diagnosis (Wiggins et al. 2006), with parents of children with AS waiting considerably longer than parents of children with classic autism (Howlin and Asgharian). The participating parents had significant resources available to them and still struggled with systems that were unhelpful and, at times, obstructive.

Parents were largely dissatisfied with initial responses from health care and school professionals. From a practice perspective, this serves as a reminder of the importance of listening to parents' concerns, affirming their struggles as real, acknowledging them as experts on their own children, and engaging in comprehensive assessment before drawing conclusions about the child or the

parents. As Gombosi (1998) aptly stated, “I don’t think we can speak about what parents need from professionals until we recognize that parents are the most important resource a child has” (p. 251). Acknowledging and accessing this expertise is a key strategy for not only establishing and strengthening the therapeutic alliance but for accessing important information to facilitate accurate diagnosis and guide appropriate treatment.

School and health professionals require education to help them recognize the often subtle presenting signs and symptoms of AS that can be masked by exceptional verbal and intellectual abilities. However, this recommendation is only feasible if a valid and reliable description of AS symptomology exists. Delayed diagnosis continues to be a serious problem and must be addressed, especially considering the numerous benefits of early diagnosis for children on the autism spectrum. Benefits include earlier access to funding and treatment, improved outcomes, reduced lifetime costs, and minimized distress for children and their parents (Autism Speaks 2013; Barbaro and Dissanayake 2009; Fenske et al. 1985; Harris and Handleman 2000). The lifetime costs of assisting a person with autism can be cut by 50 % if an early diagnosis is provided along with effective treatments and adequate family supports (Autism Society Canada 2004).

Although the current study provides a rich description of the experiences of parents raising a child with AS, its transferability to other parents of children with AS is limited. Recruitment of eligible families was achieved largely through newspaper articles and advertisements, thus privileging a particular subset of the population who had the time, energy, and resources to access a newspaper, respond to a research advertisement, and participate in a research study. Additionally, while this study included female children with AS, the sample was small and thus gender analysis was not supported. Furthermore, more interviews were conducted with mothers than fathers, which may have also biased the findings toward a more gendered view of parenting children with AS. Most importantly, these parents represented a unique sub-set of the population of parents raising children with AS (i.e., dual-parent

Caucasian families with relatively high socio-economic status and education living in Canada); as a result, the findings are not easily transferable to other parents of children with AS.

Further research into the experiences of parents raising a child with AS can address the limitations listed above by developing larger studies of more heterogeneous samples, including parents of diverse family backgrounds (e.g., education, economic, cultural, ethnic) and family types (e.g., single-parent, same-sex, skip generation families) to gain a more complete understanding of parents' experiences of raising a child with AS. AS is more frequently observed and diagnosed in male children. Consequently, the majority of studies on AS have recruited parents of male children with AS and parents of female children with AS have long been under-represented. Future studies should further investigate the influence of gender on raising a child with AS.

conclusion

parents, especially a mother. the genetic process of the relationship between father and mother gives a very strong influence on the outcome of the child. from here the importance of parents in having a clean process, such as starting from a legal marriage, a good pregnancy, a harmonious relationship and so forth.

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